# Understanding Cancer Pain Management Experiences and Needs of Chinese Migrants in Australia: A Mixed-Method Research Project

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# Abstract

## Background

Globally, pain occurs in more than half of cancer patients. Cultural beliefs and attitudes influence the way that people with cancer experience and report pain, and their pain management preferences. Chinese migrants are the largest non-English speaking population in Australia. However, little is known about their experiences and needs related to cancer pain and its management.

## Aim

To explore the pain-related experiences and needs of Chinese migrants with cancer pain who are living in Australia, and how they are influenced by culture.

## Methods

An integrated theoretical framework of Leininger's 'Theory of Culture Care Diversity and Universality' and the 'Australian Guidelines for Cancer Pain Management in Adults' underpinned this convergent mixed methods doctoral project. The project was conducted over three phases, involving: a systematic review of Chinese and English literature on pain- related experiences and needs of people with cancer from Chinese backgrounds; a series of focus groups with Chinese migrants living with cancer pain, with an embedded survey (the Chinese version of the Barriers Questionnaire); a cross-sectional survey of cancer and palliative care nurses which explored their perspectives on managing cancer pain in Chinese migrants; and data integration.

## Results

The systematic review identified that people from Chinese backgrounds experience similar levels of pain to other people with cancer and face similar barriers, including a reluctance to report pain and a fear of opioid addiction and side-effects. However, the focus group findings and survey results suggested that Chinese migrants living in Australia may have additional cultural and social reasons for not reporting pain or wanting to take opioids, and preferring to use non-pharmacological approaches that integrate traditional Chinese medicine and other complementary strategies. Findings suggest that patient education in bilingual and culturally appropriate formats aimed at encouraging help-seeking for pain and health professional education to build cultural competencies may be the key to overcoming barriers to effective pain management.

**Conclusion**

While Chinese migrants with cancer pain have similar cancer pain management fears and needs to other people living with cancer, the drivers are different and are largely attributable to a range of ‘cultural and social structural factors’. Applying the framework of Leininger’s ‘Sunrise Enabler to Discover Culture Care’ and ‘Semi-Structured Interview Guide Enabler to Assess Culture and Health’ assisted with understanding the needs of this migrant population. It also enabled the generation of a series of strategies designed to promote culturally congruent care, to help Chinese migrants living in Australia with cancer pain achieve the holistic wellbeing they desire and deserve.

# Statement of original authorship

I, Xiangfeng Xu, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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# Abbreviations

| | |
|---|---|
| **ABS** | Australian Bureau of Statistics |
| **CALD** | Culturally and Linguistically Diverse |
| **CAM** | Complementary and Alternative Medicine |
| **CM** | Complementary Medicine |
| **CNC** | Clinical Nurse Consultant |
| **CNE** | Clinical Nurse Educator |
| **CNS** | Clinical Nurse Specialist |
| **COSA** | Clinical Oncology Society of Australia |
| **ED** | Emergency Department |
| **GP** | General Practitioner |
| **IM** | Integrative Medicine |
| **JBI** | Joanna Briggs Institute |
| **Leininger's 'Culture Care Theory'** | Leininger's 'Theory of Cultural Care Diversity and Universality' |
| **Leininger's 'Semi-Structured Inquiry Guide'** | Leininger's 'Semi-Structured Inquiry Guide Enabler to Assess Culture Care and Health' |
| **Leininger's 'Sunrise Enabler'** | Leininger's 'Sunrise Enabler to Discover Culture Care' |
| **NSAIDS** | Non-Steroidal Anti-Inflammatory Drugs |
| **NSW** | New South Wales |
| **RN** | Registered Nurse |
| **S-BQT** | Short Version of Barrier Questionnaire-Taiwan |
| **SD** | Standard Deviation |
| **TCM** | Traditional Chinese Medicine |
| **TGA** | Therapeutic Goods Administration |
| **WHO** | World Health Organization |

# Glossary

| | |
|---|---|
| **Cancer pain** | Cancer pain (also known as cancer-related pain) is a symptom universally experienced by nearly all patients at some stage of their illness journey, either from the cancer itself or its treatment (American Cancer Society, 2019). |
| **Cancer pain management** | Refers to cancer pain '… screening, assessment, treatment, follow-up for general cancer pain and specific pain syndromes' (Dy, Naeim, Sanati, Walling & Lorenz, 2008, p. 3879). This approach encompasses comprehensive pain assessment, appropriate pharmacological and non-pharmacological interventions to meet individual's physical, psychological, social and spiritual needs (Brant, 2014; Paice, Bell, Kalso, & Soyannwo, 2010). |
| **Chinese cancer support group** | The cancer support groups run by the Chinese community cancer support organisations in cooperation with health care settings in Australia providing support to Chinese speakers living with cancer, to help them overcome the hardship of the cancer journey and cope with their cancer treatment via a series of educational activities and/or other assistance. |
| **Chinese migrants** | Unless otherwise specified, this term refers to people who were born in mainland China, Hong Kong, or Taiwan but are currently living in Australia. |
| **Conceptual model** | A conceptual model is a representation of reality that usually involves a simplification of a phenomenon or a specific aspect of a phenomenon to help understand it (Nilsen, 2015). |
| **'Cultural care preservation/and maintenance'** | The health professionals' actions or decisions are made in supportive ways that enable individuals to retain their care beliefs while facing handicap or death (Leininger, 2002a) |

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| **‘Cultural care accommodation and/or negotiation’** | The health professionals’ actions or decisions are made in active ways that encourage cultural acceptance and/or negotiation between diverse cultures to promote culturally congruent, safe and effective care (Leininger, 2002a). |
| **‘Cultural care repatterning and/or restructuring’** | The health professionals’ actions or decisions are made in assistive ways that facilitate individuals restructuring and modifying their lifeways and customs for optimal care outcomes (Leininger, 2002a). |
| **‘Culturally congruent care’** | This is the central concept of the Culture Care Theory (Leininger, 2002b), and “… refers to those cognitively based assistive, supportive, facilitative, or enabling acts or decisions that are tailor made to fit with individual, group, or institutional cultural values, beliefs, and lifeways in order to provide or support meaningful, beneficial, and satisfying health care, or wellbeing service” (Leininger, 1991, p.49). |
| **Culturally congruent cancer pain management** | For the purposes of this research, culturally congruent cancer pain management is operationally defined as actions and health decisions that are based on an understanding of individuals’ cultural perspectives and needs, supported by health systems, and delivered in a culturally appropriate way which enables effective cancer pain management for people from culturally and linguistically diverse backgrounds. |
| **‘Cultural and social structural factors’** | Refers to the 12 domains of inquiry including ‘Worldview’, ‘Ethnohistory’, ‘Cultural Values, Beliefs, and Lifeways’, ‘Kinship and Social Factors’, Religious/Spiritual/ Philosophical Factors’, ‘Economic Factors’, ‘Political and Legal Factors’, ‘Educational Factors’, ‘Technological Factors’, ‘Language and Communications Factors’, ‘Professional and Generic (folk lay) Care Beliefs and Practices’, and ‘General and Specific Nursing Care Factors’ (Wehbe-Alamah & McFarland, 2015). |

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|---|---|
| **'Cultural Values, Beliefs, and Lifeways'** | Refers to people's cultural values, beliefs and practices on their health decisions and reactions to their health and illness (Leininger, 2002a). Researchers may develop questions to define people's cultural values and beliefs assisting them recover or retain their health, as well as their culturally specific beliefs and health practices that their health care providers should know in order to provide culturally specific care to them (Leininger, 2002a). |
| **'Economic Factors'** | Assists researchers to reveal the financial barriers and facilitators that impact individuals' health care accessibility (Leininger, 2002a). |
| **'Educational Factors'** | Helps researchers to understand people's perspectives in relation to educational contributors to their health, and the educational information needs they would like to share with health professionals to help them stay healthy or deal with illness (Leininger, 2002a). |
| **'Ethnohistory'** | Refers to special and current events, experiences and/or conditions within people's cultural context and caring modalities over time (Leininger, 2002a). Researchers may develop questions to explore how people's cultural heritages (e.g. cultural backgrounds) and/or care experiences affect their care needs (Leininger, 2002a). |
| **'Holistic health'** | Refers to physiological, psychological, scriptural and social wellbeing (Leininger, 2002a). |
| **'General and Specific Care Factors'** | Helps researchers understand the barriers and facilitators that is appropriate to people from different cultures, for example, the meaning of care in a cultural group, and how health professionals' actions and/or attitudes can assist individuals maintain their wellbeing (Leininger, 2002a). |

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| **‘Kinship and Social Factors’** | Emphasises the impact of individuals’ families and/or social ties on their life, care and health lifeways as well as their families’ role in caring for them when they are ill or unwell (Leininger, 2002a). |
| **‘Language and Communications Factors’** | Helps researchers to identify barriers and facilitates influencing effective communications between health professionals and clients that may obstruct or enable people to receive health care, for example, how people would like others to talk to them, and what language barriers prevent them from communicating with others. (Leininger, 2002a). |
| **Leininger’s ‘Semi-Structured Inquiry Guide Enabler to Assess Culture Care’** | Known as Leininger’s ‘Semi-structured Inquiry Guide’, this enabler is a research facilitator consisting of 12 domains of inquiry, with suggested concrete and measurable inquiry mode examples for the key concepts and cultural and social structure dimensions of Leininger’s ‘Sunrise Enabler’ that can be used as a guide asking culturally specific open-ended questions to understand their care experiences and needs (Leininger, 2002a; Wehbe-Alamah, 2018). |
| **Leininger’s ‘Sunrise Enabler to Discover Culture Care’** | This is a diagram of the Leininger’s ‘Culture Care Theory’ often referring as Leininger’s ‘Sunrise Enabler’ (Wehbe-Alamah & McFarland, 2015). It is a visual aid directing researchers to broadly explore multiple factors influencing people’ health and/or care, and guide nurses and other health professionals conducting comprehensive cultural assessments (Wehbe-Alamah, 2018). |
| **‘Political and Legal Factors’** | Helps researchers to uncover the political and legal actions affecting individuals’ wellbeing, for example, what political issues have obstructed individuals to care themselves at home or in community (Leininger, 2002a). |

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| **‘Professional and Generic (folk lay) Care Beliefs and Practices’** | Helps researchers to explore from individuals’ cultural viewpoints what professional or folk (traditional) practices make sense to people, what professional or folk (traditional) practices (e.g. cultural care and food preferences) in a cultural group influence people’s wellbeing, and/or factors affecting people’s healing process at home or in the community (Leininger, 2002a). |
| **‘Religious/Spiritual/ Philosophical Factors’** | Addresses the importance of understanding people’s religious, spiritual and philosophical beliefs in their health care, for example, how these beliefs help with their healing process and assist them to face crisis, disability or even death (Leininger, 2002a). |
| **Self-management** | Self-management for people living with chronic illness refers to their capability of managing the symptoms and the consequences associated with their chronic conditions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). |
| **‘Technological Factors’** | Helps researchers to investigate people’s perceptions in relation to modern technological factors in their daily life that obstruct or enable patients to access health care and retain health (Leininger, 2002a). |
| **Theory** | A theory is “… a set of interrelated constructs, definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting the phenomena” (Kerlinger 1973 adopted by Waltz, Strickland, & Lenz, 2010, p. 3). |
| **‘Worldview’** | Refers to the way people view the world around them and their life prospects that would have an impact on their health decisions and wellbeing (Leininger, 2002a). Researchers may ask questions to explore how individuals’ views about the world around them influence their health and wellbeing (Leininger, 2002a). |

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# Anthology of publications associated with thesis

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# Chapter 1 Introduction

## 1.1 Background

Globally, Chinese migrants form one of the largest culturally and linguistically diverse (CALD) communities. In Australia, people born in Hong Kong, Taiwan, and mainland China now comprise the largest non-English-speaking migrant population ( Australian Bureau of Statistics [ABS], 2017). The number of Chinese migrants now living in Australia has increased by 46.7% since 2011, making this population the largest CALD ethnic group in Australia (ABS, 2017). The rapid inward migration of Chinese migrants to Australia since 2011 has implications for the delivery of culturally competent and appropriate health care, including cancer care.

Cancer is the leading cause of death and the biggest contributor to increased medical costs in Australia (Cancer Australia, 2017). As the number of Chinese migrants has grown in Australia, so too has the incidence of cancer in this population (Federation of Ethnic Communities' Councils of Australia, 2010). In some Australian states, the rate of Chinese migrants with some types of cancer is higher than that of the Australian-born population. For example, according to the State Cancer Registries' publicly available data, the Chinese community in New South Wales (NSW) has higher rates of cancer of the cervix, liver and stomach than the Australian-born population (Federation of Ethnic Communities' Councils of Australia, 2010).

As the incidence of cancer increase in the Chinese population living in Australia growing, there is a need to understand this population's cancer pain experiences and pain management needs.

### *1.1.1 Prevalence of cancer pain*

Cancer pain (also known as cancer-related pain) is experienced by nearly all people diagnosed with cancer at some stage during their illness journey, either from the cancer itself or its treatment (American Cancer Sociation, 2019; Brant, 2014). A recent systematic review and meta-analysis of 122 studies reporting on the prevalence of cancer pain shows that, in spite of increasing efforts to manage pain, persistent pain remains a global health problem for cancer inpatients and outpatients (van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). This systematic review found that more than a third of cancer patients (*n* = 63,533) after curative treatment, half during anti-cancer treatment, and two of third with advanced or terminal cancers reported having unrelieved cancer pain (van den

Beuken-van Everdingen et al., 2016). In patients with pain, more than 1/3 (52 studies, *n* = 32,261) suffered moderate to severe pain with a numerical rating scale (NRS) score of ⩾5 (van den Beuken-van Everdingen et al., 2016). Poorly controlled cancer pain may have an adverse impact on cancer patients' physical, emotional, psychological, social and spiritual wellbeing (Brant, 2014; Liang et al., 2015; Ruseel & Tandon, 2011; Yates et al., 2002). Cancer pain management is therefore an essential component of good cancer care (Brant, 2014).

### 1.1.2 Australian Guidelines for Cancer Pain Management in Adults

Employing a patient-centred approach, the Australian Guidelines for Cancer Pain Management in Adults (Australian Adult Cancer Pain Management Guideline Working Party, 2016) provides specific recommendations, to help all health professionals to managing cancer pain in adults. These international evidence-based guidelines were adopted for Australian context with expert consensus where evidence was found to be lacking.

These guidelines provide a series of recommendations related to screening, assessment, non-pharmacological and pharmacological strategies, as well as emphasise the importance of supporting patient education and self-management. The evidence-based guidelines are framed from a perspective that assumes optimal pain management involves multidisciplinary input from doctors, nurses and allied health professionals, and should be carried out in partnership with the patient themselves, as summarised at below:

**Pain screening**

At each clinical encounter, health professionals should use appropriate tools to assess all cancer patients' level of pain and to identify pain that might have occurred 24 hours prior to the clinical encounter. The self-reported numerical rating scale is recommended for patients who are capable of verbally reporting their pain, while the Abbey Pain Scale is useful for those unable to communicate their pain because of cognitive impairment.

**Pain assessment**

A comprehensive assessment should be conducted with a new patient with a pain score of ⩾2 on self-reported numerical scale or a pain score of ⩾3 on the Abbey Pain Scales (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

When conducting the comprehensive assessment, health professionals should holistically evaluate the patient's disease status and type of treatment, pain severity and experience, methods of current and previous pain management, as well as associated symptoms (Australian Adult Cancer Pain Management Guideline Working Party, 2016). Importantly, health professionals need to observe and discuss with the patients how they interpret the meaning of pain as well as their beliefs, knowledge and concerns about pain and its treatment (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

These guidelines also recommend that the pain assessment includes: 1) the patient's physical condition, psychosocial status and cognitive functioning; 2) risk factors for uncontrolled pain, 3) the patient's and their family's goals, expectations and preferences for pain management; and 4) any indications of an oncological emergency. All cancer patients should be reassessed when they experience new pain or a sudden, unexpected change in the intensity of their pain (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

### Pharmacological management

Health professionals are recommended to use various types and doses of analgesia depending on the patient's level of pain, its cause, and their other health conditions. While paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) are recommended for mild pain, opioids are recommended for pain that is moderate-severe and does not respond to these types of medication. As well as prescribing a routine dose, the guidelines recommend that breakthrough medication is made available to control any 'incident' or unexplained pain that may be experienced over and above their usual background pain. The guidelines acknowledge limited evidence for efficacy of opioids for neuropathic pain, which may require treatment with anticonvulsants and antidepressants. The guidelines also provide strategies about controlling analgesia-related side-effects and opioid-related toxicity to ensure patients' safety during their pain treatment. This includes the routine prescribing of laxatives for patients taking opioids to prevent constipation (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

### Non-pharmacological management

Health professionals should provide support to patients who have any psychosocial and spiritual concerns during a comprehensive assessment; and consider referring patients to a clinical psychologist for psychological therapies (e.g. cognitive behaviour therapy, relaxation techniques). Health professionals should also consider referring patients to occupational therapy or physiotherapy in order to assess patients and help them restore their functional ability. Patients should be encouraged when they wish to discuss options of using effective complementary therapies with health professionals (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

### Self-management

Self-management for people living with chronic conditions refers to their capability of managing the symptoms and the consequences associated with their chronic conditions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Implementation of self-management strategies with focus on symptom management may enable people living with cancer, to smoothly transit from their primary treatment to either survival or end-of-life phases (McCorkle et al., 2011).

Providing education regarding cancer pain and its management to empower patients as well as their family, carers and significant others to self-manage the patients' pain is an essential component of effective cancer pain management. To increase patients' awareness and capability of self-management, health professionals should provide verbal and written information on pain and its pain management to patients when they experience pain (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

Verbal and written information should include causes and common experiences of cancer pain and effective pain treatments, including non-pharmacological and pharmacological interventions, as well as common attitudes and beliefs preventing people receiving effective pain control, including fear of opioids (e.g. risk of addiction and tolerance). Clinicians are recommended to advise patients of side-effects of pain medication and the importance of reporting pain, side-effects and other concerns to health professionals (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

The evidence-based cancer pain management guidelines suggest that most cancer pain can be well controlled via a range of pharmacological and non-pharmacological interventions. However, patient related, health professional, and health care system-related barriers impede people receiving optimal pharmacological pain management (Jacobsen, Møldrup, Christrup, & Sjøgren, 2009; Luckett et al., 2013; Oldenmenger, Sillevis Smitt, van Dooren, Stoter, & van der Rijt, 2009). In addition, culture and language can be significant barriers for people living with cancer achieving optimal pain control (Lasch, 2000).

### *1.1.3 Impact of culture on cancer pain experiences*

Globalisation and migration has accelerated cultural diversity across the world (Williamson & Harrison, 2010). People from different cultural backgrounds have unique health needs (Holland & Hogg, 2010). People's cultural background can significantly influence their perspectives toward diseases and their treatment, as well as their health behaviours (Dayer-Berenson, 2014). Understanding people's culture-related health perspectives and health needs is crucial in providing effective, respectful and culturally appropriate care (Dayer-Berenson, 2014). This is particularly relevant to Chinese cancer patients, whose responses to psychological and physical symptoms vary and are largely determined by their cultural values and norms, which are often misunderstood by health professionals from different cultures (Dein, 2006).

People from ethnic groups often experience different and additional barriers to effective pain treatment, and cultural perceptions of pain and cancer often affect people's conceptualisation of their cancer pain and pain-related help-seeking behaviours (Kwok & Bhuvanakrishna, 2014). Systematic reviews and meta-analyses suggest that, compared with western cancer patients, Asian cancer patients (including Chinese cancer patients) often hesitate to report their pain and/or are less likely to adhere to recommended pain treatment (Chen, Tang, & Chen 2011; Kwok & Bhuvanakrishna, 2014). The meta-analysis shows that Asian cancer patients reported a higher level of barriers to using analgesics than western cancer patients, often related to their concerns about disease progression, drug tolerance, and drug addiction. These barriers contributing to a high prevalence of under-treated pain in Asian population (Chen et al., 2011). Further research exploring these barriers in more detail in the local context is needed to better inform optimal pain management for Chinese migrants living in Australia.
In addition to analgesic-related cancer pain management barriers, Taoism/energy, Confucianism and Buddhism - the philosophical/or religious beliefs of the Chinese may influence their cancer pain experiences (Chen, Miaskowski, Dodd, & Pantilat, 2008). Cultural factors may inadvertently act as a barrier to effective pain management for Chinese migrants living with cancer pain.

Chinese migrants living with cancer in Australia have a poorer quality of life and experience unnecessary suffering, anxiety and depression due to unmet information and support needs (Cancer Council NSW, 2017). A recent qualitative study shows that language, culture and health literacy barriers related to unmet information and support needs have adversely influenced the care outcomes of Chinese migrant cancer patients living in Australia (Lim et al., 2019). However, it is unclear whether Chinese migrants living in Australia experience the same difficulties in managing their cancer pain. Understanding Chinese migrant cancer patients' pain management perspectives and needs, as well as the related cultural and social factors, are crucial for developing strategies to facilitate culturally congruent cancer care.

### *1.1.4 The role of nursing and other health professionals in cancer pain management*

Addressing unrelieved cancer pain is an important priority that demands a more integrated approach in all aspects of cancer pain management to improve care outcomes (Williams, 2015). All health professionals in the multidisciplinary cancer care team have a responsibility to provide adequate pain management tailored to each individual's needs, throughout the processes of receiving a cancer diagnosis, active treatment, follow-up and towards the end of a person's life (Brant, 2014; Dy et al., 2008).

Nurses provide care to cancer patients from the time after their cancer diagnosis, treatment, and into their survivorship or end of life (Aranda & Yates, 2009). Nurses are at the 'front line' of cancer pain management and make contributions to all aspects of evidence-based pain assessment, management and patient education (Vallerand, 2011). Serving as advocates, nurses play an important role in providing care and support to enable cancer patients to actively take action to self-manage their cancer pain (Vallerand, 2011). Understanding nurses' experiences and perceptions about managing Chinese migrants' cancer pain management may provide an opportunity to explore cultural influences on this population's pain management from a nursing perspective.

## 1.2 Research aim and questions

This doctoral project aimed to explore the pain-related experiences and needs of Chinese migrants with cancer pain who are living in Australia, and how they are influenced by culture. It was guided by the following research questions:

1) What are the cancer pain management experiences and needs of Chinese migrants living in Australia?
2) What are the 'cultural and social structural factors' influencing their cancer pain management experience and needs?
3) What are the experiences and perceptions of Australian nurses in managing Chinese migrant patients' cancer pain?

4) What strategies are optimal to promote culturally congruent cancer pain management for Chinese migrants?

## 1.3 Definitions of key concepts

The following key definitions have been adopted for this doctoral project:

**Chinese migrants:** Unless otherwise specified, this term refers to people who were born in mainland China, Hong Kong, or Taiwan but are currently living in Australia.

**Cancer pain management:** Refers to cancer pain "… screening, assessment, treatment, and follow-up for general cancer pain and specific pain syndromes" (Dy et al., 2008, p. 3879).

**Culturally congruent care:** The central concept of Leininger's 'Culture Care Theory' refers "… to those cognitively based assistive, supportive, facilitative, or enabling acts or decisions that are tailor made to fit with individual, group, or institutional cultural values, beliefs, and lifeways in order to provide or support meaningful, beneficial, and satisfying health care, or wellbeing service" (Leininger, 1991, p.49).

**Culturally congruent cancer pain management:** For the purposes of this research, culturally-congruent cancer pain management is operationally defined as actions and health decisions that are based on an understanding of individuals' cultural perspectives and needs and supported by the health system, and delivered in a culturally appropriate way that enables effective cancer pain management for people from CALD backgrounds.

## 1.4 Overview of the studies in this doctoral project

This convergent mixed methods design project was conducted over three phases:

- Phase One: Explores current Chinese and English literature about cancer pain management experiences of people from Chinese backgrounds.
- Phase Two: including two studies:

i) Study 2: Explores the cultural influences impacting on Chinese migrants' cancer pain management experiences and needs from patient perspective;
ii) Study 3: Explores the barriers and enablers perceived by cancer-palliative nurses as impacting on Chinese migrant patients' cancer pain management experiences and needs; and

- Phase 3: Provides the conclusion and develops the strategies of culturally congruent pain management for this population (refer to table 1.1).

**Table 1.1 Overview of the phases and studies for this doctoral project**

| Phases | | Studies | Chapters |
|---|---|---|---|
| **Phase One** | Explores cancer pain management perspectives and needs from current Chinese and English literature | Study 1: Systematic review on cancer pain management perspectives and needs of patients from Chinese background | 2 |
| **Phase Two** | Explores the cultural influences impacting on Chinese migrants' cancer pain management experiences and needs from patient perspective | Study 2: Focus groups and Short Version of Barrier Questionnaire - Taiwan (S-BQT) with Chinese migrant cancer patients including: | |
| | | Study 2a = Part 1 | 5 |
| | | Study 2b = Part 2 | 6 |
| | | Study 2c = Part 3 | 7 |
| | Explores the barriers and enablers impacting on Chinese migrant patients' cancer pain management experiences and needs from nurse perspective | Study 3: Survey of Cancer and Palliative Care Nurses | 8 |
| **Phase Three** | Provides conclusion and strategies | Presentation of data integration, with meta-interferences answering research questions 2 and 4 and strategies for policy and practice | 9 |

## 1.5 Structure of the thesis

This doctoral research project is presented across nine chapters as summarised at below:

Chapter 1 outlines the research background, research aim and questions, definitions of the key concepts, overview of the phases and the studies, structure of the thesis, and significance of this doctoral project;

Chapter 2 reports a systematic review that included both Chinese and English language evidence in relation to the pain management experiences, beliefs and needs of cancer patients from Chinese backgrounds.

Chapter 3 describes the theoretical framework of Leininger's 'Culture Care Theory', including a history of its evolution and the rationale for adopting this theory.

Chapter 4 presents a justification of the project's research methodology and methods, as well as ethical considerations.

Chapter 5 reports results of S-BQT and Part 1 of findings from focus groups (Study 2a) held with Chinese migrants' regarding their cancer pain management experiences, and the influences of 'cultural and social structural factors' on their pharmacological pain treatment.

Chapter 6 reports Part 2 of findings from the focus groups (Study 2b) in relation to 'cultural and social structural factors' influencing Chinese migrants to use traditional Chinese medicine (TCM) and non-pharmacological interventions for their cancer pain management.

Chapter 7 reports Part 3 of findings from the focus groups (Study 2c) in relation to 'cultural and social structural factors' affecting Chinese migrants' cancer pain management at home.

Chapter 8 reports the results of a cross-sectional survey of cancer and palliative care nurses in relation to 'cultural and social structural factors' affecting Chinese migrants' cancer pain management from a nursing perspective, and strategies suggested by the nurses to promote culturally congruent care.

Chapter 9 is the final chapter and includes meta-interferences based on the key findings of the focus groups and the results of the nurse survey, and recommending strategies to promote culturally congruent cancer pain management for Chinese migrants living with cancer pain.

## 1.6 Significance

This doctoral project is consistent with the National Health and Medical Research Council's (2006) guide to promote research and cultural competence in health care to improve outcomes for CALD communities, and the recommendations of the National Cancer Nursing Education Project in relation to assessing cultural competence in nursing professions (Aranda & Yates, 2009).

This doctoral project sets out to generate insights into 'cultural and social structural factors' that influence Chinese migrants' cancer pain management experiences and needs. It helps health professionals better understand the potential changes that are required, in relation to provision of culturally congruent cancer pain management to this population, to improve their experiences and meet their cultural specific needs.

## 1.7 Summary

This chapter has outlined the background, research aim and questions, definitions of the key concepts, overview of the phases and the studies, and structure of the current thesis. The next chapter - Chapter 2 reports the findings of a systematic review on the cancer pain management experiences of people from Chinese backgrounds reported in Chinese and English literature.

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# Chapter 2 Prevalence of pain, types of pain management and identified pain management barriers of Chinese cancer patients: a systematic review and narrative synthesis

## 2.1 Chapter preface

Chapter 1 provided an overview of cancer pain management and highlighted its importance in maintaining cancer patients' wellbeing. It also raised concerns about cultural influences on Chinese migrants' cancer pain management.

Chapter 2 reports on Study 1 − a systematic review regarding the prevalence of pain, types of pain management and identified barriers in relation to cancer pain management for people from Chinese backgrounds reported in both Chinese and English literature. This study has been published in *Palliative and Supportive Care* in 2018 (refer Appendix A), and then reported here in an edited format.

## 2.2 Introduction

As previously described briefly in Chapter 1, culture is a factor that can significantly influence cancer patients' pain experience, coping behaviours and adherence to a recommended pain management plan (Al-Atiyyat, 2009; Lasch, 2000). Providing culturally appropriate care is an essential element of effective cancer pain management for patients from CALD backgrounds (Lasch, 2000).

The prevalence of severe pain or under-treated pain has been identified in Chinese cancer patients living in China and western countries as substantially affecting their quality of life (Deng et al., 2012; Dhingra et al., 2011; Edrington, Miaskowski, Dodd, Wong, & Padilla, 2007; Liang, Li, Wu, Wang, & Tsay, 2011; Liang et al., 2015; Liu et al., 2013). Chinese culture may significantly affect cancer patients' communication, ability to cope with the cancer diagnosis and symptoms and adherence to recommended care plans (Dayer-Berenson, 2014; Yin, Bai, & Y., 2007). The pain perceptions and experiences of cancer patients from a Chinese background may be shaped by their cultural beliefs (Chen, Miaskowski, Dodd, & Pantilat, 2008). These Chinese cultural beliefs can potentially influence people's interpretation of their experience of pain and its treatment (Chung, Wong, & Yang, 2000).

Australian research suggests that Chinese migrants with cancer may face barriers and have special needs for health care compared to other groups (Butow et al., 2010). Due to difficulties in communicating with non-Chinese speaking health professionals and navigating with new health care systems, Chinese migrant cancer patients often feel culturally isolated when approaching health professionals for their cancer care needs (Butow et al., 2010). They also perceive that western medications differ from their traditional health practices and fail to meet their needs (Butow et al., 2010).

Improving health professionals' understanding about health perspectives and the needs of Chinese cancer patients is required to ensure the development of culturally appropriate pain management interventions.

### *2.2.1 Cancer pain management*

Cancer pain is a multidimensional experience (Edrington et al., 2007; Oldenmenger, Sillevis Smitt, van Dooren, Stoter, & van der Rijt, 2009; Peng, Wu, Sun, Chen, & Huang, 2006). Cancer pain management is a complex and ongoing care process, which demands the constant efforts of health professionals across hospitals and home care throughout the process of routine cancer pain screening, assessment of pain intensity and functional impairment, treatment and follow-up (Dy et al., 2008).

Effective cancer pain management requires a coordinated multidisciplinary (Brant, 2014; Oldenmenger et al., 2009) and biopsychosocial approach (van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). This approach encompasses comprehensive pain assessment, and appropriate pharmacological and non-pharmacological interventions to meet the individual's physical, psychological, social and spiritual needs (Brant, 2014; Paice, Bell, Kalso, & Soyannwo, 2010).

Good pain management begins with identifying pain (i.e. screening) and comprehensive assessment aimed at identifying the severity, quality, type and cause of pain, as well as exacerbating and alleviating factors and the meanings attributed to the pain by the patient (Australian Adult Cancer Pain Management Guideline Working Party, 2016). Health professionals, especially nurses, play an essential role in assessing pain both at initial presentation and in an ongoing way to review the effectiveness of pain management strategies and identify changes in pain or emergence of new pain over time (Brant, 2014). Unfortunately however, many health professionals lack adequate knowledge and skills regarding cancer pain assessment, leading to poor pain management outcomes (Oldenmenger et al., 2009).

Oral analgesics are one of the most effective pharmacological interventions for cancer pain (World Health Organization, 2015). About 30 years ago, the World Health Organization (WHO) launched the 3-step cancer pain ladder to promote and guide usage of oral non-opioids and opioids in managing weak, mild and severe cancer pain.

It recommends that cancer pain be effectively controlled by administering the right dose of oral analgesics around-the-clock based on the pain assessment, and used in conjunction with adjuvants as necessary (World Health Organization, 2015).

Non-pharmacological interventions are an essential but often overlooked component of pain management for cancer patients (Brant, 2014). Non-pharmacological interventions, such as cognitive behaviour therapy, distraction, imagery, massage, Transcutaneous electrical nerve stimulation, musical therapy, and heating or cooling, have been reported as effective methods in cancer pain reduction (Brant, 2014; Yarbro, Wujcik, & Gobel, 2011). Non-pharmacological interventions might not change the underlying pathology, but can help in a variety of ways to decrease patient responses to pain, enabling them to deal with the pain positively and proactively (Yarbro et al., 2011).

However, as previously mentioned in Chapter 1, in spite of the multitude of pain management guidelines and strategies, unrelieved cancer pain persists due to patient, family, health professional, or health care system-related barriers (Brant, 2014; Oldenmenger et al., 2009; van den Beuken-van Everdingen et al., 2007). The poor outcomes of cancer pain management has remained unchanged for decades despite constant efforts and attention (Smith & Saiki, 2015; van den Beuken-van Everdingen et al., 2016). Identifying and developing adequate interventions to overcome these barriers is the cornerstone of effective cancer pain management (van den Beuken-van Everdingen et al., 2016).

### *2.2.2 Objectives*

The purpose of this review is to explore current evidence describing the pain management experiences, beliefs and needs of cancer patients from Chinese backgrounds. Integration of the findings from international and Chinese literature has special potential to understand cultural influences and the barriers affecting cancer pain management in patients from a Chinese background, and to inform the development of effective interventions for optimal pain management.

## 2.3 Study design

A protocol was developed according to the Joanna Briggs Institute’s (JBI) Systematic Review method (Joanna Briggs Institute, 2015) and the preferred reporting items for PRISMA (Systematic Reviews and Meta-Analyses) (Liberati et al., 2009), to guide the systematic review.

### *2.3.1 Eligibility criteria*

Articles were eligible if they were published in peer-reviewed English journals or the Chinese core journals between January 1990 and August 2015, and they provided empirical data describing pain management experiences reported by adult cancer patients from Chinese cultures, including Chinese migrant cancer patients living in western countries or Chinese cancer patients living in Hong Kong, Taiwan and mainland China. Studies could be either quantitative or qualitative in approach. For studies evaluating a novel intervention, baseline rather than follow-up data were included to describe experiences during usual care.

### *2.3.2 Information sources*

An initial search was undertaken via CINAHL and Medline in July 2015 with primary key words such as ‘Chinese’, ‘Chinese migrant’, ‘cancer patient’, ‘pain’ and ‘pain management’, to identify relevant studies in order to expand key words and phrases for a more in-depth search. Then a series of keys terms/words were developed for the comprehensive search in August 2015 via CINAHL, Medline, PsycINFO, Cochrane Library and China Academic Journals (CNKI). The search terms/keywords and limits were modified according to the requirements of the English and Chinese databases.

Chinese literature was mainly searched via CNKI Full-Text Database, under the subjects ‘Medicine and Public Health’ and ‘Education and Social Science’. To maximise the search scope, it was carried out in two rounds using different Chinese words with the same meanings. For example, ‘癌’, ‘癌症’ and ‘肿瘤’ have the same meaning – ‘cancer’. Both ‘病人’ and ‘患者’ refer to the ‘patient’ or ‘patients’.

Examples of the search terms and limits used for the English and Chinese databases are summarised in Tables 2.1 and 2.2, respectively.

### *2.3.3 Study selection*

The titles and abstracts of 10% of the returned articles were screened by two independent reviewers, with an inter-rater agreement of 100% achieved. The remaining articles were screened by one reviewer alone.

**Table 2.1 Key English data search terms**

| Key Search Terms and Limits Used for English Databases | |
|---|---|
| 1 | Chinese* OR Chinese people* OR Chinese migrant* OR Chinese immigrant* OR Chinese speaker* OR Chinese immigrant* OR mandarin* OR Shanghai* OR Canton* OR Taiwan* OR Hong Kong* OR Singapore* |
| 2 | cancer* OR Neoplasms* OR oncol* OR tumor* OR tumour* OR malignan* |
| 3 | experienc* OR Belief* OR Behavior* OR Behavio* OR attitude* OR health need* OR knowledge |
| 4 | pain* OR support* care OR symptom* |
| 5 | Combine 1, 2, 3, 4, & 5 with “AND” |
| Search Limits | 1. January 1990 to August 2015<br>2. Peer review in CINAHL & PsycINFO |

**Table 2.2 Key Words Used to Search in China Academic Journal Full-Text Database**

| A. Key words used for the first round of the search | |
|---|---|
| 1. | In the Article Title field: “肿瘤” OR “癌症” (‘zhong liu’ OR ‘ai zheng’, two different Chinese words that may refer to ‘cancer’) |
| 2. | In the Abstract field: “疼痛” (‘Teng tong’, a Chinese word referring to ‘pain’) |
| 3. | Combine 1 & 2 with “AND” |
| **B. Key words used for the second round of the search** | |
| 1. | In the Article Title field: “肿瘤” OR “癌” (‘zhong liu’ OR ‘ai’, the former is a Chinese word referring to ‘cancer’, whilst “ai” is a Chinese character that may combine with different Chinese characters to form new words, such as ‘zhi chang ai’- colorectal cancer.) |
| 2. | In the Abstract field: “患者” OR “病人”(‘hung zhe’ or ‘bing ren’, two different Chinese words referring to a “patient”) |
| 3. | In the Abstract field: “疼痛” (“Tengtong”, a Chinese word referring to “pain”) |
| 4. | Combine 1, 2, & 3 with “AND” |
| **Search limits for both rounds** | |
| 1. | Published from 1994a to present |
| 2. | Core journals |
| 3. | Excluded cross-language searchb |

[a] The China Academic Journals (CNKI) Full-text Database collects articles published from 1994

[b] Duplicates of articles published in Chinese that could be searched by both their Chinese title and their translated English titles were excluded

### 2.3.4 Quality appraisal

The risk of bias within studies of the selected English and Chinese articles was assessed by two independent reviewers using JBI levels of evidence (Joanna Briggs Institute, 2014a) and critical appraisal tools (Joanna Briggs Institute, 2014b). Quantitative studies were appraised using the JBI Critical Appraisal Checklist for Descriptive/Case Series Studies (Joanna Briggs Institute, 2014b). The qualitative study was appraised using the JBI QARI (Qualitative Assessment and Review Instrument)

Critical Appraisal Checklist (The Joanna Briggs Institute, 2014b). Disagreements were resolved by consultation with the third reviewer.

### 2.3.5 Data extraction

Data were extracted using an electronic proforma on study aims, population, sample size, settings, study design, outcome measures and main findings. Chinese data were extracted into the table and translated into English. The translation was cross-checked by another reviewer.

### 2.3.6 Synthesis

Heterogeneity between study designs prevented a meta-analysis. Thus narrative methods as described by Popay and colleagues (Arai et al., 2007; Popay et al., 2006) were used for data synthesis and analysis. The narrative synthesis focused on prevalence of cancer pain, type of cancer pain management, and pain management-related adherence behaviours, beliefs, needs and experiences.

## 2.4 Results

This section presents the results of the review with respect to the study characteristics, bias, prevalence of pain, and the identification of barriers.

### 2.4.1 Study characteristics

A total of 3,904 articles were retrieved from the searches, of which 23 reporting on 19 primary studies met the inclusion criteria and were selected for the review (Figure 2.1). All except one study were quantitative. The included studies predominately involved adult cancer inpatients (*n* = 6,008) and a smaller proportion of outpatients (*n* = 102) who were living in mainland China (*n* = 3,714 inpatients), Taiwan (*n* = 2,208 inpatients and 102 outpatients), or Hong Kong (*n* = 86 inpatients). Most studies included more men than women, although not all studies reported participants' gender.

All studies were conducted in urban hospitals. Most studies (*n* = 15) used an observational descriptive design (cross-sectional survey or case series). The other studies included two observational analytic studies, a pilot randomised controlled trial and a qualitative study. No studies reported information on pain, pain management-elated perspectives and health needs of Chinese migrant cancer patients living in Australia or other countries.

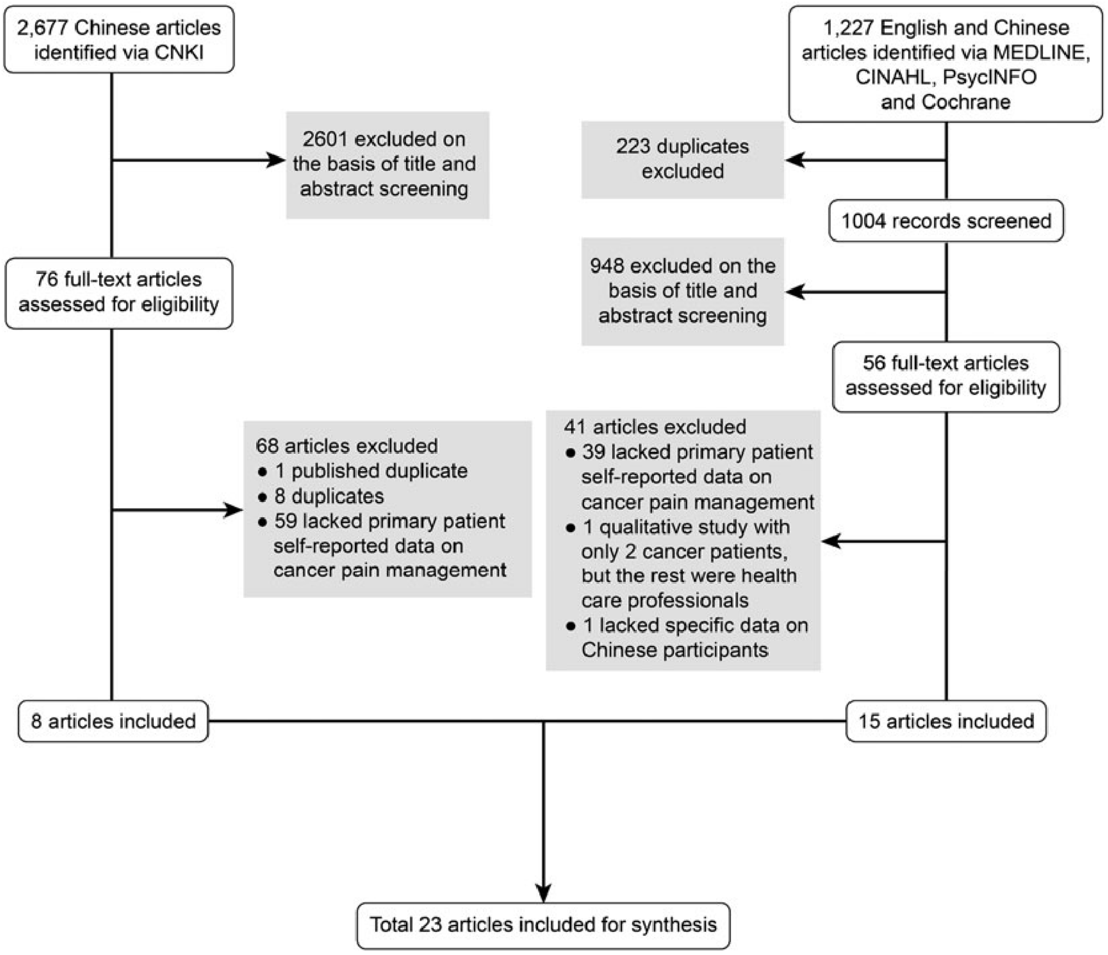

*Figure 2.1 Process and results of searching, screening and selecting articles*

### 2.4.2 Risk of bias within studies

Except for the qualitative study (Level 3.0), most of the studies in this review were rated at levels of evidence between level 4.b and 4.c. Three interventional studies were rated at level 3.e to 2.e based on their study design, but only baseline data at level 4.b were used for this review. Fourteen studies adopted a convenience sampling technique. All studies used face-to-face surveys and/or interviews to collect their data. Of the 18 quantitative studies, 12 used validated tools and six used self-developed surveys to examine pain management-related beliefs or barriers. Most of the validated measures were originally established in western populations and translated into Chinese; only one was psychometrically developed in the Chinese population (Chen et al., 2007). The levels of evidence and methodical appraisal results are summarised in Tables 2.3−2.5.

**Table 2.3 Critical appraisal results and level of evidence for Chinese studies (descriptive/case series)**

| No. of study | Critical appraisal checklist[a] | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Levels of evidence[b] |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Xia (2015) | N | Y | U | U | N/A | N/A | N/A | U | Y | 4.b |
| 2 | Song et al. (2014) | N | Y | N/A | Y | N/A | N/A | N/A | Y | Y | 4.b |
| 3 | Pang, Tang, and Song (2013) | N | N | N/A | Y | N/A | N/A | N/A | Y | Y | 4.c |
| 4 | Lin, Yang, Lai, Ling, and Zheng (2013) | N | N | N/A | N | N/A | N/A | N/A | U | Y | 4.b |
| 5 | Hu, Qiu, Mei, Ran, and Zang (2010) | N | N | N/A | N | N/A | N/A | N/A | N | U | 4.c |
| 6 | Huang, Zh, Peng, Xu, & Wang (2009) | Y | Y | U | N | Y | N/A | N/A | Y | Y | 4.b |
| 7 | Chen et al. (2007) | N | Y | Y | Y | Y | N/A | N/A | Y | Y | 4.b |
| 8 | Lu, Guan, and Ma (2006) | N | N | N/A | N | N/A | Y | N | Y | U | 3.e[d] |
|  | **Summary[c]** | N = 7, Y = 1 | N = 4, Y = 4 | N/A = 6, Y = 1, U = 1 | N = 4, Y = 3, U = 1 | N/A = 6, Y = 3 | N/A = 7, Y = 1 | N/A=7, N=1 | Y = 5, U = 2, N = 1 | Y = 6, U = 2 | 4.b–4.d |

[a] Joanna Briggs Institute's (2014b, p.181; 187-189) Critical Appraisal Checklist for Descriptive/Case Series Studies**:** Q1: Is the study based on a random or pseudo-random sample?
Q2: Are the criteria for inclusion in the sample clearly defined?
Q3: Are confounding factors identified and strategies to deal with them stated? Q4: Are outcomes assessed using objective criteria?
Q5: If comparisons are being made, is there sufficient description of groups?
Q6: Is follow-up carried out over a sufficient time period?
Q7: Are the outcomes of people who withdraw described and included in the analysis? Q8: Are outcomes measured in a reliable way? (Include reliability and validity)
Q9: Is appropriate statistical analysis used?

[b] Joanna Briggs Institute's (2014a) Levels of Evidences for Effectiveness

[c] Y = Yes, N = No, U = unclear, N/A = not applicable

[d] Baseline data used for the review with level of evidence 4.b

**Table 2.4 Critical appraisal results and level of evidence for English studies (descriptive/case series)**

[a]Joanna Briggs Institute's (2014b, p.181, 187-189) Critical Appraisal Checklist for Descriptive/Case Series Studies:

| **No. of study** | **Critical appraisal checklist[a]** | **Q1** | **Q2** | **Q3** | **Q4** | **Q5** | **Q6** | **Q7** | **Q8** | **Q9** | **Levels of evidence[b]** |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Liang et al. (2015) | N | Y | N | N/A | N | N/A | N/A | Y | Y | 4.b |
| 2 | Liang et al. (2013a) | N | Y | N | N/A | N | N/A | N/A | Y | Y | 4.b |
| | Liang et al. (2013b) | N | Y | N | N/A | N | N/A | N/A | Y | Y | 4.b |
| | Liang, Yates, Edwards, and Tsay (2012) | N | Y | N | N/A | Y | N/A | N/A | Y | Y | 4.b |
| | Liang, Yates, Edwards, and Tsay (2008a) | N | Y | Y | N/A | N | N/A | N/A | N | Y | 4.b |
| 3 | Tse et al. (2012) | N | Y | Y | N/A | N/A | N/A | N/A | Y | N/A | 3.c[c] |
| 4 | Tang, Tang, Liu, Lin, and Chen (2010) | U | Y | Y | N/A | N | N/A | N/A | N | Y | 4.b |
| | Tang (2010) | N | Y | Y | N/A | N | N/A | N/A | U | Y | 4.b |
| 5 | Lai et al. (2004) | U | Y | Y | N/A | N/A | N/A | N/A | U | N/A | 2.d[c] |
| 6 | Lai et al. (2002) | N | Y | Y | N/A | N | N/A | N/A | Y | U | 4.b |
| 7 | Lin (2001) | N | Y | N | N/A | Y | N/A | N/A | N | Y | 4.b |
| 8 | Lin (2000) | N | Y | Y | N/A | N | N/A | N/A | N | U | 4.b |
| 9 | Wills and Wootton (1999) | N | Y | N | N/A | N/A | N/A | N/A | N | U | 4.b |
| 10 | Lin and Ward (1995) | N | Y | N | N/A | Y | N/A | N/A | U | U | 4.b |
| | **Summary** | N = 12, U = 2 | Y = 14 | Y = 7, N = 7 | 14 N/A | Y = 3, N = 8, N/A = 3 | N/A = 14 | N/A = 14 | Y = 6, N = 5, U = 3 | Y = 6, N/A = 2, U = 4 | 4b−3.c |

Q1: Is the study based on a random or pseudo-random sample? Q2: Are the criteria for inclusion in the sample clearly defined? Q3: Are confounding factors identified and strategies to deal with them stated? Q4: Are outcomes assessed using objective criteria? Q5: If comparisons are being made, is there sufficient description of groups? Q6: Is follow-up carried out over a sufficient time period? Q7: Are the outcomes of people who withdraw described and included in the analysis?
Q8: Are outcomes measured in a reliable way? (Include reliability and validity) Q9: Is appropriate statistical analysis used?

[b] Joanna Briggs Institute's (2014a) Levels of Evidences for Effectiveness; [c] Y = Yes, N = No, U = Unclear, N/A = not applicable; [d] Baseline data used for the review with level of evidence 4b.

**Table 2.5 Critical appraisal results and level of evidence for English study (qualitative)**

| No. of study | Critical appraisal checklist[a,b] | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Level of evidence[c] |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Laing et al. (2008b) | U | N | Y | Y | Y | N | Y | Y | Y | Y | 3 |

[a] Joana Briggs Institute's (2014b, p.177-179) QARI (Qualitative Assessment and Review Instrument) Critical Appraisal Checklist:
Q1. There is congruity between the stated philosophical perspective and the research methodology.
Q2. There is congruity between the research methodology and the research question or objectives.
Q3. There is congruity between the research methodology and the methods used to collect data.
Q4. There is congruity between the research methodology and the representation and analysis of data.
Q5. There is congruence between the research methodology and the interpretation.
Q6. There is statement locating the researcher culturally or theoretically.
Q7. The influence of the researcher on the research, and vice versa, is addressed.
Q8. Participant, and their voice, are adequately represented.
Q9. There is evidence of ethical approval by an appropriate body.
Q10. Conclusion drawn in the research report do appear to flow from the analysis, or interpretation, of the data.
[b] Y = Yes, N = No, U = Unclear, N/A = not applicable

## 2.5 Study characteristics

Table 2.6 provides an overview of the characteristics of the studies selected for this review, following the sections that discuss aspects of the studies.

### *2.5.1 Prevalence of pain, type of pain management and adherence behaviours*

Suboptimal analgesic use, delays in receiving pain treatment or poor adherence to prescribed analgesics contributed to the burden of participants' unrelieved pain. The majority of participants across the studies (83.5% inpatients and 100% outpatients) reported experiencing pain with a duration ranging from a few days to several months.

Across studies, pharmacological rather than non-pharmacological strategies were the main form of cancer pain management used. Three studies reported using the WHO 3-step ladder to guide the prescription of analgesics (Chen et al., 2007; Hu, Qiu, Mei, Ran, & Zang, 2010; Lu, Guan, & Ma, 2006). Six studies specifically investigated the barriers of using opioids (Lai et al., 2004; Lai et al., 2002; Liang et al., 2013a; Liang et al., 2013b; Liang et al., 2015; Liang, Yates, Edwards, & Tsay, 2008a, 2008b, 2012; Pang, Tang, & Song, 2013), while the remaining 13 studies explored participants' perspectives on using analgesics.

Only two studies noted that participants used a combination of analgesics (codeine or morphine) and NSAIDs (Lin, 2000; Song et al., 2014). Another two studies described participants using TCM (e.g. acupuncture) or physiotherapy alone or in combination with analgesics for their pain control (Chen et al., 2007; Huang, 2009 ).

The following poor analgesic adhering behaviours were reported by the participants:

- failing to take regular analgesics as prescribed (Lai et al., 2004; Lai et al., 2002; Song et al., 2014; Tse et al., 2012; Wills & Wootton, 1999; Xia, 2015);
- only taking analgesics when pain occurred rather than around-the-clock analgesic regimen (Huang, 2009 ; Lin, 2000, 2001; Song et al., 2014; Tse et al., 2012) or when the pain became unbearable (Lin, Yang, Lai, Ling, & Zheng, 2013; Tse et al., 2012); and
- titrating their analgesic doses without medical guidance (Tse et al., 2012; Xia, 2015).

**Table 2.6 Overview of study characteristics**

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 1 | Liang et al. (2015)<br>Taiwan | To explore the relationship between oncology patients' pain experience and quality of life. | Inpatient ($n$ = 109)<br>A teaching hospital | Cross-sectional | Medical characteristics (i.e. opioid used and side-effects)<br>Methods of pain management<br>European Organization for Research and Treatment of Cancer Quality of Life Group Questionnaire (Version 3.0)<br>Brief Pain Inventory-Chinese Version (BPI-Chinese) | Participants reported moderate levels of pain and duration of being in pain from 1 to 49 months. Among them:<br>• 3/5 used analgesics together with other approaches to control their pain<br>• 2/5 used analgesics only to treat their pain<br>• 96.3% experienced side-effects from opioids use. |
| 2 | Xia (2015)<br>Mainland China | To evaluate adherence of elderly cancer patients to take oral analgesics and associated factors. | Inpatient with pain ($n$ = 115)<br>An oncology teaching hospital | Cross-sectional | Self-designed questionnaire for analgesics adherence assessment:<br>taking by following prescription<br>time of taking and dosage<br>adhering to long-term usage<br>continual use of analgesics | Only about 1/2 of the participants adhered to oral analgesics;<br>2/5 failed to take analgesics as per time of the prescription, and 1/4 increased the dosage of analgesics without consulting their doctor.<br>Main concerns of the participants: adverse reaction (91.53%) and addiction (84.76%).<br>Significant associated factors of adherence: age, monthly income, status of medical insurance and intensity of pain ($p < 0.05$). |
| 3 | Song et al. (2014)<br>Mainland China | To determine pain prevalence and analgesic usage of inpatients; and to explore the factors associated with under-treatment cancer pain. | Inpatients ($n$ = 617)<br>A teaching hospital | Cross-sectional | Information using analgesics: category, administration, time and adverse effects of analgesics and economic burden | 286 participants had moderate or severe cancer pain and among them:<br>• 92% of participants' medical cost was ⩽1% of their total hospital expenses<br>• 49.7% of participants used analgesics but of them only 1/2 took analgesics when pain occurred. |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 4[b] | Liang et al. (2013a)<br>Taiwan | To explore the relationship between analgesic beliefs, analgesic adherence and pain experience amongst Taiwanese cancer outpatients. | Outpatients ($n = 92$)<br>Two teaching hospitals | Cross-sectional | Pain Opioid Analgesic Beliefs Scale-Cancer (POABS-CA)<br>Opioid adherence<br>BPI-Chinese | Participants had a mean pain intensity score of ≧3 for at least 24 hours; and 33.7%−68.5% of them had negative beliefs about pain and opioids.<br>Participants with negative effect beliefs about opioids and pain were less likely to adhere to an around-the-clock analgesic regimen ($r = -0.30$, $p < 0.01$). |
| | Liang et al. (2013b) | To describe oncology outpatients' responses to their beliefs regarding pain and prescribed opioids. | Same as above | Same as above | POABS-CA | Participants' beliefs about opioids and pain:<br>• opioids are not good for a person's body (about 2/3)<br>• worried about opioid dependence (2/3)<br>• if taking opioids at too early a stage, it would have less effect later (2/3)<br>• adults should not take opioids frequently (3/5) and should endure the pain (2/5). |
| | Liang et al. (2012) | To explore levels of self-efficacy of outpatients in opioid taking for their cancer pain. | Same as above | Same as above | Opioid-taking Self-Efficacy Scale-Cancer (OTSES-CA) | Majority of participants reported low confidence in the tasks of tailoring medication regimens.<br>Participants with low education were significantly related to a lower score of self-taking opioids ($r = 0.28$, $p < 0.01$).<br>Participants without side-effects significantly had higher total self-efficacy score ($p < 0.01$) and subtotal scores ($p$ between <0.05 and <0.01), compared to those with side-effects. |
| | Liang et al. (2008a) | To explore the relationship between self-efficacy, beliefs, adherence behaviours and pain experience of outpatients in relation to opioid-taking for their cancer pain. | Same as above | Same as above | OTSES-CA<br>POABS-CA<br>Opioid adherence | Opioid beliefs and opioid-taking self-efficacy were significant predictors for participants' adherence to around-the-clock analgesic regimen ($F = 4.71$, $p < 0.01$).<br>Participants with negative opioid beliefs ($r = -30$, $p < 0.01$) and low level of self-efficacy ($r = 0.22$, $p < 0.35$) were likely to poorly adhere to an around-the clock analgesic regimen. |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 5 | Pang et al. (2013)<br>Mainland China | To investigate and explore existing problems related to pain control and barriers for optimal pain management among cancer participants and their family members; and to explore their attitudes to cancer pain and pain management. | Inpatients (*n* = 30)<br>Patients' family (*n* = 29)<br>An oncology teaching hospital | Case series | Self-designed questionnaire − patients:<br>effect of pain control<br>impact of pain on patients' sleep<br>mood and general activity<br>factors that affect patient's satisfaction about pain control<br>Numeric Rating Scale<br>Patients and their family members:<br>perceptions about pain<br>right way of using analgesics<br>perceptions about safety of opioids<br>5 other domains in relation to analgesic treatment | Participants suffered mild to severe pain at the time of survey, and of them, 5/6 had moderate or severe pain within 24 hours prior to the survey, and 1/2 only took analgesics when pain occurred.<br>Participants' and their families' perceptions about pain and analgesics:<br>• pain meant end stage of cancer<br>• analgesics should only be taken when pain occurred<br>• opioids were not safe<br>• worried about addiction to opioids<br>• better to suffer the pain and did not use any analgesics. |
| 6 | Lin et al. (2013)<br>Mainland China | To explore factors associated with cancer patients' adherence to pain treatment. | Inpatients (*n* = 228)<br>A teaching hospital | Cross-sectional | Self-designed questionnaire:<br>type of cancer, location and level of pain<br>patient's goal in relation to pain treatment<br>knowledge about pain treatment and analgesics<br>Numeric Rating Scale | 189 participants suffered from mild to severe pain but only 1/3 of them took analgesics on time.<br>Perceptions of pain treatment:<br>• only needed to reduce pain to tolerable level<br>• using opioids may result in permanent dependence<br>• analgesics should be taken when pain became unbearable<br>• long-term use of opioids might result in addiction<br>• request to increase dosage of analgesics meant addiction<br>• should stop using opioids if adverse reaction occurred<br>• dosage of morphine was associated with level of severity of the cancer. |

| **No.**[a] | **Authors/ year/location** | **Aims** | **Population/ settings** | **Study design** | **Outcome measures** | **Main findings** |
|---|---|---|---|---|---|---|
| 7 | Tse et al. *(*2012)<br>Hong Kong | To investigate the effectiveness of pain management program on pain intensity, use of PRN (taking analgesics as per need but not on an around-the-clock scheduled basis) drugs and non-pharmacological strategies for pain relief, and to explore barriers to cancer pain management. | Inpatients (*n* = 38)<br>A public hospital | Case-controlled | Numeric Rating Scale<br>Barriers questionnaire-Taiwan (BQT): Fatalism, addiction, desire to be good, fear distort physician, decreased progress, tolerance, and side-effects | Baseline assessment:<br>All participants took analgesics to relieve their pain and at least 2/3 used non-pharmacological methods for pain relief. However, they believed analgesics should be only be taken when the nurse gave it to them, and they had relatively high scores of BQT (>2) in addiction, fear of disturbing the physician, decreased process, tolerance and side-effects. |
| 8 | Hu et al. (2010)<br>Mainland China | To explore cancer patients' perceptions and attitudes toward pain treatment in hospitals, and<br>to explore their attitudes to community medical staff in relation to the treatment. | Inpatients (*n* = 120)<br>A tumour hospital | Case series | Self-designed questionnaire:<br>incident rate and type of treatment for pain<br>perceptions and attitudes to analgesics and pain treatment<br>perceptions about pain treatment at community hospital (i.e. accessibility to the service, availability of analgesics) | 2/5 of participants had cancer pain and of them:<br>• 2/3 worried about adverse effects<br>• 92.3% wished to receive more information on pain treatment and analgesics<br>• only 1/3 regularly took analgesics<br>• 1/3 took analgesics when pain occurred<br>• 1/4 refused analgesics due to worry about adverse effects<br>• 3/4 perceived possible inconvenience to get analgesics at community hospitals<br>• 4/5 thought community hospitals cannot provide satisfactory pain treatment.<br>Type of pain treatment: analgesic (59.6%), physical therapy plus taking rest (26.9%); chemotherapy and radiotherapy (13.5%) |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 9[c] | Tang et al. (2010a)<br>Taiwan | To characterise cancer patients' status and satisfaction with pain management. | Terminally ill cancer inpatients ($n$ = 1370)<br>24 hospitals | Cross-sectional | Pain intensify score (0−5)<br>Toolkit of instruments to measure end-of-life care<br>Self-developed questionnaire − patients' perceptions of clinicians' pain management practice with four questions regarding the amount of pain medication received, duration of waiting for pain medication, understanding pain treatment and pain relief experiences | All participants experienced pain and about 1/2 of them were not satisfied with pain relief within one week of admission because they received inadequate amount of pain medication and/ or took too long to receive pain medication.<br>Significant correlation factors of participants' satisfaction: age ($r$ = 0.05, $p$ = 0.05); pain intensity ($r$ = −0.18, $p$ < 0.0001). |
| | Tang (2010b) | To investigate the diffusion effects of a hospice unit on improvement of terminally ill inpatients perceived quality of cancer pain management. | Same as above | Same as above | Pain relief experiences, duration of waiting for pain medication and amount of pain medication received. | Participants from hospice groups ($n$ = 672) were 2.4 times more likely to report unrelieved pain prior to admission.<br>Participants from non-hospice groups ($n$ = 698) were significantly more likely to wait for too long for pain medication ($p$ < 0.05).<br>The participants in both groups ($n$ = 1370):<br>• 1/2 had unrelieved pain prior to admission<br>• 2/5 received inadequate analgesics<br>• 2/5 still had unrelieved pain 7 days after hospital admission. |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 10 | Huang et al. (2009)<br>Mainland China | To investigate the characteristics and treatment of cancer pain of cancer patients in Shanghai. | Inpatient (*n* = 1131)<br>Level 2 or 3 hospitals or level 1 palliative cancer care hospitals with ≥300 beds | Cross-sectional | Intensity visual analogue scale<br>Self-designed questionnaire:<br>pain treatment<br>patients' perceptions of analgesics<br>satisfaction with pain treatment as well as associated factors | Among the participants:<br>• average interval from feeling pain to get treatment was 4.1 months<br>• 2/5 only took analgesics when pain occurred<br>• 2/5 feared addiction<br>• 2/3 could not get treatment when cancer pain occurred<br>• 1/5 had difficulty getting pain treatment<br>• about 1/2 used two or more methods for pain treatment<br>• 2/3 accessed the cancer pain clinic for pain control<br>• only 5.5% might get full reimbursement for their pain treatment.<br>The most rated effective treatment: analgesics (79.1%), physical therapy (8.1%) and traditional Chinese medicine (4.7%).<br>1/6 were dissatisfied with pain control because of adverse reactions, inefficient pain control, inadequate dosage of analgesics and limited usage of analgesics due to financial burden. |
| 11 | Liang et al. (2008b)<br>Taiwan | To explore outpatients' tasks and behaviours related to opioid-taking for cancer pain and factors affecting their self-efficacy of opioid-taking at home | Outpatients (*n* = 10) with pain<br>Two teaching hospitals | Semi-structured interview | Self-developed interview guide based on theoretical framework of self-efficacy | Factors associated with participants' opioids-taking self-efficacy:<br>• communication between health professions and the patients in relation to pain<br>• knowledge about effects of opioids, side-effects and self-monitoring<br>• capability of adjusting or swabbing their pain medication according to their condition<br>• difficulties adhering to scheduled opioids due to limited access to opioids and after-hours pain service<br>• support from family and doctors<br>• concern about accessibility and financial situation, side-effects of opioids and disease progression or worsening. |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 12 | Chen et al. (2007)<br>Mainland China | To explore pain behaviours of cancer patients in the Zhanjiang area, and the influence of psychosocial factors on their pain behaviours. | Inpatients (*n* = 1197)<br>A tertiary hospital | Cross-sectional | Modified Questionnaire of National Cancer pain prevalence and associated factors for pain treatment<br>Pain assessment scale | 4/5 of participants experienced mild to severe levels of pain, among them:<br>• only 1/5 used strong opioids<br>• about 1/5 used acupuncture, physical therapy or traditional Chinese medications.<br>Among 303 participants who had pain but never received pain treatment:<br>• 4/5 refused analgesics but requested acupuncture, scraping, moxa moxibustion, massage or physical therapy<br>• 1/5 refused any pain treatment because of fear of addiction, (1/2) side-effects, (1/3) pain endurance belief (1/5) or due to economic or other reasons (1.65%). |
| 13 | Lu et al. (2006)<br>Mainland China | To evaluate effects of educational program on cancer patients' pain control. | Inpatients (*n* = 112)<br>A cancer hospital | Observational study without a control group | Patients' compliance with pain treatment<br>Level of pain relief<br>Satisfaction with their pain control<br>Modified BQT | All participants had pain and received oral analgesics or a patch for pain treatment by following the WHO 3-step ladder, and among them:<br>• only 2/5 adhered to around-the-clock pain treatment<br>• only 1/5 were satisfied with the level of pain control.<br>Total scores of the participants' barriers to pain and pain treatment were high at 2.81 ± 0.54, and all sub-scores were ≥2.<br>Barriers perceived were addiction, dependence, tolerance and side-effects of using opioids, difficulty getting drugs as pain worsens, fear of pain relief interfering with cancer treatment, fear of disturbing nurse and family, tolerating pain meant strength, economic burden and uncontrollable pain. |
| 14 | Lai et al. (2004)<br>Taiwan | To evaluate effects of a brief structured pain education program on inpatients' cancer pain experience. | Inpatient (*n* = 30)<br>A medical centre | A pilot randomised controlled trial | BPI-Chinese.<br>POABS-CA.<br>Coping Strategies Questionnaire-Catastrophizing and CSQ sense control over pain measures (CSQ-Cat) | Baseline assessment:<br>• all participants were in pain for around 4 months<br>• all had high scores (⩾2.9) in negative effect beliefs about using opioids, pain endurance beliefs and catastrophising, and had a low sense of control pain score (1.90 ± 1.58). |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 15 | Lai et al. (2002)<br>Taiwan | To explore oncology inpatients' pain beliefs and adherence to prescribed analgesics;<br>To identify predictors of adherence to analgesics. | Inpatients ($n$ = 194)<br>4 teaching hospitals | Cross-sectional | Analgesic adherence: patient self-reported prescribed analgesic-taking options<br>POABS-CA<br>Survey of Pain Attitude<br>Pain Numerical Rating Scale | Duration of experienced pain: 3−7months with mean intensity of pain at 3.49 ± 1.77 and peak intensity of pain up to 7.26 ± 2.39 for at least 7 days.<br>1/3 of participants failed to adhere to prescribed analgesics.<br>Lower control belief (odds ratio = 0.393, $p$ = 0.0001) and higher medication belief (odds ratio = 2.153, $p$ = 0.02) were two significant predictors of participants' analgesic adherence. |
| 16 | Lin (2001)<br>Taiwan | To examine congruity between cancer patients' and their families' perceptions about cancer pain, and to determine if the congruity associated with patients' concerns about reporting their pain and using analgesics. | 89 dyads of inpatients and family caregivers<br>Two teaching hospitals | Cross-sectional | Patients:<br>BQT<br>BPI-Chinese Eastern Cooperative Oncology Group (ECOG) performance status scale.<br>Family caregivers: BPI-Chinese | 2/3 of dyad participants and family caregivers did not have congruence in cancer pain intensity.<br>Non-congruent group participants had significantly higher scores than those in congruent group in the following aspects:<br>• disease progression and religious fatalism ($p < 0.01$)<br>• tolerance and total BQT scores ($p < 0.05$).<br>The participants in both groups had high scores (>2) in fatalism, addiction, distract physicians, disease progression, tolerance, side-effects and PRN. |
| 17 | Lin (2000)<br>Taiwan | To compare attitudes between cancer patients and their family towards cancer pain management. | 159 dyads of inpatients and family caregivers (total $n$ = 318)<br>A teaching hospital | Cross-sectional | Patients:<br>BQT<br>BPI-Chinese<br>ECOG performance status scale<br>Pain management Index (PMI).<br>Family caregivers: BQT | The patients had high sub-scores of BQT (≥3) in tolerance, disease progression, PRN, addiction and side-effects.<br>Only 2/3 accurately used prescribed analgesics which significantly had lower BQT total scores than those who were under-medicated ($p < 0.05$).<br>More than 1/2 hesitated in taking analgesics in the last months and had significantly higher scores in addiction ($p < 0.01$), PRN tolerance and the total BQT ($p < 0.001$). The hesitance was significantly associated with their family caregivers' BQT scores ($p < 0.01$).<br>Family caregiver's total BQT scores were significant predictors of patient accuracy in using analgesics ($p < 0.05$). |

| No.[a] | Authors/ year/location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 18 | Wills and Wootton (1999)<br>Hong Kong | To identify misconceptions and concerns related to cancer pain management among Hong Kong Chinese patients. | Inpatients (*n* = 48)<br>A teaching hospital | Cross sectional | 9 common concerns and misconceptions about analgesia divided into five subscales: good patients, fatalism, character building, addiction and side-effects by Gordon and Ward (1995)<br>Visual Analog Scale | 35 participants had pain<br>1/4 avoided taking analgesics when admitted to hospital<br>4/5 did not want to distract physicians with their pain<br>2/5 were not willing to disturb nurses with their pain as they thought nurse were very busy and needed to take care of other participants as well<br>4/5 agreed that pain was unavoidable and a part of their admission to the hospital<br>2/3 believed pain was uncontrollable based on their previous hospitalisation experience<br>1/2 believed that analgesics could early cause addiction and should be the last option for pain management<br>2/3 were unwilling to tolerant the side-effects. |
| 19 | Lin and Ward, 1995<br>Taiwan | To investigate cancer patients' concerns about reporting and using analgesics.<br>To explore the relationship between patients' concerns and their adequacy of analgesic usage. | Inpatients (*n* = 63)<br>Five teaching hospitals | Cross sectional | BQT<br>BPI-Chinese<br>PMI<br>Medication sheet | The concerns most strongly held by the participants were tolerance, disease progression, time interval and addiction.<br>4/5 wanted to save analgesics for the worst pain.<br>More than 1/2 hesitated reporting pain in the last month and those participants were found having significant higher scores on fatalism, fear of addiction, distracting physicians, concerns about time interval and total BQT.<br>Among the participants (*n* = 36) reported pain at last 24 hours prior to data collection, 2/3 had negative PMI scores which indicated inadequate amount of using analgesics. |

[a] The number of the studies are listed in a chronological order
[b] Four articles were written based on one study
[c] Two articles were written based on one study

### *2.5.2 Identified barriers*

The barriers that prevented the participants reporting their cancer pain, receiving pain treatment, adhering to the prescribed analgesics and achieving optimal pain control are further described below.

#### Patient-related barriers

The patient-related barriers mostly arose from the participants' beliefs regarding cancer pain and analgesics, including pain-related beliefs and analgesics-related misconceptions.

***Pain-related beliefs***

Participants' conceptualisation of their pain experiences significantly influenced their pain management behaviours (Lai et al., 2002) and decision-making (Lai et al., 2004; Liang et al., 2013b; Lin et al., 2013; Wills & Wootton, 1999). 'Fatalism' was identified as a major obstacle to preventing participants from using analgesics to relieve their cancer pain (Lin, 2000, 2001; Wills & Wootton, 1999). Inpatients with higher fatalism scores considered pain as an inevitable experience of hospitalisation, hesitated to use analgesics, and often endured pain for months (Lin, 2000; Wills & Wootton, 1999).

Participants with a higher 'desire to be good' score, as measured by the 'Barriers Questionnaire', were more reluctant to talk about their pain, because they did not want to disturb their nurses or doctors (Lin, 2000, 2001; Wills & Wootton, 1999). In addition, many participants believed that pain was an indication of 'disease progression' (Liang et al., 2008a; Lin, 2000, 2001; Lin & Ward, 1995; Tse et al., 2012). This belief discouraged them from accepting pain treatment (Liang et al., 2008b; Lin et al., 2013); and made them reluctant to report their pain to health professionals (Lin, 2000, 2001; Lin & Ward, 1995; Tse et al., 2012), or to adhere to an around-the-clock analgesic regimen (Liang et al., 2013a; Liang et al., 2008a).

'Pain endurance belief' refers to "the belief that one should endure as much pain as possible") (Lai et al., 2002 p. 416). 'Pain control belief' is a belief "that one can control his/her pain" (Lai et al., 2002 p. 416). The high scores of 'pain endurance belief' and the lower scores of 'pain control belief' were significant negative predictors of analgesic adherence (Lai et al., 2004; Liang et al., 2013b).

In several studies, participants described the need to 'be brave' (Chen et al., 2007; Pang et al., 2013) or to 'bear the pain' (Lin et al., 2013). In fact, some participants did not realise that their pain could be relieved (Lin et al., 2013; Lu et al., 2006; Pang et al., 2013).

### ***Analgesics-related misconceptions***

Cancer patients with lower education levels (Chen et al., 2007; Xia, 2015) and an older age (Xia, 2015) or misconceptions about analgesics had greater difficulty adhering to analgesics.

In the studies investigating Chinese cancer patients' perspectives on opioid use, the participants commonly held 'negative effect beliefs' (Lai et al., 2004; Lai et al., 2002; Liang et al., 2013a; Liang et al., 2013b; Liang et al., 2015; Liang et al., 2008a, 2008b, 2012). The 'negative effect beliefs' is "a belief that opioids have negative effects on the body" (Lai et al., 2002 p.416). Participants with a high opioid 'negative effect belief' ($r = -30$, $p < 0.01$) were less likely to adhere to an around-the-clock analgesic regimen (Liang et al., 2013b; Liang et al., 2008a). Concerns about side-effects and addictions were also reported as barriers to using opioids (Pang et al., 2013). In contrast, the patients' belief that medications could be effective in treating pain (Lai et al., 2002) and high self-efficacy for administering opioids (Liang et al., 2008a, 2008b, 2012) were indicators of better adherence to opioids for cancer pain treatment.

In the studies exploring participants' perspective on analgesics in general, the findings suggest that poor analgesic adherence was mainly linked to a disproportionate 'fear of addiction' or 'analgesic dependence' (Chen et al., 2007; Huang, 2009 ; Lin, 2000, 2001; Lin & Ward, 1995; Lin et al., 2013; Tse et al., 2012; Wills & Wootton, 1999; Xia, 2015), and 'concerns about side-effects' (Chen et al., 2007; Huang, 2009 ; Lin, 2001; Lin et al., 2013; Tang, 2010; Tse et al., 2012; Wills & Wootton, 1999; Xia, 2015).

### **Family-related barriers**

The participants in the qualitative study regarding cancer patients' opioid-taking task and behaviours perceived their family as the 'bridge' between themselves and their health care providers, and considered that family support was central to helping them cope with their pain and pain treatment (Liang et al., 2008b). A family member's perspectives on cancer pain and its management may have an impact on participants' adherence to analgesics.

In a few studies involving both patients and their families, some family members perceived pain as an indicator of 'disease progression' and worried that taking analgesics to control the pain would mask warning signs of cancer progression (Lin, 2000; Pang et al., 2013). Analgesic side-effects and safety (Lin, 2000, 2001; Pang et al., 2013), addictions and tolerance (Lin, 2000) were also major concerns of the family members.

Congruency between patients’ and families’ cancer pain management perceptions is essential for analgesic adherence (Lin, 2000, 2001).The perception of barriers among family caregivers was a significant negative predictor of patients’ accuracy and aptitude in using analgesics ($p < 0.05$) (Lin, 2000), and a predictor of patients’ hesitation to take analgesics ($p < 0.01$) (Lin, 2000).The non-congruent group of patients had significantly higher ($p < 0.01$ or $< 0.05$) total barrier scores and sub-scores on ‘disease progression’, ‘religious fatalism’ and ‘tolerance’ than those in the congruent group, and were less likely to adhere to their pain treatment (Lin, 2000).

#### Health professional-related barriers

The main health professional-related barriers reported by the participants were ineffective management of analgesic side-effects (Huang, 2009 ; Lin et al., 2013) or delays in treating side-effects (Chen et al., 2007; Hu et al., 2010; Pang et al., 2013). Inefficient pain control also led to participants’ dissatisfaction with their pain management (Huang, 2009 ; Lin et al., 2013). Poor communication and a lack of information on pain treatment were barriers to optimal pain control (Liang et al., 2008b).

#### Health care system-related barriers

Participants had difficulty accessing opioids after hours (Liang et al., 2008b) and obtaining analgesics to manage unexpected pain exacerbations (Pang et al., 2013). Participants were also dissatisfied with delays to their cancer pain treatment and the limited supply of analgesics, which was not commensurate with the dosing regimen required to control their pain (Huang, 2009 ; Lin & Ward, 1995; Tang, 2010; Tang, Tang, Liu, Lin, & Chen, 2010).

Participants with low incomes (Chen et al., 2007; Xia, 2015) or those without health insurance (Huang, 2009 ; Liang et al., 2008b; Lu et al., 2006; Xia, 2015) had even more limited access to analgesics due to concerns about affordability. Even participants with health insurance, they had limited access to analgesics and quality pain treatment, because the amount of insurance funds contributing to pain treatment was extremely restricted (Song et al., 2014). Participants also worried that community hospitals might not be able to provide analgesics and appropriate treatment for their cancer pain (Hu, Qiu, Mei, Ran, & Zang, 2010).

## 2.6 Discussion

This systematic review revealed a range of patient, family, health professional and health care system-related barriers that contributed to the experience of unrelieved pain, delay in receiving pain treatment and poor adherence to prescribed analgesics in Chinese people living with cancer.

The patients' pain beliefs, such as 'fatalism' and 'desire to be good', 'pain endurance beliefs', low 'pain control beliefs' and 'concerns about disease progression', have analogies with those reported in the western literature (Oldenmenger, Sillevis Smitt, van Dooren, Stoter, & van der Rijt, 2009). However, the cultural influences underpinning these beliefs need to be addressed to help health professionals understand Chinese cancer patients' pain management-related behaviours and needs.

Buddhism teaches that "pain is a power, unwanted but existent …" (Chen, Miaskowski, Dodd, & Pantilat, 2008, p.105). This perspective leads people to view pain as a 'natural thing' − an indicator of their body reacting to the cancer (Chen et al., 2008, p.105; Im, Liu, Kim, & Chee, 2008). This fatalism can extend beyond pain to the cancer itself (Chung, Wong, & Yang, 2000). Cancer pain is considered both fate associated with misery and a reminder of life; what patients can do when confronted with pain is to wait until death comes (Chung et al., 2000).

The desire to be 'a good patient' may stem from the influence of Confucianism. Confucianism encourages people to strive for a harmonious relationship with nature and others (Dayer-Berenson, 2014). Chinese patients' desire to maintain harmonious relationships with others may lead to a reluctance to 'bother' health professionals with their health problems (Dayer-Berenson, 2014; Tjuin et al., 2007).

The 'pain endurance belief' is also likely associated with the influence of Confucianism. Chinese people in general are not comfortable expressing feelings in front of others when they experience hardship. This stoicism is seen as important to winning others' respect. Therefore, Chinese people often perceive pain as a 'trial' that tests their strength and think that pain is part of the sensation of being human (Chen et al., 2008). Whilst cultural beliefs of this kind may help with coping in some instances, they have the potential to generate feelings of helplessness and misery in Chinese cancer patients (Chung et al., 2000) .The patients may tend to suffer in silence rather than seek help before their pain becomes severe (Chen et al., 2008).

In addition, Chinese cancer patients perceive pain as an indicator of disease progression (Liang, Yates, Edwards, & Tsay, 2008a; Lin, 2000, 2001; Lin & Ward, 1995; Tse et al., 2012).They worry that if their pain is controlled, this could eventually prevent the warning signs of cancer from reoccurring or advancing (Chen et al., 2008). This may also explain why Chinese cancer patients tend to suffer the pain instead of obtaining help.

The ‘negative effect belief’ about opioids and ‘fear of addiction’ among Chinese cancer patients are very likely due to a lack of cancer pain and treatment information (Lai et al., 2004; Lu, Guan, & Ma, 2006; Tse et al., 2012) or inefficient communication between patients and health professionals (Liang, Yates, Edwards, & Tsay, 2008b). Without adequate information, the patients may find that it is difficult to communicate with health professionals about their concerns and to know where to seek help (Butow et al., 2010; Liang et al., 2008b).

As with patient-related barriers, the strong influence of family’s beliefs on pain management reported by Chinese cancer patients reflects the cultural importance of family relationships, loyalty, obligation, obedience, cooperation, interdependence and reciprocity in Chinese society (Dayer-Berenson, 2014). In a traditional Chinese family, health decisions are based on a process of family consensus in which usually the oldest family members or the eldest son has the highest influence. Being able to stay with family helps overcome hardships (Chung et al., 2000). However, this closeness can change patients’ pain perceptions, as they may fear that the cancer will spread to other family members or they may feel shamed in front of their friends (Chung et al., 2000).

The stigma and concern over social networks may prevent Chinese cancer patients from sharing their experiences of pain with their families. This dynamic has implications for how health professionals engage family members in shared decision-making regarding pain management. Strategies aiming to empower cancer patients and their families to self-manage pain is essential for optimal pain management (Luckett et al., 2013).

Patient education in relation to reporting pain and the use of analgesics is an essential method to improve cancer patients’ knowledge of, and adherence to analgesics (Oldenmenger et al., 2009). Educational interventions for families about managing side-effects, disease progression and around-the-clock analgesics are also important as Chinese cancer patients are heavily dependent on their families, especially once they are in palliative care (Lin, 2000).

The health professional-related barriers reported by the patients in this study are consistent with those reported by physicians and nurses (Oldenmenger et al., 2009), which may be associated with health professionals’ analgesic beliefs (e.g. concerns about addiction and side-effects), and inadequate knowledge and skills in cancer pain mangement (Li et al., 2013; Oldenmenger et al., 2009).

The limited reports of using the WHO 3-step ladder to guide pain treatment and inadequate prescription of opioids for cancer patients reflect the importance of increasing health care professionals' awareness of analgesic use in cancer pain management. The outcome of pain treatment can only be improved when routine pain education and appropriate doses of opioids are provided and the treatment is regularly adjusted (Dy et al., 2008). Health policies need to be reinforced to provide training programs for health professionals, to enhance their knowledge and skills in pain control, and to promote opioid usage in Chinese cancer patients (Lin et al., 2016).

The inadequate prescription of opioids and the limited access to opioids reported in the included studies was similar to the findings of western researchers, in which opioid-related fears have been commonly observed (Flemming, 2010) and were likely associated with the government restriction of opioid usage (OPEN Minds, 2005). Although understanding of the effectiveness and safety of opioids in chronic pain management is gradually increasing and the importance of opioids in pain relief has been addressed, opioid use remains restricted because many national laws are focused on controlling misconduct, abuse and addiction (OPEN Minds, 2005). The rules and regulations should be updated to eliminate the fear of opioids (OPEN Minds, 2005).

At the health care system level, limited access to analgesics, a lack of after-hours access to opioids and concerns about the quality of pain management services at local community hospitals suggest that health service reforms should focus on increasing affordability and accessibility of analgesic and community-based pain services, and supporting pain self-management of the cancer patients and their families at home.

The similarities between the barriers reported in Chinese populations and in the western literature may partly be because most of the validated measures used in the included studies were developed for non-Chinese speaking populations and only focused on patients' perspectives to pain and analgesics. Evaluating the cultural-social influential factors underneath unrelieved cancer pain is urged to inform effective interventions for cancer pain management (Jacobsen, Møldrup, Christrup, & Sjøgren, 2009). A reliable and valid instrument should be developed to ensure better coverage of barriers that reflect specific Chinese cultural considerations.

## 2.7 Strengths and limitations

The generalisability of findings in this systematic review may be limited due to the small numbers of articles identified and several methodological factors. The majority of the studies used a cross-sectional design and a convenience sampling technique. More than half were conducted at a single study site. All studies were undertaken in the hospital settings of metropolitan areas and the participants' demographic data in some studies were unclear, so it was uncertain if the studies included participants from remote areas.

Only a small numbers of participants were outpatients. Therefore, the barriers and needs reported in this systematic review may not be able to reflect the pain management barriers and specific experiences of cancer patients in the inpatient settings when they discharged. The fact that the majority of participants in the included studies were males may potentially have led to bias because of gender differences in pain and pain management perspectives.

Despite the limitations, the findings of this review have been strengthened by adhering to the review protocol with multiple reviewers involved throughout the process of search, quality appraisal, data extraction and analysis and reporting, to maintain consistence and rigour. The Chinese data translation was cross-checked by a highly efficient bilingual-speaking academic to ensure completeness and accuracy.

Even though the sample size in some studies was small, in total the findings of this review are based on primary data reported by more than 6,000 Chinese cancer patients. It may provide accountable information to health professionals and researchers for future development in clinical practice and research, to improve outcomes of cancer pain management for people from Chinese backgrounds.

## 2.8 Summary

Cancer patients from Chinese backgrounds are more likely to seek TCM and to engage with culture-related health practices for their pain control due to a series of patient, family, health and system-related barriers. However, there is no direct evidence about cultural beliefs underpinning their barriers to using analgesics. This review is also not able to provide information about the needs and barriers of Chinese cancer patients in relation to non-pharmacological interventions, since existing the literature has mainly focused on the pharmacological analgesia. Future studies based on the cancer pain management guidelines addressing this area are needed to inform the development of multidisciplinary and biopsychosocial pain management approaches that are culturally appropriate.

Another notable gap in the literature concerns the absence of studies focusing on Chinese migrants' cancer pain management-related experiences. Further research directed by cultural care theories or models is required to identify cancer pain management-related barriers and cultural influential factors in Chinese migrants living in countries that have different cultures, especially those who have less support after they are discharged home and are receiving pain treatment at clinics or community services.

The following chapter describes Leininger’s ‘Culture Care Theory’ – the theoretical framework of this doctoral project, to exploring cultural influences on the cancer pain management of Chinese migrants with cancer pain living in Australia.

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# Chapter 3 Theoretical framework

In Chapter 2, the systematic review of the English and Chinese literature revealed a range of patient, family, health professional, and health system-related barriers affecting Chinese patients' cancer pain-reporting behaviours. This systematic review suggested that collectively these factors may contribute to Chinese people's unrelieved cancer pain (Xu, Luckett, Wang, Lovell, & Phillips, 2018). The conclusion urged that further research informed by cultural care frameworks to be undertaken for better understanding Chinese migrants' cancer pain needs (Xu et al., 2018).

Cultural considerations are critical to understanding a person's cancer care experiences (Dein, 2006), including how best to optimise their cancer pain management (Al-Atiyyat, 2009). This chapter considers the usefulness of cultural care frameworks, and provides a rationale for adopting Leininger's 'Culture Care Theory' for this doctoral project.

## 3.1 Importance of theoretical frameworks in research

Cultural influence in health care is a complex concept. Over the past decades, a number of cultural care theories and models have been developed to enable health professionals to deliver health care to people from diverse backgrounds in more appropriate and sensitive ways (Dayer-Berenson, 2014; Holland & Hogg, 2010).

A theory is "… a set of interrelated constructs, definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting the phenomena" (Kerlinger 1973 adopted by Waltz, Strickland, & Lenz, 2010,p.3). A conceptual model is a representation of reality that usually involves a simplification of a phenomenon or a specific aspect of a phenomenon to help people understand it (Nilsen, 2015).

Theoretical or conceptual frameworks can be used in the progress of a scientific enquiry, to direct research development towards descriptions and explanations of a natural phenomenon in health care as well as uncovering reasons underpinning its occurrence (Polit & Beck, 2012).

As previously discussed in Chapter 1, culture can significantly affect people's cancer pain care outcomes (Lasch, 2000). Uncontrolled cancer pain is a persisting and multi-dimensional health issue requiring cultural and social considerations for improvement (Brant, 2014; Lasch, 2000; Odenmenger, Smitt, Dooren, Gerrit, & Rijit, 2009; Ruseel & Tandon, 2011). Adopting a cultural care framework that assists in a better understanding of cultural influences on Chinese migrants' cancer pain and pain management perspectives is critical for informing culturally congruent pain care.

Employing a cultural care theory or model with characteristics of middle range theories is feasible for research with a focus on clinical practice and research (Smith, 2018). A middle range theory refers to the theories that provide specific knowledge with concrete concepts and empirical indicators from meta-perspectives, to inform health care practice and research activities and promote a better understanding on the specific concepts or phenomena in nursing and/or other health disciplines (Smith, 2018).

## 3.2 Review of cultural care theories/models

Guided by Smith's (2018) 'Framework of Evaluation of Middle Range Theories', a critical appraisal was conducted to identify an appropriate cultural care theory or model to guide this doctoral project. This critical appraisal involved comparing and contrasting the concepts and structures of available cultural care theories and models. It was initially conducted at the outset of this doctoral project in 2016 and refined in 2018.

Smith's (2018) Framework of Evaluation of Middle Range Theories provides a guide for the structured critical analysis on theories and models. The structured critical analysis process enables health professionals gain a deep understanding of concepts, structure, assumptions and application scopes of theories and models, and help them identify a middle range theory or model that is appropriate to be used as a theoretical framework for their studies (Smith, 2018).

### *3.2.1 Methods*

The methods of critical appraisal on the cultural care theories and models are detailed at below.

**Searching strategies**

A systematic search of the literature was conducted over three stages:

**Stage 1:** Initial search was performed to identify primary resources of cultural care theories and models published in original textbooks, text book chapters or peer reviewed journal articles, via University of Technology Sydney Library catalogue, and electronic health databases (e.g. CINAHL, MEDLINE).

Search terms included “culture”, “cultural care theory”, “cultural care model”, “cultural theory”, “cultural model”, “transcultural care theory”, “transcultural care model”, “cross-cultural theory” , “cross-cultural model”, “cultural competence” or “cultural competency”. Snowball technique was used to identify the original articles or book chapters about theories and models.

Whilst no limits were placed on the year of publication, the latest version of the theories or models were selected as the main source for critique when different versions were identified.

**Stage 2:** Using the theorists’ names or titles of the theories or the models as the search term, to identify the primary resource of research papers and reports of empirical works written by the theorists and their associates related to the identified theories and models, to track the history of theory evolution.

**Stage 3:** During the final stage, the search focused on resources (textbooks/journals) published between January 2007– March 2016, and written by other researchers about reviewing on the identified theories and models. Publishing examples of using the theories and models as theoretical frameworks in research and practice were identified.

**Eligible criteria**

To be eligible for inclusion, the theory or the model had to: 1) have a primary focus on cultural care; 2) have been developed specifically to improve health practice and/or research; and 3) published in peer review textbook or journal. Grey literature was not included.

### Criteria of critical appraisal

The critical analysis focused on three criteria of the Smith's appraisal framework: 1) substantive foundation, 2) structural integrity, and 3) functional adequacy (Smith, 2018), as described at below:

**Substantive foundation:** The substantive foundation step was used to explore the meanings and essential elements of cultural care frameworks. This phase was designed to determine whether or not the theory or the model has been developed with a focus on cultural care, was underpinned by established assumptions that are specific and consistent with the focus; provide a substantive knowledge about concerns to a specific cultural care phenomenon at a level of middle-range; and emerged out of a well-documented research and practice experiences related to health care (Smith, 2018).

**Structure integrity:** The evaluation of structure integrity focuses on whether or not: 1) the theory or the model provided clear definitions of the key concepts; 2) the theory or the model concepts were at a low level of abstraction that are interpretable and measurable; 3) there was no a need to provide more concepts to explain the cultural care phenomenon; and 4) the concepts of the theory or the model was organised in a way that demonstrates a logical linkage among the concepts (Smith, 2018).

**Functional adequacy:** Functional adequacy explores whether or not: 1) the theory or the model is applicable in different environments and populations; 2) the empirical indicators of the concepts has been defined; 3) there were published examples of applying the theory or the model in practice; and 4) the theory or the model has been evolved through a series of scholarly investigations (Smith, 2018).

### *3.2.2 Results*

Out of 20 identified theories and models, five met the inclusion criteria and included for the review. These five theoretical theories and models were: Giger and Davidhizar's Transcultural Assessment Model (Giger and Davidhizar's Model) (Giger, 2018), Leininger's Theory of Culture Care Diversity and Universality (Leininger's 'Culture Care Theory') (McFarland & Wehbe-Alamah, 2015c), Theory of Cultural Marginality (Choi's theory) (Choi, 2014), PEN-3 Cultural Model (Iwelunmor, Newsome, & Airhihenbuwa, 2014), and Purnell Model for Cultural Competence (Purnell's Model) (Purnell, 2014). The included theories and models were initially developed between 1960s - 2000s and evolved. The latest versions were used as the main references for the critical appraisal.

#### Substantive foundation of included theories/models

The substantive foundations of the five included theories and models are outlined in Table 3.1. The results show that all identified theories and models have been used to contribute substantive knowledge to a range of specific cultural care phenomena. Among the five included theories and models, three of them, namely Giger and Davidhizar's Model (Giger, 2018), Leininger' Cultural Care Theory (McFarland & Wehbe-Alamah, 2015c), and Purnell's Model (Purnell, 2014) are built upon specific philosophical assumptions that are congruent with their focus. The congruency between the assumptions and the focus has enabled each to elicit a clear picture about the context meaning of the theory or the model. However, Choi's theory and the PEN-3 Cultural Model do not provide identifiable philosophical assumptions to specify its origins and ontological foundations. The lack of philosophical assumptions may cause confusion and misunderstanding, when researchers apply them to direct research or assessment in relation to cultural care phenomenon.

**Table 3.1 Substantive foundations of selected cultural care theories/models**

| Theories/models, author and country | Cultural care focus | Assumptions are specified and congruent with the focus | The theory/model provides substantive knowledge about concerns to a specified cultural care phenomenon | The original is grounded in health care or clinical or nursing practice and research experience |
|---|---|---|---|---|
| **Giger & Davidhizar's Model**<br>(Giger, 2018)<br>USA | Yes (culturally appropriate and competent care) | Yes (based on Leininger's 'Culture Care Theory') | Yes (cultural effects on culturally specific illness and behaviours and its assessment) | Yes (nursing education and practice) |
| **Leininger's 'Culture Care Theory'**<br>(McFarland & Wehbe-Alamah, 2015c)<br>USA | Yes (culturally congruent care) | Yes, e.g. "Culturally congruent and therapeutic care occurs when cultural care values, beliefs, expression, and patterns are explicitly known and use appropriately, sensitively, and meaning fully with people of diverse or similar cultures" (p. 8). | Yes (cultural diversity and its influences on health care) | Yes (practice, education and research in anthropology; nursing and other health disciplines) |
| **Choi's Theory**<br>(Choi, 2014)<br>USA | Yes (marginal living and cross-cultural care) | Not provided | Yes (the cross-cultural conflicts between cultures and its impact on health care) | Yes (migrant adolescent health) |
| **PEN-3 Cultural Model**<br>(Iwelunmor, Newsome, & Airhihenbuwa, 2014)<br>USA | Yes (culture empowerment) | Not provided | Yes (impact of culture on health behaviours and health outcomes) | Yes (public health) |
| **Purnell's Model**<br>(Purnell, 2014)<br>USA | Yes (culturally competent care) | Yes, e.g. "Culture has powerful influence on one's interpretation of and responses to health care" (p. 8) | Yes (the need of cultural competence) | Yes (health practice, education and research) |

### Structure integrity of idenfied theories/models

The critical appraisal found that only Giger and Davidhizar's Model (Giger, 2018) and Leininger's Cultural Care Theory (McFarland & Wehbe-Alamah, 2015c) fully meet the structural integrity criteria (refer to Table 3.2). The theorists of Giger and Davidhizar's Model and Leininger's 'Culture Care Theory' both have clearly defined the key concepts related to their cultural care frameworks, and developed a series of empirical indicators for each of their concepts. They have also developed examples of questions and/or assessment items to illustrate how these concepts can be measured in health research. All key concepts of the frameworks are logically integrated and presented in a diagrammatic form to enhance understanding.

The theorists of Choi's Theory (Choi, 2014) and Purnell's Model (Purnell, 2014) have also clearly defined the key concepts and provided conceptual models to explain the relationship between the concepts. However, it would be clearer if Choi may provide empirical examples, to help researchers understand how the key concepts of the Choi's Theory, such as 'marginal living', 'cross-cultural conflict recognition' and 'easing cultural tension', may be used to inform development of research questions or assessment items to explore cultural factors affecting migrant adolescent' health. Purnell has also provided a conceptual model to help researcher understand the key concepts of the cultural competences in health care, but failed to demonstrate logical relationships between the concepts.

PEN-3 Cultural Model (Iwelunmor, Newsome, & Airhihenbuwa, 2014) needs to be further developed to clearly define the meaning of 'cultural identity, relationships and expectations', and explains why cultural empowerment is important and what care outcome is expected by providing the cultural competent care to people.

**Table 3.2 Structure integrity of cultural theories/models**

| Theories/models, author and country | The concepts are clearly defined | The concepts are at a middle-range level of abstraction | There is no more concepts than needed to explain the phenomenon | The concepts and relationships among them are logically represented in a model |
|---|---|---|---|---|
| **Giger & Davidhizar's Model**<br>(Giger, 2018)<br>USA | Yes (e.g. culture, transcultural nursing care, culturally diverse nursing care, culturally competent care, culturally unique, individuals and culturally sensitive environment) | Measurable | No more concepts required | Yes (the Giger and Davidhizar's transcultural assessment) |
| **Leininger's 'Culture Care Theory'**<br>(McFarland & Wehbe-Alamah, 2015c)<br>USA | Yes (e.g. culture, culturally congruent care, emic and etic care, cultural diversity, cultural care universality, worldview) | Measurable | No more concepts required | Yes (e.g. Leininger's 'Sunrise Enabler to Discover Cultural Care') |
| **Choi's Theory**<br>(Choi, 2014)<br>USA | Yes (e.g. marginal living, cross-cultural conflict recognition, easing cultural tension) | Not measurable | No more concepts required | Yes (The cultural marginality) |
| **PEN-3 Cultural Model**<br>(Iwelunmor, Newsome, & Airhihenbuwa, 2014)<br>USA | No (cultural identity, relationships and expectations, and cultural empowerment were mentioned but did not clearly defend) | Not measurable | Yes (e.g. the concept about cultural care outcome is needed to explain why cultural empowerment is important) | No (the PEN-3 Cultural Model is presented but the logical relationship among the concept is unclear) |
| **Purnell's Model**<br>(Purnell, 2014)<br>USA | Yes (e.g. culture, cultural awareness, cultural sensitivity, cultural competence) | Measurable | No more concepts required | No (the Purnell Model for Cultural Competence is presented but the logical relationships among the concepts are unclear) |

### Functional adequacy of identified theories and models

The functional adequacy (refer to Table 3.3) of the included cultural theories and models varies considerably, as described below:

#### *Giger and Davidhizar's Transcultural Assessment Model*

Giger and Davidhizar's Model is informed by Leininger's Transcultural Care Theory and other researchers' works about communication, space phenomena and anthropology (Giger, 2018). Giger and Davidhizar's Model (2002) was initially used as a conceptual framework for developing an undergraduate program to facilitate nursing student assessment and caring for people from culturally devise backgrounds. It was then refined and extended through a series of research studies, and used as a practical tool to explore the effects of cultural factors on people's health and culturally specific behaviours of illness and wellness (Giger, 2018).

Giger and Davidhizar's Model clearly defines five key concepts of 'transcultural nursing', 'culturally diverse nursing care', 'culturally competent care', 'cultural competence', 'culturally unique individuals', and 'culturally sensitive environments' (Giger, 2018). The central ideas of this model is that health care providers need to firstly recognise their client's cultural background, and see them as a 'culturally unique individual' before assessing their cultural illness and wellbeing needs via six dimensions (Giger, 2018):

**'Communication':** Giger and Davidhizar suggest that culture may affect people's feelings, and verbal and non-verbal expression in relation to their illness and wellbeing (Giger, 2018). The communication barriers between nurses and patients as well as their families, especially among those from different cultures, can cause anger and helplessness in both nurses and their clients (Giger, 2018).

Assessing patients' communication needs is essential to identify racial, cultural and social obstructs for a mutual understanding between nurses and patients (Giger, 2018).

**'Space':** Assessment on space focuses on an individual's comfort level in relation to both inner and outer personal space, which the dimension of the comfort zone

**Table 3.3 Functional adequacy of cultural theories/models**

| Theories/ Models | The theory can be applied to a variety of practice environments & client groups | Empirical indicators have been identified for concepts of the theory | There are published examples of research related to the theory | The theory has evolved through scholarly inquiry |
|---|---|---|---|---|
| **Giger and Davidhizar's Model**<br>**(Giger, 2018)**<br>**USA** | Yes (applied in nursing practice, research and education with focus on migrant groups in America) | Yes (provided examples of assessment questions and explanations about health perspectives and health practices in 23 cultural groups in America) | Substantial | Evolved though a series of scholarly inquiries and research since 1988 |
| **Leininger's 'Culture Care Theory'**<br>**(McFarland & Wehbe-Alamah, 2015c)**<br>**USA** | Yes (applied in health practice, research and education for patients and health professionals from different disciplines and environments) | Yes (provided 8 enablers with examples of empirical indicators to facilitate researchers and health professionals) | Substantial | Evolved though a series of scholarly inquiries and research since 1960s |
| **Choi's Theory**<br>**(Choi, 2014)**<br>**USA** | Yes (applied in nursing practice and research with focus migrant adolescent) | Not identified | Limited | Developed since 2006 |
| **PEN-3 Cultural Model**<br>**(Iwelunmor, Newsome, & Airhihenbuwa, 2014)**<br>**USA** | Yes (applied for patients with HIV, cancer, diabetes, malaria with focus on public health care) | Not identified | Limited | Developed since 1995 |
| **Purnell's Model**<br>**(Purnell, 2014)**<br>**USA** | Yes (applied for patients and health care team members in all health sittings, with focus on migrant groups in America) | Yes (provided questions to guide the assessment and explanations about health perspectives and health practices of people from 23 cultural backgrounds in America) | Limited | Developed since 2000 |

differs in different cultures (Giger, 2018). So instead of using a geographical approach, nurses need to pay attention to one’s spatial behaviours related to their degree of spatial comfort, their perceptions of the space and how close they would like to stand when they talk with their family and others (Giger, 2018). In the meantime, it is important that nurses recognise their own cultural bond and cultural viewpoints, accept themselves as a unique person with differences between them and their clients (Giger, 2018).

**‘Social organisation’:** The pattern of one’s cultural behaviours are shaped from the enculturation that is relevant to their cultural bonds, family relationships, cultural viewpoints and the transcultural life events (e.g. child bearing, illness and death) (Giger, 2018). To be able to understand culture and the culture-specific behaviours, nurses need to assess the culture based on the whole picture of the social context (e.g. one’s marital status, family relationships, perceptions of social activities, profession and political views (Giger, 2018)

**‘Time’:** In cultural care, time can be defined as clock time, which is universally used, and social time that is conceptually different in cultural groups and is related to the patterns and orientations of social processes and social life (Giger, 2018). Usually nurses with western cultural backgrounds are more familiar with clock time, while people from other cultures may prefer social time (Giger, 2018). The divergence may lead to conflict between nurses and their clients or to the medication errors that need to be assessed and addressed in nursing care (Giger, 2018).

**‘Environment control’:** Environment in cultural care is broader than peoples’ residential or treatment space, and extends to cultural health practices and cultural values existing across or within cultural groups that may affect their help-seeking behaviours (Giger, 2018). People who perceive themselves as having the power to control their health and their life internally and externally are more likely to take action to make changes towards good health (Giger, 2018).

**‘Biological variation’:** Biological cultural differences can be distinguished in people with different cultural backgrounds relating to physical and psychological characteristics as well as incidences of diseases and nutritional status associated with nutritional preferences (e.g. food patterns and habits) (Giger, 2018).

One of the key features of Giger and Davidhizar’s Model is that it provides specific assessment and techniques with case studies for 23 cultural groups in America (e.g. African−Americans, Chinese−Americans).

Since it was established, the model has been applied in various nursing clinical practices and research in various specialties of nursing disciplines to develop cultural care plans and cultural care models for specific diseases (Giger, 2018); and cultural competence and educational programs for different nursing disciplines (Giger, 2018; Shen, 2015).

### *Choi's Theory of Cultural Marginality*

Choi's Theory emerged in 2001 in response to increased concerns about the mental health of American immigrant adolescents. It was founded on the theories of acculturation, which was first defined by the Social Science Research Council (Choi, 2014), Vega et al.'s Theory of Acculturative Stress (1998 as adopted by Choi, 2014) and Park's Theory of Marginality (1928 adopted by Choi, 2014).

Immigrant adolescents face challenges when they are exposed to social situations and environments that are contradictory to their original culture, and they may feel acculturative stress when they have to adjust their social behaviours and perspectives to adopt the changes (Choi, 2014). Health professionals need to be aware of the unique experiences of individuals from a distinctive cultural background, to facilitate culture relevant care that is grounded on the understanding of key concepts of 'marginal living', 'cross-cultural conflict recognition', 'contextual/person influences', 'negotiation between cultural of origin and new culture', and 'easing cultural tension' (Choi, 2014).

As previously discussed, the meanings of these key concepts of Choi's Theory are clearly defined, in which 'marginal living' refers to the interactive status of conflicts and tensions that immigrant adolescents may encounter during the transcription process that are stimulated by living between their original and new cultures (Choi, 2014). Acknowledgment of this cross-cultural conflict is the first step to distinguishing two contradicting cultures in marginal living, to explore the contextual/personal influences underpinning the conflict and cultural tension (Choi, 2014). By adjusting their response patterns and negotiating between the two different cultures, people who encounter marginal living may ease the cultural tension and resolve their cross-cultural conflict (Choi, 2014).

As a newly emerged theory, Choi's Theory of Cultural Marginality has been employed as theoretical framework in nursing practice and research addressing American migrant adolescent health (Choi, 2014). With further development of the specific assumptions consistent with the focus of the theory and the empirical indicators for each core concepts to help researchers better understand the theory, Choi's Theory has the potential to be used in other populations who are experiencing cross-cultural transitions.

### *The PEN-3 Model*

The PEN-3 Model was developed to address the importance of including the cultural component in public health and health education programs (Airhihenbuwa 1989 & 1995 adopted by Airhihenbuwa, Ford, & Iwelunmor, 2014). It is grounded in public health and the health education paradigm (Airhihenbuwa et al., 2014).

The PEN-3 Model consists three domains, ‘cultural identities’, ‘relationships and expectations’, and ‘cultural empowerment’. ‘Cultural identities’ includes the term ‘person’, which includes patients and health professionals, extended family and the neighbourhood (Airhihenbuwa et al., 2014). The family is seen as an effective tool and starting point for cultural care (Iwelunmor, Newsome, & Airhihenbuwa, 2014).

The domain of ‘relationship and expectations’ help to explore individuals’ health beliefs and cultural values, other social influential factors and enablers (e.g. social resources), and/or the natural roles of family and kin in the process of health decision-making (Iwelunmor et al., 2014).

The ‘cultural empowerment’ domain guides the action of identifying the positive, extensile and negative influential factors related to an individual’s Cultural values and beliefs. Through the assessment process, the beneficial factors need to be defined and promoted to develop strategies that help people overcome the barriers and change their health behaviours (Iwelunmor et al., 2014).

The PEN-3 Model has been used as the theoretical framework in 45 studies, which it centralises culture in studies of health behaviours and integrates culturally relevant factors in development of the interventions for people with HIV, cancer, diabetes, malaria and other public health issues (Iwelunmor et al., 2014).

Despite its widespread use, this model has a number of limitations. Since this model was first published in 1995, there have been few additional articles introducing this model, and no textbook or textbook chapters describing the model could be identified. No published evidence can prove that this model has evolved through a series of research activities since its emergence. It would be of more useful if the theorists may provide clear definitions about the concepts (e.g. culturally specified health behaviours and health outcomes) of this model and established specific assumptions, to provide a clear picture about the meaning of the key concepts and the application scopes of the PEN-3 Model in health practice and research.

### Purnell Model for Cultural Competence

The Purnell's Model was initially developed in 1995 as an organisational framework to direct cultural assessment in nursing disciplines. It is research-based and conceptualised from multiple theories of organisational, administrative, communication and family development (Purnell, 2000).

Similar to Giger and Davidhizar's Model, the Purnell's Model addresses the needs of cultural diversity in the United States, and the influences of peoples' cultural characteristics and immigration status, as well as the importance of culturally competent health care (Purnell, 2014).

The central concept of the Purnell's Model is 'cultural competence', which is defined in a set of 12 statements. It urges health professionals to develop awareness of the cultural influences associated with peoples' cultural backgrounds, cultural characteristics, and to develop knowledge of their culture-related health needs and the specific meanings of health and illness. Health professionals need to advance their knowledge and skills through continuous education programs. In the meantime, health professionals need to accept and respect the cultural differences between cultures and between the health professionals and patients, while promoting health decisions that are congruent to patients' and families' Cultural values and beliefs (Purnell, 2014).

To be able to understand people's cultural beliefs, values, health needs and practice, the health professionals may adopt the Purnell's Model as a guide to develop the assessment of three core aspects, community, health and person, over 12 domains: 'inhabited localities', 'topography', 'communication', 'family role and organisation', 'workforce issues', 'bicultural ecology', 'high-risk behaviours', 'nutrition', 'pregnancy', 'spirituality', 'health care practice' and 'health care practitioner' (Purnell, 2014).

The Purnell's Model provides specific sample questions and observations of assessment about each domain with detailed information about the cultural characteristics of people from ethnic cultural groups cultural – the 23 American migrant groups. The Purnell's Model may be used as framework to direct research investigating cultural beliefs and practices (Purnell, 2014), and has been applied by health professionals in all practice settings (Purnell, 2014), education and research (Purnell, 2002).

The downside of the Purnell's Model is that although the theorist claims that it was built upon multiple theories and research studies, and has been used across all practice settings and health disciplines, but no references related to these statements are provided in theorist's article (Purnell, 2000) or in the textbook (Purnell, 2014).

As previously discussed, another weakness is that the conceptual diagram of the Purnell's Model does not demonstrate the logistical interconnections between the defined key concepts; and, as the theorist states, there is an undefined area in the centre of the diagram that needs to be explored by further research (Purnell, 2014).

***Leininger's Theory of Culture Care Diversity and Universality***

Table 3.3 clearly demonstrates that Leininger's 'Culture Care Theory' has good functional adequacy, with the details reported in the section 3.3.

### *3.2.3 Brief summary of the critical appraisal results*

The results of critical appraisal on the five included theories and molders are summarized in Table 3.4.

While all the above theories/models show potentials in facilitating cultural care in health and research, the results of the critical appraisal indicate that only Giger and Davidhizar's Model and Leininger's 'Culture Care Theory' have met all criteria of substantive foundation, structure integrity and functional adequacy, which demonstrate a good quality required for a middle-range theory.

Leininger's 'Culture Care Theory' was selected to guide this doctoral project because it has been broadly used by researchers to explore the influences of 'cultural and social structural factors' on people's health care and wellbeing around the world (Dayer-Berenson, 2014; McFarland & Wehbe-Alamah, 2015a).

## 3.3 Leininger's Theory of Culture Care Diversity and Universality

Leininger's 'Culture Care Theory' was developed by Dr Madeleine Leininger in the 1960s (McFarland & Wehbe-Alamah, 2015a). Leininger's 'Culture Care Theory' is grounded in Leininger's philosophy of life and values, comprehensive nursing experiences, and anthological viewpoints (Leininger, 2002). Since it was initially developed as the Transcultural Nursing Care Theory (Leininger, 1991) in the 1960s and applied in the disciplines of nursing, Leininger's 'Culture Care Theory' has subsequently evolved over decades through a series of scientific inquiries, and it is now the most well-known cultural theoretical framework for health research (Holland & Hogg, 2010; Ray, 2013).

**Table 3.4 Summary of critical appraisal results on cultural care theories/models**

| Criteria | Criteria items | Giger & Davidhizar's Model | Leininger's Culture Care Theory | Choi's Theory | PEN-3 Cultural Model | Purnell's Model |
|---|---|---|---|---|---|---|
| **Substantive foundations** | Cultural care focus | √ | √ | √ | √ | √ |
| | Assumptions are specified and congruent with the focus | √ | √ | | | √ |
| | The theory provides substantive knowledge about concerns to a specified cultural care phenomenon | √ | √ | √ | √ | √ |
| | The original is grounded in health care or clinical or nursing practice and research experience | √ | √ | √ | √ | √ |
| **Structure integrity** | The concepts are clearly defined | √ | √ | √ | | √ |
| | The concepts are at a middle-range level of abstraction | √ | √ | | | √ |
| | There is no more concepts than needed to explain the phenomenon | √ | √ | √ | | √ |
| | The concepts and relationships among them are logically represented in a model | √ | √ | √ | | |
| **Functional adequacy** | The theory can be applied to a variety of practice environments & client groups | √ | √ | √ | √ | √ |
| | Empirical indicators have been identified for concepts of the theory | √ | √ | | | √ |
| | There are published examples of research related to the theory | √ | √ | | | |
| | The theory has evolved through scholarly inquiry | √ | √ | √ | √ | √ |
| **Total** | | 12/12 | 12/12 | 8/12 | 5/12 | 9/12 |

### *3.3.1 The theorist and evolution of Leininger's 'Culture Care Theory'*

Leininger was an American nurse and professional nurse anthropologist with extensive experience in psychiatric nursing and education (Alexander, Deagle, Buthler, Dougherty, & Robards, 1986). She recognised the profound effect of cultural background on people's health care, and defined the interrelationship of culture and people's health thinking, decisions and actions (Alexander et al., 1986; Hanink, 2019; Leininger & McFarland, 2010). Then, she constructed Leininger's 'Culture Care Theory' in directing the development of empirical evidence to promote cultural understanding in health practice (Alexander et al., 1986; McFarland & Wehbe-Alamah, 2015a). Over the six decades, Leininger's 'Culture Care Theory' evolved through a series of scientific inquiries and have been used across the globe, to guide scientific investigations unveiling influences of cultural diversity on people's health care experiences, practices and needs in different health care settings (Dayer-Berenson, 2014a).

The strong evidences of development and widespread use of this theory reflect its capacity to allow for direct exploration of the meanings and actions of multifaceted cultural care(Dayer-Berenson, 2014; McFarland & Wehbe-Alamah, 2015a). It helps to elaborate and explicate the interconnections of care and the phenomena of cultural differences and similarities between diverse, or among similar cultures (Dayer-Berenson, 2014; McFarland & Wehbe-Alamah, 2015a).

### *3.3.2 Core conceptual elements of Leininger's 'Culture Care Theory'*

Leininger's 'Culture Care Theory' provides clear definitions about the core conceptual elements (e.g. culture, culture congruent care and enablers), to help researchers understand the complex concept of cultural care (McFarland & Wehbe-Alamah, 2015a).

As defined in Chapter 1, culturally congruent care is the core concept of Leininger's 'Culture Care Theory', which reflects the goal of the theory to facilitate activities in the development of culturally based knowledge and action modes to inform culturally appropriate and meaningful care that are favourable and beneficial to people's health and holistic wellbeing (McFarland & Wehbe-Alamah, 2015a). To help researchers understand this core concept, Leininger (2002) developed the 'Sunrise Enabler to Discover Cultural Care' with concrete details about how the concept may be assessed.

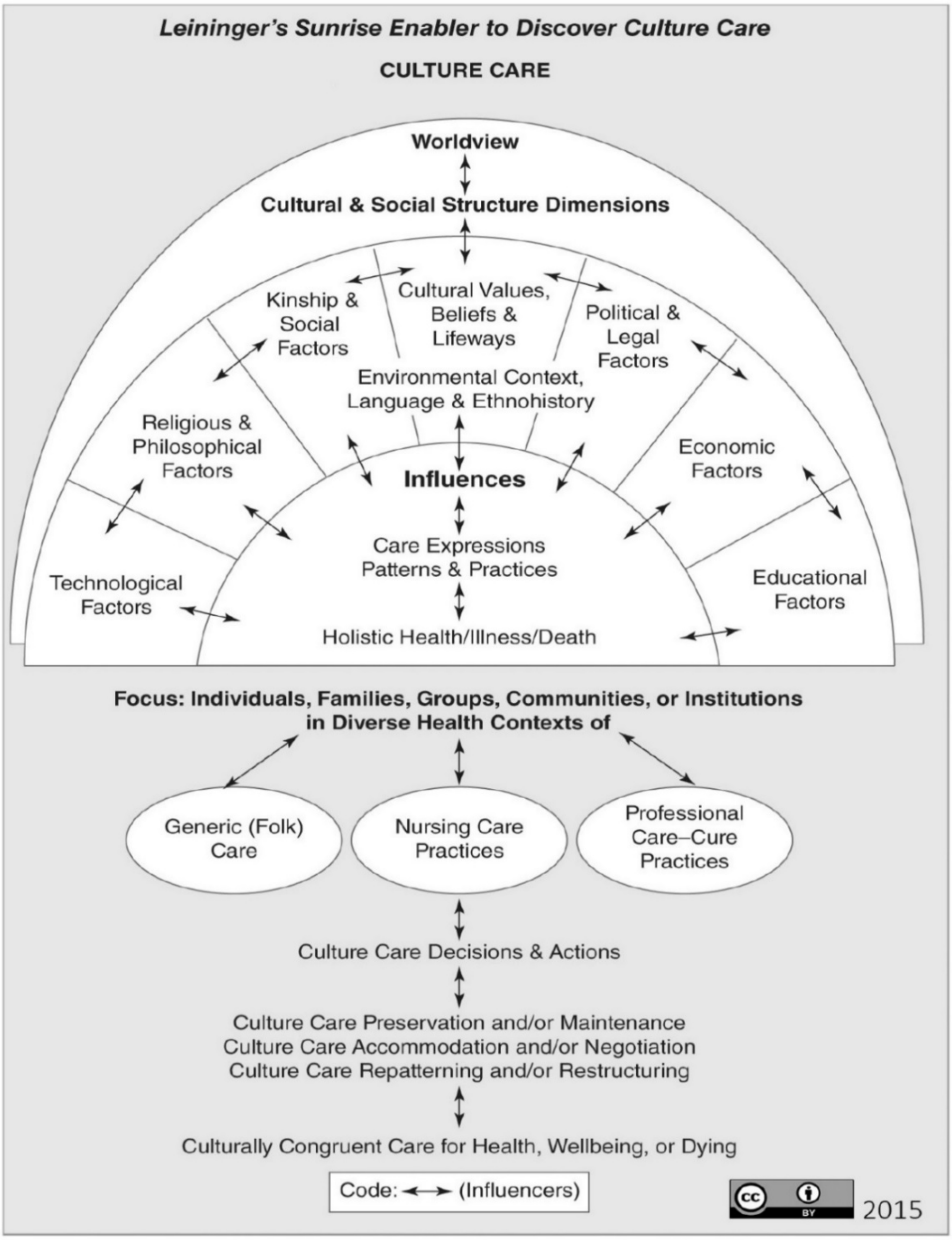

*Figure 3.1 Leininger's Sunrise Enabler to Discover Culture Care' Modified by McFarland & Wehbe-Alamah (2015b, np).*

This document is replicated from *http://www.madeleine-leininger.com/cc/sunrise2015.pdf*, which is available under the Creative Commons Attribution 4.0 International License. No permission is required to display it in this thesis

### 'Sunrise Enabler to Discover Cultural Care'

Leininger's 'Sunrise Enabler to Discover Cultural Care' is a diagram of Leininger's 'Culture Care Theory' often referred to as Leininger's 'Sunrise Enabler' (Wehbe-Alamah & McFarland, 2015). It is a visual aid (refer to Figure 3.1) directing researchers to broadly explore multiple factors influencing people' health and care, and guide nurses and other health professionals conducting comprehensive cultural assessments.

This visual tool illustrates linkages between the key concepts and the interrelationships between culturally congruent care, cultural care decisions and actions, and 'cultural and social structural factors' (Leininger, 2002b; Wehbe-Alamah & McFarland, 2015).

For care to be culturally congruent, it needs to be built upon the three 'cultural decision and action modes' of Leininger's 'Sunrise Enabler' (Leininger, 2002a) including:

**'Cultural care preservation/and maintenance':** Health professionals' actions or decisions are made in supportive ways that enable individuals retaining their care beliefs and/ or facing handicaps or death (Leininger, 2002a).
**'Cultural care accommodation and/or negotiation':** Health professionals' actions or decisions are made in active ways that encourage cultural acceptance and/or negotiation between diverse cultures, to promote culturally congruent, safe and effective care (Leininger, 2002a).

**'Cultural care repatterning and/or restructuring':** Health professionals' actions or decisions are made in assistive ways that facilitate individuals restructuring and modifying their lifeways and customs for optimal care outcomes (Leininger, 2002a).

The 'cultural decision and action modes' are needed to develop good understanding of cultural care and related influential factors that have an impact on people's holistic health, disease and death, to promote holistic wellbeing (Leininger, 2002a).

### Semi-Structured Inquiry Guide to assess culture and health

One of the key features of Leininger's 'Culture Care Theory' (Leininger, 1988, 2002b; McFarland & Wehbe-Alamah, 2015a) is that it provides a holistic and multidimensional theoretical foundation for cultural care that combines a wide range of humanistic dimensions associated with 'cultural and social structural factor' that may potentially influence people's health and care.

Leininger's 'Culture Care Theory' acknowledges the essential role of the cultural and social influencers (e.g. religion/ spirituality, kinship, politics, economics, Cultural values and beliefs associated with gender and class differences). These 'cultural and social structural factors' may impact cultural care values, beliefs and practices ( Leininger, 1996); and change care meanings, expressions, patterns and practices in individuals from different cultures (McFarland & Wehbe-Alamah, 2015a).

In order to help researchers and health professionals assess the influences of ‘cultural and social structural factors’, Leininger developed a ‘Semi-Structured Inquiry Guide Enabler to Assess Culture Care and Health’ (Known as Leininger’s ‘Semi-Structured Inquiry Guide’). Leininger’s ‘Semi-Structured Inquiry Guide’ is conceptualised around Leininger’s ‘Culture Care Theory’, which it is a research facilitator consisting of 12 domains of inquiry

‘Cultural and social structural factors’ refer to the 12 domains of inquiry − ‘Worldview’, ‘Ethnohistory’, ‘Cultural Values, Beliefs, and Lifeways’, ‘Kinship and Social Factors’, ‘Religious/Spiritual/Philosophical Factors’, ‘Economic Factors’, ‘Political and Legal Factors’, ‘Educational Factors’, ‘Technological Factors’, ‘Language and Communications Factors’, ‘Professional and Generic (folk lay) Care Beliefs and Practices’, and ‘General and Specific Nursing Care Factors’ (Wehbe-Alamah & McFarland, 2015). This 12 domain of inquiry are defined in Table 3.5.

The 12 domains of inquiry are equipped with suggested concrete and measurable inquiry examples for the key concepts, and cultural and social structure dimensions of Leininger’s ‘Sunrise Enabler’. These examples can be used as a guide to develop culturally specific open-ended questions, to explore influences of ‘cultural and social structural factors’ on people’s care experiences and needs (Wehbe-Alamah & McFarland, 2015), as well as their care expressions, patterns and practices in relation to their health and care (Leininger, 2002a).

### *3.3.3 Rationale for using Leininger’s ‘Culture Care Theory’*

As discussed in previous chapters, cancer pain is a multidimensional symptom that has a negative impact on cancer patients’ physical, psychological, social and/or spiritual wellbeing (Brant, 2014).

Employing Leininger’s ‘Semi-Structure Inquiry Guide’ together with the ‘Sunrise Enabler’ assists researchers to identify cultural values, traditions, customs and values within and between different ethnic groups, and incorporate individual’s social structures factors into care provision (Williamson & Harrison, 2010). It also fosters exploration of the cultural factors that may cause cultural distress and pain, and helps to minimise the risk of frustration and non-compliance with recommended care (Dayer-Berenson, 2014).

**Table 3.5 Defining 12 domain of Leininger’s Semi-Structured Interview Guide**

**‘Worldview’ domain:** Refers to the way people view the world around them and their prospects toward living their life, which has an impact on their health decisions and wellbeing(Leininger, 2002a) . Researchers may ask questions to explore how individuals’ views of the world around them influence their health and wellbeing(Leininger, 2002a) .

**‘Ethnohistory’ domain:** Originated from anthropology and was reconceptualised by Leininger in a nursing perspective, referring to special and current events, experiences and conditions within people’s cultural context and caring modalities over time (Wehbe-Alamah & McFarland, 2015). Researchers may develop questions to explore how people’s cultural heritages (e.g. cultural background) and care experiences affect their care needs (Leininger, 2002a).

**‘Cultural Values, Beliefs, and Lifeways’ domain:** Refers to people’s cultural values, beliefs and practices on their health decisions and reactions to their health and illness (Leininger, 2002a). Researchers may develop questions to define people’s cultural values and beliefs that could assist them recover or retain their health, as well as their culturally specific beliefs and health practices that their health care providers should know in order to provide culturally specific care (Leininger, 2002a).

**‘Kinship and Social Factors’ domain:** Emphasises the impact of individuals’ families and social ties on their life, caring and health lifeways as well as their families’ role in caring for them when they are ill or unwell (Leininger, 2002a).

**‘Religious/Spiritual/Philosophical Factors’ domain:** Addresses the importance of understanding people’s religious, spiritual and philosophical beliefs in their health care – how these beliefs help with their healing process and assist them to face crises, disability or even death (Leininger, 2002a).

**‘Educational Factors’ domain:** Helps researchers understand people’s perspectives in relation to educational contributors to their health, and their educational information needs that they would like to share with health professionals to help them stay healthy or deal with their illness (Leininger, 2002a).

**‘Technological Factors’ domain:** Helps researchers to investigate people’s perceptions in relation to modern technological factors in their daily life that obstruct or enable patients to access health care and retain health (Leininger, 2002a).

**‘Language and Communications Factors’ domain:** Helps researchers to identify barriers and facilitates influencing effective communication between health professional and clients that may obstruct or enable people to receive health care, for example, how people would like others to talk to them, and whether there are there any language barriers preventing them from communicating with others (Leininger, 2002a).

**‘Economic Factors’ domain:** Assist researchers to reveal the financial barriers and facilitators that impact individuals’ accessibility to health care (Leininger, 2002a).

**‘Political and Legal Factors’ domain:** Helps researchers to uncover the political and legal actions affecting individuals’ wellbeing, for example, any political issues that have obstructed individuals from caring for themselves at home or in the community (Leininger, 2002a).

**‘Professional and Generic (folk lay) Care Beliefs and Practices’ domain:** Helps researchers to explore from individuals’ cultural viewpoints what professional or folk (traditional) practices make sense to people, what professional or folk (traditional) practices (e.g. cultural care and food preferences) in a cultural group influence people’s wellbeing, and factors that affect people’s healing process at home or in the community (Leininger, 2002a).

**‘General and specific care factors’ domain:** Helps researchers understand the barriers and facilitates good care that is appropriate to people from different cultures, for example, the meaning of care in a cultural group, and how health professionals’ actions and attitudes assist individuals to maintain their wellbeing (Leininger, 2002a).

Importantly, the other cultural theory and models included in this review have either only focused on the cultural influential factors on immigrant populations ( Choi, 2014; Giger, 2018; Purnell, 2014); or some need to be further developed to provide clear assumptions, definitions and/or conceptual diagrams (Choi, 2014; Iwelunmor, Newsome, & Airhihenbuwa, 2014; Purnell, 2014).

Leininger's 'Culture Care Theory' offers a useful guide for researchers, to explore the impact of 'cultural and social structural factors' on people's health care experiences and needs from both patient and nurse perspectives (McFarland & Wehbe-Alamah, 2015a). It is especially suited to work aimed at understanding the complex cultural contexts of Chinese migrants who come from diverse geographic and ethnic backgrounds of Hong Kong, Taiwan, and mainland China with 56 ethnic groups.

While Leininger's 'Culture Care Theory' can help researchers understand the culture-specific factors affecting Chinese migrants' cancer patient management needs, the Australian Guidelines for Cancer Pain Management in Adults as introduced in the Chapter 1 helps to identify evidence-based strategies to achieve pain management in the Australian context.

## 3.4 Summary

This chapter outlined the results of critical appraisal on five cultural care theories and models, with details that introduced Leininger's 'Cultural Care Theory' and provided a rationale for use this theory informing the doctoral research reported in this thesis. The next chapter outlines the research design, study methods and ethical considerations of the research undertaken.

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# Chapter 4 Research design and methods

## 4.1 Introduction

Chapter two reported a systematic review that identified Chinese people may experience persistent cancer pain because of limited use of analgesics, delays in receiving treatment, reluctance to report their pain, and/or low adherence to recommended analgesic regimens (Xu, Luckett, Wang, Lovell, & Phillips, 2018). A range of patient, family, health professional, and/or health care system-related barriers contribute to the unrelieved cancer pain experiences of Chinese people living in China. While these identified barriers of using analgesics may be associated with religious (Buddhism) and/or philosophical beliefs (Confucianism/Taoism), previous research has not directly explored the impact of cultural influences on Chinese people's pain experiences and practices. Few English or Chinese studies have explored non-pharmacological cancer pain experiences of Chinese people living in China, and little is known about the pain management experiences and needs of Chinese migrants (Xu et al., 2018).

Understanding experiences of Chinese migrants living with cancer pain, and cultural-social structural factors affecting their pain management may assist with the development of culturally congruent care strategies. Addressing their cultural needs may help to overcome the barriers to optimising their pain management. As discussed in Chapter 3, this doctoral project is underpinned by Leininger's Cultural Care Theory (McFarland & Wehbe-Alamah, 2015c), and informed by the evidence-based Australian Guidelines for Cancer Pain Management in Adults (Australian Adult Cancer Pain Management Guideline Working Party, 2016)

This chapter outlines research design, methodological approaches, and ethical considerations of this doctoral project.

## 4.2 Research design and objectives

This doctoral project employed a convergent mixed methods design to explore how:

- 'cultural and social structural factors' may influence the cancer pain management experiences and needs of Chinese migrants living with cancer pain in Australia;
- Australian cancer and palliative care nurses perceive and understand the cultural influences on Chinese migrants' cancer pain management needs, and their experiences of caring for this population; and

- Applying a cultural theory assists with identifying strategies that might better enable Chinese migrants' to more effectively manage their cancer pain.

## 4.3 Mixed methods research

A mixed methods design was considered appropriate for this doctoral project as it sought to understand the perspectives and experiences of Chinese migrants living with cancer pain, and the cancer and palliative care nurses providing pain care to this population.

Mixed methods research designs emerged in response to the need to consider different perspectives in order to uncover complex social and behavioural phenomena in their real environments (Bazeley, 2018). A mixed methods design involves collecting and integrating qualitative and quantitative data through a series of rigorously designed research procedures to answer specific research questions (Creswell & Creswell, 2018). Combining data from multiple sources enables researchers to integrate qualitative and quantitative study findings to develop a deeper understanding of the phenomenon under investigation (Creswell & Creswell, 2018). The mixed methods overcome the limitations of a single study (Creswell & Plano Clark, 2018).

In mixed methods research, conclusions are drawn through analysing multiple sources and types of data, and synthesising this information to generate useful findings that provide a deep insight to the research topics (Bazeley, 2018).

### *4.3.1 Research paradigm of mixed methods research*

The term ‘research paradigm’ refers to the ontological (the nature of reality), epistemological (the nature of knowledge and its generation), and methodological (the ways in which research is conducted) beliefs that provide a philosophical foundation to guide the way researchers design and conduct a study by which phenomena are investigated to produce new knowledge (Land & Harvey, 2017). Positivism, interpretivism and pragmatism are the three most commonly used research paradigms in health care (Land & Harvey, 2017).

The philosophical foundation underpinning mixed methods research is pragmatism (Johnson & Onwuegbuzie, 2004). Pragmatism combines both positivist and interpretivist positions (Land & Harvey, 2017). This research paradigm values both ‘emic’ (i.e. insider) and ‘etic’ (i.e. outsider) perspectives. It assumes that multiple forms of reality exist, and that incorporating these different forms assists with finding solutions for real-world problems (Christ, 2013).

Pragmatism also allows researchers to combine inductive and deductive processes to identify substantive contents and gaps in existing knowledge that extend to social, historical, political and cultural contexts (Christ, 2013). Research undertaken within a paradigm of pragmatism offers a practical way for researchers to explore the meaning and context of a health care phenomenon, and to generate knowledge objectively and/or subjectively (Land & Harvey, 2017).

### *4.3.2 Rationale for using a mixed methods approach*

Cultural influences on people's health care and culturally congruent care are complex and multidimensional concepts (Leininger, 2002). Using a single approach to data collection was considered unlikely to capture the full dimensionality of culture influences on Chinese migrants' cancer pain experiences and practice. Therefore, this doctoral research project employed a convergent mixed methods design. A convergent design allows qualitative and quantitative data to be collected concurrently, before the data is separately analysed and integrated (Creswell & Plano Clark, 2018).

A convergent mixed methods design was considered as the most appropriated for this project. This design addresses the research objectives, while allowing for an in-depth exploration of Chinese migrants' cancer pain management perspectives and needs from both the patient and the health professional perspectives. Integrating the findings of this doctoral project (Study 2 and Study 3), in accordance with Leininger' Cultural Care Theory, the Australian Guidelines for Cancer Pain Management in Adults, and the current literature, allowed for generating a series of strategies to address the identified gaps in relation to Chinese migrants' cancer pain management needs. The meta-inferences enable the identification of opportunities to strengthen current clinical practice(s) and culturally congruent cancer pain care, as well as informing future research that promotes culturally congruent cancer pain management practices.

### *4.3.3 Overview of mixed methods design and studies in this doctoral project*

Each mixed methods design research can be predominately qualitative or quantitative, or both components are afforded equal status, depending on the research purpose, research questions, and the priority of qualitative and quantitative approaches in a research project (Johnson, Onwuegbuzie, & Turner, 2007; Land & Harvey, 2017). The priority of the methods is symbolised using capital and lower case letters (QUAL, qual, QUAN, quan). The way qualitative and quantitative elements are combined is indicated with symbols of plus (+) and arrow (→) (Bazeley, 2018; Johnson et al., 2007).

In this doctoral project, a convergent and qualitative dominant design was used to answer the research questions. Qualitative dominant mixed methods research is explanatory and depends on a qualitative and critical thinking process to answer the research questions, while the quantitative components may collect additional information to assist better understanding of the investigated phenomenon (Johnson et al., 2007). This convergent mixed methods designed doctoral project was conducted via three phases (refer to Figure 4.1) informed by Creswell and Plano Clark's (Creswell & Plano Clark, 2018) approach:

- Phase One: Study 1- A systematic review as reported in Chapter 2;
- Phase Two:
  - *i)* Study 2 - Focus groups with Chinese migrants living with cancer pain with an embedded patient questionnaire;
  - ii) Study 3 - The nurse survey with Australian cancer and palliative care nurses; and
- Phase Three: Data interpretation and development of strategies via data integration and meta-inferences.

The following sections outline the methodological approaches of Study 2 and Study 3, while the methods of Study 1 have been reported in Chapter 2.

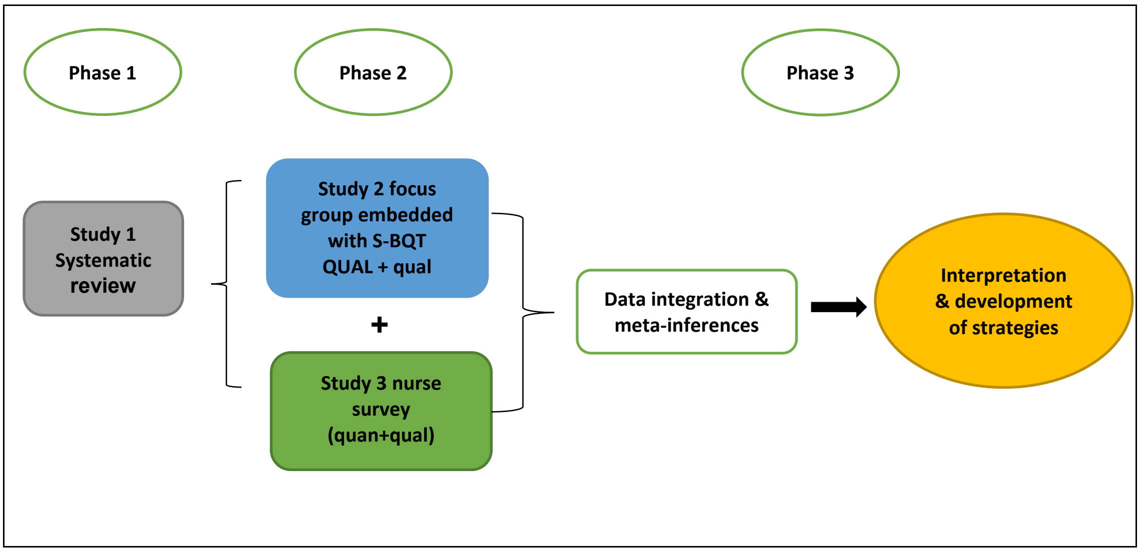

*Figure 4.1 Diagram of convergent mixed methods design for this doctoral project, adapted from Creswell and Plano Clark (2018).*

## 4.4 Methodological approach of Study 2: Focus groups and patient questionnaire

This section outlines the methods of Study 2, which involved a series of focus groups with Chinese migrants living with cancer pain who also completed the Short Version of Barriers Questionnaire - Taiwan (S-BQT).

### *4.4.1 Purpose*

The purpose of Study 2 was to explore ‘cultural and social structural factors’ that may influence the cancer pain management experiences and needs of Chinese migrants living with cancer pain in Australia.

### *4.4.2 Methods*

Focus group methodology was used to serve the purpose of this study. This method is an effective technique and a safe way to engage CALD populations in a group discussion, to derive rich data for deep understanding of their perspective regarding health care and informing clinical practice to meet their care needs (Halcomb, 2007).

Focus groups are also an effective way to empower vulnerable people, and to ensure that the interviewers do not influence the participants’ perspectives (Ayres, 2007). The focus group format helps to create a safe environment for people to share their experiences about a phenomenon, which is critical to gaining valuable insight on a specific research topic (Krueger & Casey, 2009). The conversational nature of focus groups provides an opportunity to explore participants’ perspectives and experiences in relation to complex cultural issues (Streuber & Carpenter, 2011).

### *4.4.3 Context: Settings and language*

Focus group participants were recruited between May and August 2017, via a cancer care centre and two palliative care units of two public hospitals as well as three Chinese cancer support groups in Sydney, New South Wales (NSW), Australia. The three Chinese cancer support groups were run by a Chinese organisation with a head office located in Sydney, which provide support to Chinese migrant cancer patients, in cooperation with the two participating study sites.

These focus groups were conducted at three venues of Chinese cancer groups. Two were located at the communities and one was in a study site. These venues were close to participants’ homes or the sites of the invitation where participants usually attended their follow-up clinics and/or took part into the activities of Chinese cancer support groups.

The researchers offered the participants the option of attending either a Mandarin or Cantonese focus group, since most Chinese living in Australia speak Mandarin and/or Cantonese at home (ABS, 2017). Conducting the focus groups in participants' primary language enabled them to clearly express their ideas and concerns related to their pain and pain management experiences.

Documentations used in this study, for example the Participant Information Sheet and Consent Form (PIS & CF); the Part A of the questionnaire; and questioning route used in this study, were initially developed in English and reviewed by all co-researchers. Then all the files were translated into Chinese by a Chinese-English speaking researcher. The PIS&CF was cross-checked by bilingual academic staff. The S-BQT was tested in Chinese and published in English (Chou, Rau, & Lin, 2011).

The study materials used in the focus groups were prepared in both simplified Chinese or traditional Chinese versions for participants to choose from (refer Appendices B-E). The simplified Chinese and traditional Chinese are two different styles of characters with the same meaning and pronunciation. The former is used in mainland China and the latter is mainly used in Hong Kong and Taiwan.

### *4.4.4 Sampling strategies*

**Eligibility criteria**

The participants in these focus groups included Chinese migrants who had a confirmed cancer diagnosis and were eligible to participate if they:

- were adults (age⩾18) and born in Hong Kong, Taiwan or mainland China;
- felt they were well enough to take part in a focus group conducted in Mandarin or Cantonese;
- were receiving and/or had received cancer pain treatment in an ambulatory cancer and/or palliative care setting during the past two years;
- were willing to participate in this study; and
- could give written consent in English, simplified Chinese or traditional Chinese.
- Participants who were not able to meet the above inclusion criteria were excluded.

**Recruitment and screening**

Purpose sampling method and snowball technique were employed to recruit participants who were willing to share their pain management related experiences and make contributions to the group discussion.

Although participants were invited via two study sites, the majority were recruited from Chinese cancer support groups at the study sites or from a community venue close to the study sites. This cancer support group was open to anyone who was diagnosed with cancer and was receiving cancer treatment at a health care setting.

Flyers with study information and the investigators' contact methods were displayed at the study sites and/or Chinese cancer support groups frequented by large numbers of Chinese migrant cancer patients; and/or provided by the physicians, nurses, care coordinators and/or other care providers at study sites, and/or provided to the potential participants by volunteers of the Chinese cancer support groups.

Potential participants who expressed an interest in participating in the focus groups were provided with a copy of the Participant Information Sheet and Consent Form (PIS&CF); and referred onto the researcher by the study sites trial nurse and care coordinators, and/or the Chinese cancer support group coordinators.

All potential participants were screened for eligibility during phone calls from the Mandarin-speaking researcher and/or a Cantonese-speaking research assistant. If the potential participant met the eligibility requirement and was interested in taking part into the study, the researcher and/or the research assistant answered any questions about the study and/or the information provided on the PIS&CF before providing them with details about the next focus group date, time and venue.

For those who were not eligible or unwilling to participate, the researcher/research assistant expressed appreciation for their time and advised them that none of their doctors, nurses or care coordinators would be aware of the conversation.

### *4.4.5 Theoretical framework for developing questioning route, data analysis and reporting*

As previously discussed in Chapter 3, the 12 domains of Leininger's 'Semi-Structure Interview Guide' and 'Sunrise Enabler' (Wehbe-Alamah & McFarland, 2015), as well as Australian Guidelines for Cancer Pain Management in Adults (Australian Adult Cancer Pain Management Guideline Working Party, 2016), informed the development of the question route for these focus groups. Considering the length of focus group discussion and the participants' health conditions, the 12 domains of Leininger's Semi-Structure Interview Guide were combined with ten open-ended questions developed in the question route (refer Table 4.1).

**Table 4.1 Focus group question route - Patient (English)**

Researcher's notes: The questions are developed based on the Leininger' 12 Domain of Semi-Structured Interview Guide. These domains are listed for the purpose of data analysis and should not be mentioned during the focus group.

**A. Domain 1 'Worldview'， Domain 2 'Ethnohistory' & Domain 12 'General and specific nursing care factors'**

1. I am interested to find out a little about your cancer pain. How did the pain affect your life?
2. How do you decide to seek assistance for your cancer pain?
3. What is the meaning of pain management to you?
4. Have you found any barriers or facilitators for you managing your pain at home?

**B. Domain 4 'Cultural values, beliefs, and lifeways'& Domain 5 'Religious/spiritual/philosophical factors'**

5. Do you think the Chinese cultural and social values may influence your cancer pain management experiences and needs? (Please Clarify).

**C. Domain 11 'Professional and generic (folk or lay) care beliefs and practices**

6. How can different health professionals best help you manage your cancer pain?

**D. Domain 3 'Kinship and social factors'**

7. What are the things that your family members and/or friends do to support you manage your cancer pain management?

**E. Domain 7 'Economic factors & Domain 8 'Political and legal factors'**

8. I am wondering if there are any economic or other factors that have ever limited your access to cancer pain management services.

**F. Domain 6 'Technological factors', Domain 9 'Educational factors & Domain 10 'Language and communications factors'**

9. How would you like to communicate your pain management related issues with others (e.g. your doctors/nurses/families)?
10. What information and technology support do you need to help you control your cancer pain?

The open-ended question format was designed to allow flexibility for participants to share their stories and life experiences. This approach would also enable the researchers to gather cultural-specific information (Wehbe-Alamah & McFarland, 2015) related to the participants' pain and pain management experiences.

### *4.4.6 Data collection methods*

The data collected during the focus groups included qualitative data and quantitative data. The data collection procedures for the qualitative data is reported at below, while the quantitative data collection methods of the focus group are reported in Section 4.4.11.

Participants were assigned to Mandarin or Cantonese focus groups in accordance with their language preferences, with this information recorded in the enrolment form (refer to Appendix F). All eligible participants were phoned and/or sent a text message one to two days prior to the focus group, detailing the focus group date, time and venue.

The focus groups were facilitated by a Mandarin speaking researcher or a Cantonese speaking assistant, with each group lasting about 60-90 minutes. Participants were encouraged to use examples elaborating their unique perceptions and recollecting their specific experience related to the topic. The ideal size for the focus group was five to eight participants, to ensure that each participant had the opportunity to share their unique personal perspectives and/or experiences (Krueger, 2006).

### *4.4.7 Data collection instrument and technologies*

Open-ended questions and prompting questions were utilised to promote discussion during the focus group. The summary of each focus group was reviewed by two researchers immediately after the focus group being undertaken. The order of open-ended questions was adjusted to facilitate a free flowing discussion and to promote collaborative participation.

Each focus group was recorded with two audio recorders, after informed consent had been obtained from all participants. The field notes were taken by a scribe to capture additional information during the focus groups. A summary was written after a brief discussion with the facilitator and/or the scribe.

All focus group participants were respectively assigned an identification number (ID) and the focus group ID. This identification number was consistently used in all questionnaires and audio files. For example, the first focus group was coded as FG-1, while the audio file (AF) was labelled accordingly as FG-1 AF, and the individual participant was coded as P1, etc.

### *4.4.8 Qualitative data processing and analysis*

The qualitative thematic data analysis plan for the focus group transcripts was developed prior to the data analysis process began and was designed to ensure a rigorous process was followed. Informed by Chandler and Reynolds (2013) guidance on developing qualitative research protocols and standard operational procedures for preparing and translating focus group transcripts, a transcription and translation protocol ( refer to Appendix G) was developed by the researchers to guide the process of preparing and translating transcripts of the focus group audio files to ensure the quality of translating.

The thematic analysis is a common method used in qualitative studies to identify themes, with focus on the patterns and meanings across a dataset related to research objectives (Bazeley, 2013). In this doctoral project, thematic analysis with integration of detective and inductive reasoning methods informed by Bazeley (2013) and Guest et al.(2012) were adopted for the data analysis. NVivo 11 for windows was used to aid with the coding and merging, and grouping the codes into categories, and then into the themes, in referencing to the coding approaches of Saldaña (2009).

The steps of integrated thematic analysis applied in this study included:

**Step 1. Preparing for coding**

Leininger's 'Semi-Structure Interview Guide' and 'Sunrise Enabler' (Wehbe-Alamah & McFarland, 2015), as well as Australian Guidelines for Cancer Pain Management in Adults (Australian Adult Cancer Pain Management Guideline Working Party, 2016) were used as a broad guide to developing the anchor codes and classifying the codes into the categories and theorising the themes. When data observed from line by line coding of transcripts or field notes did not fit into the framework, they were grouped into new categories to form the new theme.

The research objectives, research questions, questioning route, prompting questions, field notes, and focus group summaries were reviewed. The transcripts were read line by line. This process helps the researchers gain an insight on the trends and patterns of data (Guest et al., 2012), and provides a 'true' understanding of the data to increase the consistency of the coding and the interpretation of the data (Bazeley, 2013).

As suggested by Adu (2015), short phrases were used to label questions and prompting questions of the questioning route in all focus transcripts using the "Heading

Style" of the word document. For example, the focus group question 1, "I am interested to find out a little about your cancer pain. "How did the pain affect your life?", was labelled as "Q1. Pain related experiences". This kind of 'anchor code' was used in NVivo as the notes for auto coding, to gather participants' responses related to each question across the five focus groups in one place for coding. The contents of transcripts with important information were kept under or moved to relevant focus group questions. This approach is easier for categorising data (Krueger & Casey, 2009).

*Step 2. Selecting coding methods and determining the unit of coding*

An integrated structural and 'Vivo' coding' (creating a new nodes in NVivo by selecting the text) method was employed. In the first cycle of coding, words, phases, sentences or paragraphs consisting of meaningful texts related to the research objectives and research questions, were coded (Bazeley, 2013; Saldaña, 2009).

### Step 3. Establishing a codebook

A codebook was established in NVivo with a set of codes relevant to research objectives, research questions, and the researcher's understanding the data. Then, the codebook was refined through the coding process to help the researcher keep track what the data presented and meant.

The process of refining the codebook is essential in thematic analysis to assist researchers to systematically classify data into categories, assign structural codes to segments, and analyse the interconnection of meanings to the research questions (Guest et al., 2012).

### Step 4. Preliminary coding – the first circle of coding

The English transcripts were line by line coded by a researcher focusing on participants' experiences, beliefs, attitudes, behaviours and needs in relation to pain and pain management, and relevant Chinese cultural and social elements.

The codes were reviewed and refined after consultation with another researcher. The codes with similar meaning were merged into one code after going through the first focus group transcript. The refined new codes were used for the secondary coding.

### Step 5. Secondary coding – the second circle of coding

In this step, the analysis focused on group dynamics and interactions, and comparing and contrasting to identify the trends, patterns and relationships among the codes. The codes were recoded and sorted into categories. The categories in NVivo are referred as ‘parent code’- category, and ‘child code’ – subcategory.

**Step 6. Constructing new themes and building thematic understanding**

The categories and subcategories were synthesized to form themes and/or subthemes. Each theme was clearly defined and supported with the evidence – the words, phases, sentences or paragraphs quoted from the transcripts.

**Step 7. Integrating quantitative and quantitative elements**

Upon the data analysis being completed, the themes, subthemes, and key elements of the qualitative findings were integrated with quantitative results. The data integration methods are detailed in Section 4.6.

### *4.4.9 Researcher characteristics and reflexivity*

As a Chinese born registered nurse, I have worked for more than 30 years in China and Australia, including nine years of working in a Chinese oncology hospital. I hence have an in-depth understanding of Chinese and Australian health care systems,

My Chinese background and health care experiences in both counties enables me to contextualise Chinese migrant cancer patients’ care experiences and needs. I have an understanding of the meaning behind their stories, and the challenges they may face navigating with a foreign health care system in the quest to manage their persistent cancer pain.

The doctorial supervisors all bring different perspectives to this project as native English-speaking researchers and health professionals from different disciplines. Individually, the supervision team has extensive cancer and palliative care pain management research expertise, with two of the supervisors being registered health practitioners (a palliative care medical specialist and a palliative care nurse specialist). In addition to the supervision team, the input from two bilingual Chinese research assistants from different disciplines, who assisted with the focus groups, added significantly to the project’s rigour. The research team’s contributions to this research project have provided an insight from both Australian and Chinese contexts into how the findings of the study can be interpreted to inform the health practice in Australia.

### *4.4.10 Techniques to enhance trustworthiness*

The development and data reporting of focus groups in this thesis is in accordance with O'Brien’s Standards for Reporting Qualitative Research (SRQR) (2014). The trustworthiness of the study was ensured via a series of procedures to establish the credibility, transferability, dependability and confirmability required for the qualitative research (Amankwaa, 2016; Connelly, 2016).

### Establishing credibility

The credibility of this study was established via a series of activities to ensure the validity of the study (Amankwaa, 2016; Guest et al., 2012). Validity in qualitative research refers to "…credibility and accuracy of processes and outcome associated with a research study"(Guest et al., 2012, p.7).

Before the study commenced, a research project protocol was developed by a researcher, and reviewed by all co-researchers, principal investigators of the study sites, and the Scientific Stand Committee of South Eastern Sydney Local Health District Human Research Ethics Office. The protocol was used to guide the process of recruitment, focus group conduction, data collection and analysis. The research protocol was distributed to all investigators and research nurses involved in the study. Site visits were conducted and training was provided to the researcher and two research assistants prior to the focus group commencing. All these activities were undertaken to ensure the study was compliant with the approved protocol.

### Establishing transferability

The transferability was established using a series of approaches, to ensure the findings may be potentially applicable in another context (Amankwaa, 2016; Polit & Beck, 2016). These approaches included providing detailed descriptions about the phenomena of the study, context, settings, locations, and people involved in the study (Amankwaa, 2016; Polit & Beck, 2016).

As previously discussed, the development of the study was guided via a theoretical framework of Leininger's Cultural Care Theory and Australian Guidelines for Cancer Pain Management in Adults, and informed by the systematic review to both English and Chinese literature regarding pain management experiences of cancer patients from Chinese backgrounds. As suggested by Amankwaa (2016), all questions developed and used in the focus groups were crafted and reviewed via a peer reviewing process for clarity. The background, significance, context, study settings, locations, and populations of the study were clearly described.

### Establishing confirmability

The confirmability in a qualitative research was established with procedures in place to minimise the bias of researchers in relation to interpreting the data and reporting the findings (Amankwaa, 2016).

In this study, a data analysis plan was developed by a researcher and reviewed by a co-researcher. Guided by Chandler and Reynolds' (2013) "Guidance on developing qualitative research protocols and suggested standard operational procedures", a transcription and translation protocol was established to inform the process of preparing and translating focus group transcripts. Audio files were transcribed by a research assistant and checked by the researcher. The transcripts were translated by the researcher, and then cross checked by a bilingual research assistant. The disagreement about the translation was resolved via discussion.

The codebooks were developed and refined via each coding. The results of coding were peer reviewed and discussed via peer debriefing (Connelly, 2016; Guest et al., 2012). The interpretation and reporting of the findings were discussed via peer debriefing and reflexivity with the research team (Amankwaa, 2016).

### Establishing dependability

The dependability in qualitative research is similar to establishing the reliability in quantitative research via data audits and peer review (Connelly, 2016). In qualitative research, checking coding reliability is a critical process to ensure the validity of the conclusions made from the codes (Bazeley, 2013). Comparing the coding results of two independent coders on a sample of material to check inter-coder agreement is an important process to examine the coding reliability (Bazeley, 2013). However, instead of expecting a total agreement between two coders, it would be more realistic to achieve a certain level of consistency of coding (intra-coder agreement) by the same person across the whole research project (Bazeley, 2013).

In a team project, the inter and intra-coder agreement on coding are achieved by: 1) developing the codes related to the project and structured using theoretical frameworks; 2) discussing within the team the categories of codes and coding approach to achieve an agreement at early stage of coding; and 3) using computer software (e.g. NVivo) to check for inter-coder agreement (Bazeley, 2013).

In this study, the transcripts were reviewed by an Anglo-Australian researchers with culture related elements highlighted for coding; and the coding on all transcripts was undertaken by a Chinese-speaking researcher. This method provided an insight on the different perspectives of researchers from outside the culture (etic), as well as inside (emic); and helped to capture all instances that may have been missed by Chinese or non-Chinese background researchers.

The intra-coder agreement was achieved by adhering to the agreed coding approach and the refined codes. The coding results were checked by the researcher through two circles of coding with focus on the consistency and relevance.

### *4.4.11 Embedded Short Version of Barrier Questionnaire –Taiwan*

The S-BQT was embedded with the focus group. All focus group participants completed a patient questionnaire which included two parts:

**Part A:** Included a demographic information sheet used to obtain participants' characteristics. It also included a self-reported numerical rating scale (0 means no pain; 10 means the worst pain), and a series of close-ended questions about pain treatment methods they used.

**Part B:** The S-BQT was developed and validated by Lin and her colleagues (Chou et al., 2011). The original validation study involved Chinese cancer patients (N=183) living in Taiwan and reported a Cronbach's alpha score of 0.86 and test-retest score of 0.83 at two-weeks (Chou et al., 2011). The S-BQT included nine concise items designed to assess cancer patients' barriers to taking regular analgesics and/or reporting the presence of pain, with higher scores indicating higher barriers to using analgesics and/or reporting cancer pain (Chou et al., 2011). Email permission to use the S-BQT in this doctoral project was provided by Professor Lin at Taipei Medical University.

While the focus group method was predominantly used to promote meaningful discussion and generate rich data related to the topic, the S-BQT was embedded with quantitative measurement to provide extra information related to Chinese migrants' pain reporting and use of analgesics for their cancer pain.

#### Quantitative data analysis

All quantitative data collected during the focus groups were entered into the Excel spread sheet; and then imported to SPSS 24 to allow for descriptive data analysis. A codebook for S-BQT was developed to guide the data entry. The codebook assigned descriptive coding information for each variable; and was very useful in keeping the accuracy of data entry.

## 4.5 Methodological approaches of Study 3: Survey of Cancer and Palliative Care Nurses

Study 3 involved a cross-sectional survey that was conducted over a 12-month period from 9 May 2017 until 23 May 2018, with Australian cancer and palliative care nurses.

### *4.5.1 Study settings, participants and sampling*

**Study sites**

Participants were recruited using several recruitment strategies via: 1) ambulatory care of cancer and palliative care centres/clinics of seven study sites in Sydney, NSW; 2) three major cancer and palliative care peak bodies in Australia; and 3) a series of national cancer and palliative care conferences, seminars, institutional research meetings, and educational workshops.

**Eligibility criteria of participants**

The cross-sectional survey involved registered nurses (RNs) working in cancer and/or palliative care services across Australia. This survey was open to RNs working in different roles, such as clinical nurse specialists (CNS), Nurse Managers, Practice Nurses, Research Nurses, and/or Research Coordinators, who:

- had experience in caring for Chinese migrant patients with cancer pain in the last five years, and
- were currently working at or had worked in an ambulatory care service of cancer care or palliative care settings.

The eligibility criteria were listed as three questions in Part A of the nurse survey (refer to Appendix I). When the nurses answered “no” to any of the above questions, the survey stopped.

### *4.5.2 Sampling*

Convenience sampling and snowball technique were employed to encourage participation. The posters of invitation (refer to Appendix H) were displayed at the study sites, or at the venues of conferences, workshops, etc. Invitations were sent to the nurses via emails of the health settings and peak bodies to encourage participation.

### *4.5.3 Designing the survey*

Following an extensive review of the literature and failure to identify a suitable survey instrument, the Survey of Cancer and Palliative Nurses (the nurse survey) (refer to Appendix I) was developed. This survey was informed by the existing literature and

Leininger's 'Cultural Care Theory', and was reviewed by the co-researchers, principal investigators, and the Scientific Standing Committee of South Eastern Sydney Local Health District Human Research Ethics Office; and revised accordingly. This nurse survey contained three parts, as summarised below:

**Part A** was the questionnaire to determine participants' eligibility.

**Part B** consisted of 11 closed-ended questions to capture: 1) participants' demographic characteristics, 2) their training experiences related to cancer pain management and culturally-congruent/competent care, and 3) their perception of the influences of Chinese backgrounds on Chinese patients' pain management.

**Part C** included two open-ended questions to: 1) explore 'nurses' opinions about in which ways culture have influenced Chinese cancer patients' pain management needs; and 2) about what education or resources would be beneficial in helping to meet the patients' pain management needs.

### *4.5.4 Piloting the survey*

The survey was initially conducted online with invitations sent to all members of an Australian national cancer nursing body. Following this piloting, the survey was slightly modified and distributed to potential participants at the study sites and/or at the cancer/palliative care nursing conferences, seminars, etc.

### *4.5.5 Data collection and analysis*

Participants either completed the online survey or put the completed survey in a sealed box or in a prepaid envelope to send back to the researchers.

A data analysis plan with a codebook for data entry was developed by one researcher and reviewed by another, to ensure quality of data entry and validity of data analysis.

The data from close-ended questions were entered into the Excel spreadsheet and then uploaded into SPSS24 to analyse. Descriptive statistics were used to measure central tendency (e.g. frequency, mean), and/or the variability (standard deviation) of the variables. Missing data were imputed with a dummy number or mean for the analysis and reported in the results.

The data extracted from the open-ended questions were entered into the spreadsheet and individually reviewed by two researchers. Then, the data were uploaded to NVivo 11 for coding, merging and grouping the codes into categories and then into the themes and subthemes.

## 4.6 Data integration

Data integration in mixed methods research design is an importation process to make interpretation and/or conclusion, by comparing qualitative findings and quantitative results, and evaluating how this information has addressed the research questions (Creswell & Plano Clark, 2018). This process allows for interpretation and/or conclusions to be drawn from the meta-inferences. This final stage of mixed methods analysis adds deep insights, which are beyond the information generated by a single qualitative or quantitative study, and enhance the values of the research (Teddies & Tashakkori, 2009).

Informed by Creswell and Piano Clark (2018) and Teddies and Tashakkori (Teddies & Tashakkori, 2009), the data integration and meta-inferences for this doctoral project were carried out at two levels. Firstly, the focus group findings and results of S-BQT were integrated, before the findings were integrated with the results of the nurse survey.

The visual diagram for the convergent mixed methods design procedures, including data collection and analysis methods of this doctoral project, is outlined in Figure 4.2.

| Phases | Study design | Procedures | Instrument | Data collection | Data analysis |
|---|---|---|---|---|---|
| 1 | Quant+qual | Study 1<br>Systematic<br>Review | JBI Critical Appraisal tools<br>JBI level of evidence | Concept mapping<br>Tabulation<br>Grouping | Descriptive statistic<br>Narrative synthesis |
| 2 | Qual+quan<br>+ | Study 2<br>Focus groups, patient questionnaire<br>and S-BQT | Questioning route<br>Demographic data sheet<br>S-BQT<br>NVivo 11<br>SPSS V24 | Group discussion<br>Audio recording<br>Note taking | Transcription, translation and coding<br>Intergraded thematic analysis<br>Descriptive statistic |
| | quant+qual | Study 3<br>Survey of Cancer and Palliative Care Nurses | Self-developed survey<br>SPSS<br>NVivo 11 | Survey<br>Online survey | Descriptive statistics<br>Narrative synthesis |
| 3 | Findings merged & compared | Integration and interpretation | | Concept mapping<br>Tabulation<br>Grouping | Narrative synthesis<br>Meta-interference<br>Join display tables |

*Figure 4.2 Diagram for the convergent mixed methods design procedures of the project, adapted from Creswell and Plano Clark (2018) and Johnson et al. (2007).*

### 4.6.1 Integration of focus group findings and the results of S-BQT

At this level, the integration for the focus group Part 1 findings and the results of S-BQT (Study 2a) was undertaken to assist better understanding of Chinese migrants' pharmacological practice and pain reporting behaviours. This was important because the systematic review reported in Chapter 2 identified that Chinese people living in China held a range of patient-related barriers, in relation to adherence to analgesics and reporting of pain, which prevented them from achieving optimal pain management (Xu et al., 2018).

The results of nine items of S-BQT reported by the participants were integrated with the themes and sub-themes defined from qualitative data. The key elements that influenced Chinese migrants' pharmacological pain management and the consequences of the influences were extracted, and put into relevant columns against the results of S-BQT in a joint display table. The meta-interferences based on the comparison and contrast were made and reported in a section of Chapter 5.

### 4.6.2 Integration of focus group findings and results of the nurse survey

At this level, the quantitative results and qualitative findings of the focus groups (e.g. theme, subthemes/key elements) and the results of nurse survey were integrated and presented in two joint display tables and reported in Chapter 9.

The joint display table for research question 2 was presented in line with the 12 domains of Leininger's 'Semi-Structured Inquiry Guide' and 'Sunrise Enabler', with the meta-interferences highlighting 'cultural and social structural factors' influencing Chinese migrants' cancer pain management needs.

The joint display table for research question 4 was illustrated in line with three cultural decision and action modes of Leininger's 'Sunrise Enable', with the meta-inferences facilitating development of strategies for providing culturally congruent pain management to Chinese migrants living with cancer pain.

### 4.6.3 Defining convergence labels in the joint display tables

After contrasting and comparing the qualitative findings and quantitative results, the degree of data convergence was labelled in the joint display tables in accordance with the approaches of Bazeley (2018) and Fitzpatrick (2014), to determine if the qualitative findings and the qualitative results were consistent (*confirmed)*; or consistent and providing a deep insight into Chinese migrants' cancer pain management and/or influential factors (*confirmed and deepened*); or partially or completely contradicted

(*contradicted*). While the themes, subthemes and/or key elements were only identified in the qualitative findings or the quantitative results but provided valuable information contributing better understanding to Chinese migrants' cancer pain management and influential factors, the label 'enhanced' was used. The label 'complemented and extended' was utilised when the defined qualitative themes and sub-themes of the focus group and the nurse survey were complementary and added additional information for a better understanding on the influential factors contributed to Chinese migrants' cancer pain management.

## 4.7 Ethics considerations pertaining to human subjects

This research project was undertaken in compliance with the National Statement on Ethical Conduct in Human Research and Australian Code for the Responsible Conduct of Research. An ethics approval was obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee on 21 December 2016 (HREC reference no: 16/294) (refer to Appendix J), The Site-Specific Assessment approvals for study sites were respectively obtained from the local Research Governance Officers before the recruitment commenced.

The ethics considerations including an informed consent process, strategies of minimising potential risks, confidentiality and privacy, data usage, storage and security were discussed as follows.

### *4.7.1 Informed consent process for the focus group*

Informed written consent was obtained prior to data collection. The participant Information Sheet and Consent Form Information Patients was provided to the participants, with detailed information about: the purposes of study; investigators and key person to contact; durations of participating and process of consent; right to rejection; potential risk and benefits of participating; protection of confidentially; intention to publish the study results; and the contact information for Research Support Officer of Human Research Ethics Committee.

All participants were given time to ask questions about the study and voice concerns about the consent before they signed the consent form. The decision to participate was made after the participants' questions and concerns related to participating in the study were addressed.

All participants were also informed that rejection to participating or early withdrawing would not have any impact on their (the patients) relationships with the health professionals or on their treatment.

### 4.7.2 Strategies of minimising potential risks

The potential risks were taken into account throughout the study with strategies established when developing research protocol to minimise the risks.

**Considerations for Chinese migrants with cancer pain**

Since the focus group requires extra time from the participants' routine clinical visits, the researcher was very mindful when arranging time and dates of focus groups that were flexible and upon the participants' preferences. The focus groups were conducted at the study sites where participants usually visited, or at Chinese cancer support groups that were close to the site of the invitation.

When the participants arrived, the facilitator and research assistant asked the participants how they felt and if they were physically well enough to stay for the focus group; and advised them that they could leave at any time when they felt tired.

***Managing breakthrough pain***

A strategy was established to manage participants' pain and/or any new cancer pain that may have occurred during the focus groups.

For those participants who were receiving cancer pain treatment, the facilitator contacted them prior to the focus groups and reminded them to bring their pain medications with them. Participants were also advised if significant breakthrough or new pain occurred during the focus group, the focus group would be stopped.

When the focus group was in the cancer or palliative care centre/unit, the facilitator was able to seek support from a physician or a nurse within the department after the permission was sought from the participants.

Where the focus group was conducted in the community, the facilitator asked the patient about their access to support through their cancer or palliative care team and assisted them as necessary, if the pain occurred. Alternatively, participants were asked whether they would like to take a taxi or call an ambulance to take them to their GP or the nearest Emergency Department.

If it was discovered that a participant had not received adequate pain management (e.g. if a participant was unaware that their level of pain was greater than it should and needed treatment), the facilitator would discuss this with the participant and suggest her/him visit their medical team at the hospital or their GP to seek help.

Whilst this process was in place, it was not used, as no participants experienced breakthrough pain that they could not manage themselves.

### *Managing psychological distress*

The researchers were aware that the participants may feel anxious when disagreements occur during group discussion. To avoid this risk, the facilitator started by asking everyone to respect each other, which all the information discussed in this room was confidential, and not to discuss what was shared after leaving the room. The facilitator also reassured participants that different opinions were acceptable but explained the need for respectful discussion. These points were reiterated during the discussion if there were any signs of conflict. The facilitator advised the participants that they were free to skip questions if they were uncomfortable or felt distressed.

The following plan was in place if participants experienced distress during the focus group:

All focus groups were facilitated or assisted by a Chinese-English-speaking researcher who was an experienced Registered Nurse of Australia and academic of the Faculty of Health of UTS, and were assisted by another Mandarin-speaking or Cantonese-speaking staff member.

Participants were reminded that they could seek support from the Cancer Council's free, confidential telephone information and support service, should they become distressed during or after the focus groups. The health care interpreter service was available if they required language support. The Clinical Consultation and Assessment Service of the Transcultural Mental Health Service was available for free for anyone from a culturally and linguistically diverse community and living in NSW, and experiencing a mental health issue. They also had access to professional psychological counselling by asking for a referral through their GP, if they chose to take up this opportunity.

Participants were also invited to contact the site principal investigator to ask about counselling services available at the hospital. Contact details for the site principal investigators were included in the PIS&CF.

### *Maintaining confidentiality and privacy*

The participation in focus groups was voluntary and confidential. The focus groups were respectively held at a meeting room, to ensure participants' privacy and freedom in expressing their opinions.

The facilitator referred to participants' English names during the focus group. Pre-determined identification numbers (ID) were allocated to every focus group and participant, which were consistently used for the focus group questionnaires and audio files. Except for the written consent, no audio or written data files recorded the participants' full name. Participants could only be tracked by their ID. Their identified information would not be exposed to the public or mentioned in the reports and manuscripts.

**Considerations for the cancer and palliative care nurses**

Participating in the nurse survey was voluntary and confidential, and rejection of participation would not affect the nurses' employment and/or memberships. Completion of the survey was taken as evidence of informed consent. No identifiable information needed to be provided in the survey.

### *4.7.3 Data usage, storage and security*

During the focus group, all consent forms, questionnaires and audio recorders were held tightly and securely by the researcher. After the focus group, all documentation and data were stored in a locked cabinet at Faculty of Health of UTS and a password secured computer and hard drive.

The data and the identifiable documentations (e.g. the consent forms) were stored separately. Data access was restricted to researchers and research assistants for data entry, management and analysis; and the ethics committee for monitoring.

The results extracted from the data sets will be published in a peer-reviewed journal, presented at academic conferences or workshops, and used for writing this doctoral thesis. The data may also be used to develop interventions in future studies. Upon study completion, all the data, files and documents related to ethics and research governance were archived and will be retained for five years.

## 4.8 Summary

Chapter 4 discussed the research paradigm underpinning mixed methods research and justification of adopting convergent mixed methods design to answer the research questions; and described methodological approaches and ethics considerations of this doctoral project. The chapter sets up boundaries for study procedures and discussion of substantive findings and results.

As outlined in Chapter 1, the findings of the focus groups are reported in Chapters 5-7 (Study 2a, Study 2b and Study 2c), and the results of the nurse survey are reported in Chapter 8 (Study 3). A discussion is presented at the end of each chapter in reference to current literature and/or practice guidelines

The main findings and gaps highlighted in the discussion of each chapter were integrated to answer the research questions from both patient and nursing perspectives, and results of data integration and interpretation are reported in Chapter 9.

The next chapter reports Study 2a – the focus group Part 1 findings and the results of embedded patient questionnaires including S-BQT.

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# Chapter 5 'Cultural and Social Structure Dimensions': The 'cultural and social structural factors' affecting Chinese migrants' perceptions and responses to cancer pain and pharmacological pain management

## 5.1 Introduction

As discussed in Chapter 4, a series of focus groups were undertaken in Cantonese and Mandarin with Chinese migrants living with cancer pain in Australia. The focus groups sought to better understand the 'cultural and social structural factors' that affected their cancer pain management.

This chapter reports on the focus group Part 1 findings related to Chinese migrants' cancer pain experiences, and the 'cultural and social structural factors' affecting participants' perception and responses to the pain and its pharmacological management. The results of patient questionnaire including S-BQT nested with the focus groups are also reported.

The methodological considerations related to this study have been discussed in Chapter 4. Other aspects of the focus group findings are reported in Chapters 6 and 7.

## 5.2 Sociodemographic and clinical characteristics

A total of 24 participants contributed to one of five focus groups conducted in Cantonese (*n* = 2) or Mandarin (*n* = 3). The mean duration of each focus group was 75.27 minutes (standard deviation [*SD*] ±17.0)

All study participants lived in metropolitan Sydney, NSW. The mean age of participants was 59.4 years (*SD* ±9.8). All participants had lived in Australia on average for 20.9 years (*SD* ±8.6). The majority of participants were female (*n* = 22, 91.7%) (Refer to Table 5.1). Two-thirds participants (*n* = 15, 62.5%) had attended a specialist palliative care service, and more than a third (*n* = 9, 37.5%) visited a General Practitioner (GP) for the management of their cancer pain.

**Table 5.1 Characteristics of participants**

| | *N* | % |
|---|---|---|
| **Gender** | | |
| Female | 22 | 91.7 |
| Male | 2 | 8.3 |
| **Marital status** | | |
| Single | 1 | 4.2 |
| Married | 20 | 83.3 |
| Divorced/separated | 2 | 8.3 |
| Widowed | 1 | 4.2 |
| **Language spoken at home** | | |
| Mandarin | 8 | 33.3 |
| Cantonese | 16 | 66.7 |
| **Education** | | |
| Primary School | 4 | 16.7 |
| Middle school | 6 | 25.0 |
| Secondary School | 5 | 20.8 |
| Diploma | 2 | 8.3 |
| Advanced diploma | 4 | 16.7 |
| Bachelor's Degree | 3 | 12.5 |
| **Employment** | | |
| Part time | 4 | 16.7 |
| Retired | 10 | 41.7 |
| Unemployed | 7 | 29.2 |
| Housewife | 3 | 12.5 |
| **Type of cancer** | | |
| Breast | 12 | 50.0 |
| Lung | 6 | 25.0 |
| Colorectal | 2 | 8.3 |
| Ovarian | 1 | 4.2 |
| Nasopharyngeal | 1 | 4.2 |
| Bowel | 1 | 4.2 |
| Pancreatic | 1 | 4.2 |
| **Care centre for pain treatment** | | |
| Cancer care centre | 15 | 62.5 |
| General Practitioner | 9 | 37.5 |

## 5.3 Level of pain and strategies for pain management

Nearly all participants (*n* = 23, 95%) reported having cancer pain, with three quarters (*n* = 18, 75%) having lived with moderate to severe pain ($\overline{x}$ = 5.58, *SD* ±2.62) on the 0−10 Numeric Rating Scale for the past two years. The top three pain management strategies utilised by participants were massage (*n* = 14, 58.3%), paracetamol (*n* = 11, 45.8%), and heat (*n* = 10, 41.7%).

Despite most participants experiencing moderate to severe pain, only a third (*n* = 8, 33%) used opioids to manage their cancer pain. The majority (*n* = 23, 96%) used non-pharmacological pain management strategies. Three-quarters used non-opioid analgesics (*n* = 18, 75%), and a half (*n* = 12, 50%) used TCM for pain management.

**Table 5.2 Pain management strategies reported by patient participants**

| | *N* | % |
|---|---|---|
| **Non-opioid medications** | **18** | **75.0** |
| Non-opioid medications | 18 | 75.0 |
| Aspirin | 3 | 12.5 |
| Paracetamol | 11 | 45.8 |
| Nurofen | 5 | 20.8 |
| Other weak pain meds | 3 | 12.5 |
| **Opioids** | **8** | **33.3** |
| Codeine | 3 | 12.5 |
| Oxycodone | 2 | 8.3 |
| Methadone | 1 | 4.2 |
| Fentanyl | 1 | 4.2 |
| Lyrica | 1 | 4.2 |
| **Traditional Chinese medicine** | **12** | **50.0** |
| Chinese herbs | 7 | 29.2 |
| Acupuncture | 6 | 25.0 |
| Cupping | 1 | 4.2 |
| **Non-pharmacological therapies** | **23** | **95.8** |
| Massage | 14 | 58.3 |
| Heat | 10 | 41.7 |
| Ice | 3 | 12.5 |
| Music | 8 | 33.3 |
| Qigong | 8 | 33.3 |
| Tai chi | 5 | 20.8 |
| Ice | 3 | 12.5 |

## 5.4 Findings of focus group: Part 1

As described in the previous section, all participants had experienced varying levels of cancer pain. The data emerging from the integrative thematic analysis revealed the following four themes and seven subthemes in relation to their pain experiences and pharmacological pain management, in accordance with 'Cultural and Social Structure Dimensions' in Leininger's 'Sunrise Enabler' and Leininger's 'Semi-Structure Interview Guide'(Wehbe-Alamah & McFarland, 2015):

1) Negative consequence of living with chronic cancer pain
2) Philosophical health beliefs shape Chinese people's perceptions of their cancer pain:

   i) the body can self-heal
   ii) cancer pain is self-provoked

3) Cultural values and beliefs influence how Chinese people respond to their cancer pain:
   i) cancer pain is inevitable
   ii) Chinese people express their pain differently compared to local people
4) Conflicting views on using opioids for cancer pain:
   i) culture-related negative medication beliefs
   ii) western biomedical model-related opioid fears
   iii) opioids extend life for people with terminal cancer

### *5.4.1 Negative consequence of living with chronic cancer pain*

All of the participants had lived with poorly controlled chronic cancer pain since their cancer treatment started. They attributed this unexpected chronic pain to the side-effects of chemotherapy or radiotherapy which had changed their lives forever.

> *Before the chemotherapy treatment, I had never experienced any sore knees or sore heels; there was no pain at all. It was only after the chemotherapy that those parts became painful, which has affected me since then … It was painful! Suddenly, it made me feel like an old person, because I did not expect such pain. (P1, female, 62 years old and breast cancer)*

While living with cancer had an all-encompassing adverse impact on participants' wellbeing, the added burden of living with chronic cancer pain had lowered their self-esteem and amplified the impact cancer had on their daily life. The multidimensional impacts and burden of chronic cancer pain was omnipresent for these participants.

> *I do not like myself now. The pain is constantly disturbing me and annoying me … The quality of our daily life is not good … I feel that most of time we are suffering from the pain … In fact, these diseases (cancer) cannot only affect people's cells but also the mind as well as other aspects of people's wellbeing. When people are under the great pressures, it can affect all aspects of their wellbeing. (P3, female, 55 years old and breast cancer)*

Chronic cancer pain not only decreased participant's mobility, it also interfered with their daily activities and impacted adversely on their sleep hygiene.

> *It has been almost two years since I had operation. However, I wake up every night because of different levels of pain and this problem has lasted for one year. Till now, the pain occurs every time when I roll over my body in bed. Even though the pain is not*

> *sharp, it can wake me up which affects my sleep quality and makes me feel bad in the morning. (P3, female, 55 years old and breast cancer)*

The presence of chronic cancer pain had forced many participants to modify and restrict their daily activities.

> *I must be very careful when I am doing something. I don't dare move too much, because I would feel very painful if I move too much. So, when I feel the pain, I do not want to continue. I must sit down to rest until the pain becomes less acute. If I force myself to continue, it would be very painful. (P12, female, 66 years old and lung cancer)*

Many expressed frustration that little could be done to alleviate their chronic cancer pain.

> *I cannot do anything when the pain persists for the entire day … Right now I can only do housework for less than one or two hours. After cooking, my whole body is changed as if I was carrying a piano and it is painful … These problems cannot be resolved. (P4, female, 61 years old and breast cancer)*

Nearly all participants descried how chronic cancer pain impacted adversely on their psychological wellbeing and their ability to continue working.

> *The pain makes me feel unwell. My mood is blue, and I have a bad temper due to the pain. Sometimes the pain occurred making me wonder whether I should go to work or not. (P4, female, 61 years old and breast cancer)*

Some participants described how their chronic pain impacted on their ability to remain in paid employment due to disability, loss of confidence or fatigue, which affected their psychosocial wellbeing.

> *Before I was working like a non-stop car tyre. But now I feel as if I was a flat tyre. I have no energy and I am very tired. I worry whether I would be capable to do my job well as I did before, and I have the pressure after being sick for a long time. (P16, female, 48 years old and nasopharyngeal cancer)*

An inability to return to work had a roll-on effect and contributed to loss of income and inability to carry out household tasks. These inabilities increased their social distress, lowered their self-esteem, and increased their sense of vulnerability, especially when they were physically unwell. These feelings deepened when their family responded with negative attitudes.

> *If I told my husband about it (painful hands and feet), he would not know why the pain occurred and did not know why I felt it so hard. It was better to say nothing. Also, they (family) would feel very annoyed if I told them about my pain ... Like, I did not tell anybody … I would feel very embarrassed if my friends see me hanging a urine bag. (P9, female, 69 years old and colorectal cancer)*

### *5.4.2 Philosophical health beliefs shape Chinese people's perceptions of their cancer pain*

Two subthemes emerged from this theme.

**The body can self-heal**

Participants believed that if they adopted a healthy regimen involving a balanced diet and regular exercise then the body would heal itself. In keeping with this belief, they perceived that their cancer pain would be relieved when their body returned to normal functioning.

> *I always think that our bodies also have the ability of self-healing. We should take care of ourselves at all aspects of our diet and daily life. Paying attention to doing the exercises may be helpful. You may help yourself in pain management. (P21, female, 53 years old and breast cancer)*

Participants suggested that the Chinese saying that 'men do not cry easily' (other participants from P19's group) reflected Chinese men's capacity to stoically endure their cancer pain, and the belief that the body would take care of the pain and that it would pass.

> *As a man, it is impossible for me to 'wow' 'wow' shout out in front of my wife and my daughter − this is the nature. (P19, male, 67 years old and breast cancer)*
>
> *I did not take the medication at home, but I endured it. Sometimes, I grabbed the bed when I was in pain, my hands were sweating, and my cloth was soaking in the sweat. The pain would go away after a while. (P19, male, 67 years old and bowel cancer)*

**Cancer pain is self-provoked**

Some participants believed that cancer was self-provoked and that their cancer pain was brought on by themselves because of bad temper, unhealthy lifestyle and eating behaviours. They felt that they "*deserve the pain*" (P23, female, 63 years old and bowel cancer) and have to accept it.

> *Firstly, it is because of our lifestyle. Secondly, it is because of our diet − we eat everything … The unhealthy things we had would gradually build up in our body. So, when we get older, our immunity becomes weak and we would become unwell. It is just like you plant a seed deeply in the soil. It will germinate after a period when it was exposed to the sun or when the opportunities come … I think my pain is caused by myself. It is attracted by the things we planted. So, we should accept it. It would be fine to bear a little bit of pain. People would not be able to help us even when we tell them. For example, if we tell our children about the pain, they would be worried about us, but*

> *they do not have any solutions to help us reduce the pain. (P24, male, 87 years old and pancreatic cancer)*

Acceptance of cancer and its associated pain helped to relieve their psychological distress and strengthen their ability to cope with their cancer treatment and pain.

> *Our temper would harm our body. Cancer is caused by the bad temper … For me, when my doctor said that my pancreas tumour was very large, I was not afraid of it and I was willing to accept it, because I attracted this stuff by myself. … I want to rely on myself to find the way relieving the pain … I have not told the doctor about the pain. I feel I may control it myself. It has not reached the level that I could not bear. (P24, male, 87 years old and pancreatic cancer)*

The perception of deserving the pain, and a strong desire to control their own pain affected the way participants conceptualised their cancer pain experience and derived them to normalise their level of pain. This was best exemplified by one participant (P24, male, 87 years old and pancreatic cancer) who reported having a pain score of '0' for two years, even though during the focus group he mentioned suffering pain at night.

### *5.4.3 Cultural values and beliefs influence how Chinese people respond to their cancer pain*

The degree to which Chinese cultural values and beliefs versus personality impacted on participants was a source of some debate, with two schools of thought. The first, which the majority of participants subscribed to, was that their implicit and explicit cultural values and beliefs shaped how they managed their cancer pain.

> *Cultural background certainly plays a significant role on pain management. Sometimes it is consciously and sometimes it is unconsciously. (P19, male, 67 years old and bowel cancer)*

A smaller number of participants suggested that personality and emotional factors determined how each individual perceived and managed their cancer pain.

> *I think it is because of the personality instead of the cultural background. For example, even though we are all Chinese, but some people choose to take pain medications when they are in pain, while others decide to take pain medications regularly even when they are not in pain. I feel that the way people choose to treat their pain depends on their personalities instead of their cultural backgrounds. (P15, female, 49 years old and breast cancer)*

Despite these opposing views, participants unanimously agreed that Chinese people have unique viewpoints about pain treatment and would like to use their own ways to deal with pain.

### Cancer pain is inevitable

Participants suggested that as Chinese people believe that cancer pain is an inevitable part of the cancer treatment, it was easier for them to accept living with unrelieved cancer pain.

> *The most popular words which Chinese people often said to themselves when they go to see the doctor are that 'the medication is bitter, but it would be good for the treatment'. Sometimes when you take the medication, it could be bitter and may cause pain. This is a part of the process which it happens when you are sick. (P23, female, 63 years old and bowel cancer)*

Since cancer pain was inescapable, taking analgesics would not resolve the problem. While these participants might be willing to acknowledge and report having cancer pain to health professionals, they would not adhere to recommended cancer pain treatment.

> *I did tell the doctor when I had pain … however, since pain is a part of the cancer treatment, I cannot always take pain medications. The pain will still be here after the effect of pain medication has gone. I know that. I would bear with it as long as I can. (P23, female, 63 years old and bowel cancer)*

In part, this was because participants perceived that cancer treatment takes precedent over pain management that may jeopardise the effectiveness of their chemotherapy or radiotherapy. However, they feared that the pain indicated that the cancer had spread to other parts of their bodies, so reassurance from cancer care professionals was an important part of care.

> *Chinese people would think about what disease may have caused the pain and would have the disease treated. The treatment may induce the pain; so, we should accept it. The most important thing is to treat the disease. I feel that most of Chinese would think of this way. (P23, female, 63 years old and bowel cancer)*

Overall in Chinese culture, survival from cancer is more important than pain relief. Knowing the cause of pain may reduce the level of distress and ease the pain.

### Chinese people express their pain differently comared to local people

Participants perceived that compared to Australians (local people) Chinese people respond differently to pain. For some this difference was shaped by family traditions; this was most obvious amongst the older Chinese migrant cohort who tended to be more reserved and more reluctant to bother others with concerns about their cancer pain.

> *My father grew up from a very poor family. Their life was miserable. He was bearing the misery himself and did not want to trouble others. (P24, male, 87 years old and pancreatic cancer)*

> *They are afraid to bother others. My parents are the same … However, nowadays the children would not be the same as far as I know (P23, female, 63 years old and bowel cancer)*

While these views and attitudes may have served prior generations of Chinese people well, participants thought that not talking about or acknowledging their cancer pain was no longer appropriate, as it was likely to cause more suffering.

> *Because my mother is like this. She would say she was fine, even when she was suffering from the pain and almost lost her consciousness. That is not right. This is overcorrected. (P23, female, 63 years old and bowel cancer)*

Compared to Chinese people, the participants suggested that Australians are less concerned about asking for help to manage their cancer pain and less likely to put up with unrelieved cancer pain. Some participants thought that this was a better way of managing cancer pain.

> *Local people are very straightforward. Compared to us, they accept life, death and disease easily … I feel that the way how the local people deal with pain is correct. I find they do not care. They would say where the pain is located. We would make self-judgement about the pain first, before we ask the doctor. I feel this is not good … I think we need to learn this from the local people. (P23, female, 63 years old and bowel cancer)*

Some participants also suggested that local people speak more openly about their pain because they value their quality of life and have fewer cultural considerations shaping their help-seeking behaviours.

> *(They) pay more attention to the quality of life; while our Chinese people are used to enduring the great hardship for more important tasks. The local people would think if I can get relief and why I have to suffer. (P17, female, 54 years old and breast cancer)*

As a result, participants thought that local people on the whole would prefer to take pain medication freely to control their pain, whereas Chinese people would prefer to bear the pain.

> *Chinese people are better at bearing pain... Chinese people usually only take pain medications when we need to. (P5, female, 55 years old and ovarian cancer)*

For many participants, culture created high expectations that they could endure pain. This belief increased participants' pain tolerance level and enabled them to normalise their pain and negate the need for analgesics.

> *With regards to my own experience of cancer pain, I think the pain is not too bad, it is just physical pain. I do not think it is a big deal. When I stayed in the hospital, the nurse asked me if I wanted to take the painkillers. I said no, I was not in pain, so I did not want to take it. The nurse told me that it was better to take it, because she was afraid that the pain may occur at night. In fact, I did not feel pain. I do not know the other people's experience. Perhaps Chinese are very good at bearing with the pain. I did not think I was in pain. I thought it was just the skin-cut pain. It was like you were scratched when you did gardening … those people who stayed in the same ward with me screamed for the whole night and always complaint about the pain. I did not feel the pain at all. (P23, female, 63 years old and bowel cancer)*

### 5.4.4 Conflicting views on using opioids for cancer pain

Participants held a range of complex and often conflicting, beliefs and views about using opioids and other weak analgesics to manage their cancer pain.

**Culture-related negative medication beliefs**

According to participants, negative medication beliefs were broadly held by Chinese people, with many believing that all medications are harmful to the body and its systems. Therefore, taking too many medications including pain medications are not good for the body.

> *Chinese believe that too many medications are not good for the body, and think that taking painkiller for an extended period of time is harmful. (P5, female, 55 years old and ovarian cancer)*

All medications, including cancer and pain medications, are considered toxic. Chemotherapy and other cancer treatments are perceived to accumulate toxins in people's bodies. So, taking strong analgesics while receiving cancer treatment is an extra burden to the body system.

> *I think all the medications are toxins. We have already had too many toxins in our body, because we had cancer and we have already used too many chemo and radiation medications which are very poisonous. If you add more toxins, the liver and kidney would not stand them. So, it is better not to take it. (P17, female, 54 years old and breast cancer)*

The strong analgesics are particularly harmful to the vital organs (e.g. brain, kidneys and stomach) "*because they are poisons*" (Participants in focus group 2).

> *I had the most severe pain when I just had surgery done. I thought that kind of pain was reasonable. The doctor said to me I may ask for the painkillers, but I did not ask because I thought the morphine was not good. It does harm to the brain. (P20, female, 47 years old and breast cancer)*
>
> *Those medications may damage kidney, stomach etc. (P24, male, 87 years old and pancreatic cancer)*

For many participants, their reluctance to taking analgesics was stemmed from their fear of negative medication effects, which they ascribed to the different reactions to pain medications likely caused by the physical divergence between oriental and western people.

> *I think that it is because the physique of oriental and western people is different … Our physique is different, so the medication we are taking would have different effects. (P3, female, 55 years old and breast cancer)*
>
> *It might be because they (local people) have already taken a lot of medications, so they get used to it; but we have done less so we are not getting used to it. Sometimes the medications make us vomit. So, we’re afraid of pain medications. (P7, female, 70 years old and lung cancer)*

For these reasons, most participants were extremely resistant to taking opioids. They would endure pain or take weak analgesics, hoping to find less harmful non-pharmacological strategies.

> *I hope that we do not have to take medications but use a healthier way to relieve pain. (P2, female, 54 years old and lung cancer)*
>
> *I did not take it. I just took the antibiotics and the poison I am using now – the chemo. He (the doctor) said to me that I only need take Panadol (brand name for paracetamol) when I am in pain. I would not take Panadol if I can bear the pain. (P12, female, 65 years old and lung cancer)*

Although weak analgesics were considered less harmful, participants often reduced the dose as long as they could bear the pain. They would reject taking weak analgesics to avoid further damage to their body, when they underwent cancer treatment. However, this approach often led to acute pain crisis.

> *She (the doctor) said to me I may take Panadol when I had pain. I thought that the chemotherapy had already damaged both normal cells and cancer cells in my body, so I should not take too many pain medications. Also, I knew that Panadol was not a strong pain medication and I did not think it had effects. So, I did not take it regularly, but took it when I was in pain. I only took one tablet even though I should take two tablets according to the medication instruction. However, the pain was not controlled and became extreme.*

> *I eventually fell on the floor and could not stand up after I went to the toilet. So, my husband sent me to the hospital. (P13, female, 45 years old and breast cancer)*

**Western biomedical model-related opioid fears**

Apart from culture-related negative medication beliefs, opioid fears such as addiction, side-effects, resistance, dependence and unexpected health implications also contributed to participants' rejection or poor adherence to the use of opioids for cancer pain.

> *I endured the pain from time to time, and sometimes I felt that I may overcome the pain by enduring the pain. So, I simply did not use those painkillers. In the questionnaire I did just now, it asked about addiction of the painkillers. I thought it was likely to be addicted to the painkillers, because it may lead to hallucinations. When the pictures that I never saw before appeared in my mind, I felt that my mind seemed to become unstable. I was afraid when my pain was controlled, where my mind would become chaotic. I did not dare to use (the painkillers). I was afraid that it would become a problem when my mind become chaotic. (P19, male, 67 years old and bowel cancer)*

Some participants thought that they should only take opioids when needed. Otherwise taking too many strong analgesics can cause drug resistance.

> *It would lose the effect if we take too much … The pain would not be controlled even when you take it. (P9, female, 69 years old and colorectal cancer)*

Most participants were very concerned about experiencing opioid side-effects (e.g. constipation, nausea and vomiting). Experiences of serious side-effects can also lead to rejection of opioids.

> *Perhaps it was. My whole body was cold and sweating after one tablet. I became very weak and cannot stand. My son called the help line. The person explained to me via the phone that the medication was too strong for me and asked me to take half of the tablet. However, one tablet had made me in cold sweat. It was too strong, so I did not want to take it anymore. I restarted Panadol, and thought that if Panadol did not work, I would go to the hospital … I have never used it after that. (P13, female, 45 years old and breast cancer)*

There was also a perception that the side-effects of opioids were amplified when the participants were receiving cancer treatment.

> *These pain medications are not good because during the chemotherapy, if you take too many pain medications you will not be able to go to the toilet. (P2, female, 54 years old and lung cancer)*

Participants were concerned that these side-effects would be chronic and persistent even after they stopped taking them.

> *Also, I am afraid that the side-effects become a kind of inertia. (P9, female, 69 years old and colorectal cancer)*

Other participants detailed how frightening some severe opioid side-effects were, such as hallucinations, colouring their view of using strong analgesics.

> *I went to [name removed] Hospital … There was a device after the surgery. When I pressed the button, it injected some solution to stop the pain. However, after I pressed the button, hallucination appeared (in my mind) ... Semi-consciously some strange maps of the stars and clouds appeared in my mind which was hard to describe. I was frightened and stopped using it after I had the hallucination even when I was in pain. The nurse said to me that the device was very good and suggested me to use it. I said to myself that I had already had the hallucination and I was afraid that I would become confused. So, I determined to stop using it. I hardly endured it when I was in pain. (P19, male, 67 years old and bowel cancer)*

### Opioids extend life for people with terminal cancer

Despite negative medication beliefs and opioid fears, participants acknowledged that there was a role for opioids, especially when the cancer pain became too severe.

> *Taking the pain medication may relieve the pain for a while. There is no choice when the pain becomes severe. So, if he (the doctor) gives you medications that may relieve your pain, you would have to take it, no matter what it is. The medications we are taking right now is poison, so it is the same. Therefore, if it is painful, you have to take it even if it is poison. (P2, female, 54 years old and lung cancer)*

While most participants were extremely resistant to taking opioids, they stated that they would not hesitate to take these medications if they were at the end of life.

> *When the time comes, I would eat any kind of pain medications. At that time, it doesn't really matter. (P11, female, 62 years old and breast cancer)*

The reason was likely because most participants worried that pain would become extremely severe at the end stage of cancer and beyond their control. They have to accept opioids, so they can be free of pain.

> *I feel that if my health condition is so serious, I should take it and accept it. Because I heard from my friend that if the pain is unbearable, we must take it. Only pain medications, like morphine, may stop that kind of pain so that we may sleep well at night. Previously, when I stayed at hospital, I made a friend. She was at the end stage of cancer. She said to me, she had to take several tablets of morphine every day. I had*

> *never heard before that the pain could be so bad. I asked her, and she said to me the pain was very severe, and she could not sleep without taking pain medications. Panadol was like vitamins and did not work for her. She said to me I had to accept and take it when I come to the end stage. So, I would take it, because I do not want to have this kind of pain and I do not want to suffer. (P14, female, 59 years old and breast cancer)*

Once the disease had progressed, some participants believed that strong pain relief might act to extend their life. Participants suggested that once they were nearing the end of life, a deep fear of having an uncomfortable death combined with a strong desire to survive would help them overcome their opioid-related concerns.

> *I think in my experience, probably 30 years ago I knew that having cancer could be very painful, and painkillers cannot relieve pain … Before the pain will torture you to death, but now the medicine would be able to make you sleep well. (P9, female, 69 years old and colorectal cancer)*

> *This is right. We – the cancer patients − have thoughts of death. We think of the death every day. Taking these pain medications would extend the life. (P12, female, 65 years old and lung cancer)*

Although participants would not reject using opioids when pain became severe or at the end of life, it seemed that not everyone desired to know what kind of pain medications they were taking, because they did not want the psychological pressure.

> *I did not know much about the medications you just mentioned. I do not want to know when I am sick. I force myself to take the medications. I do not want to know that these drugs are originally morphine. I do not want to scare myself. So, I have never learnt the drug names you mentioned. I would just ignore it and take it anyway … because I do not want to have psychological pressure. (I do not want to think that) I have eaten some morphine into my stomach. I would just ignore it and take it first. I do not want to know if it is harmful. (P12, female, 65 years old and lung cancer)*

### 5.4.5 Summary of focus group findings

Overall, Chinese culture influenced Chinese people's perspectives of cancer pain management. Their perceptions of cancer pain and its treatment were shaped by their philosophical health beliefs and cultural value and beliefs about cancer and/or cancer pain, and their conflicting views on using opioids for cancer pain. These factors affected their expression and responses to cancer pain and resulted in strong resistance to opioids during their cancer treatment. The next section presents the results from the S-BQT.

## 5.5 Results of Short Version of the Barriers Questionnaire-Taiwan

As described in Section 5.3, participants who contributed to the qualitative study also completed the 9-item S-BQT.

Participants reported a total mean score of 3.28 (*SD* ±0.89) in the S-BQT, indicating that they had a higher barrier to using analgesics and reporting pain (Li et al., 2013). The highest mean score of the S-BQT subscales was 'side-effects' ($\overline{x}$4.71, *SD* ±0.75), followed by 'tolerate' ($\overline{x}$ = 4.33, *SD* ±1.27) and 'disease progress' ($\overline{x}$ = 4.33 ±1.20). The lowest mean score of the S-BQT subscales was 'religious fatalism ($\overline{x}$ = 1.50, *SD* ±1.89) (refer to Table 5.3). The results of the nine S-BQT subscales were further interpreted to correspond to the focus group findings in the next section.

**Table 5.3 Barriers Questionnaire-Taiwan scores of all participants**

| Subscale | Mean (*SD*) | Level of score* |
|---|---|---|
| Addiction | 3.46 (1.69) | Higher |
| Disease progress | 4.33 (1.20) | Higher |
| Tolerate | 4.33 (1.27) | Higher |
| Fatalism | 3.38 (1.88) | Higher |
| Religious fatalism | 1.50 (1.89) | Lower |
| As needed | 3.17 (2.20) | Higher |
| Side-effects | 4.71 (.75) | Higher |
| Fear of distracting physicians | 2.17 (1.76) | Moderate |
| A desire to be good | 2.54 (1.7) | Moderate |
| **Total S-BQT** | **3.28 (0.89)** | **Higher** |

*The scores of S-BQT and its subscales are graded as lower (0-1), moderate (2-3) and higher (>3) (Chou, Rau, & Lin, 2011).

## 5.6 Integration of the short version of the Barriers Questionnaire-Taiwan results and focus group findings

The key elements extracted from the focus group findings Part 1 and the results of S-BQT are integrated and summarised in Table 5.4. The integrated findings are presented alongside with the relevant themes and subthemes as described in Section 5.4. The meta-interferences of the data integration are detailed in Sections 5.6.1-5.6.3 and further discussed in Section 5.7.

**Table 5.4 Integration of the focus group findings and Barriers Questionnaire − Taiwan results**

| Focus group findings (QUAL) | | | | S-BQT (qual) | | Convergence label |
|---|---|---|---|---|---|---|
| Themes | Sub-themes | Key elements extracted from themes/subthemes | Consequence | Results of Subscale | Item descriptions* | |
| **Conflicting views on using opioids for cancer pain** | Culture-related negative medication beliefs | All medications are harmful<br>All medications including anti-cancer and pain medications are toxic<br>Opioids are poisons and are harmful to the vital organs | Rejection of opioids<br>Endurance of pain or only taking weak analgesics<br>Reduction of the dose or rejection of weak analgesics during cancer treatment | **Higher score of 'side-effects'** | Pain medication will cause harm to kidney or liver or stomach | Confirmed and deepened |
| | Western biomedical model-related opioid fears | Extreme concerns about side-effects of opioids<br>Frightened of severe opioid side-effect experiences | Rejection of opioids<br>Endurance of pain | | | |
| | | Fear of addiction to opioids | Rejection of opioids or poor adherence to opioids<br>Denial of being using opioids | **Higher score of 'addiction'** | I am afraid to get addicted to pain medication | Confirmed and deepened |
| | | Taking too many medications can cause drug resistance and dependence | Only taking opioids when needed | **Higher score of 'as needed'** | Pain medications are better given on an as-needed instead of on an around-the-clock basis | Confirmed and deepened |
| | Opioids extend life for people with terminal cancer | Afraid of losing control to extreme pain<br>Fear of being tortured to death by the severe pain<br>Strong pain relief extending life at the end stage of cancer | Saving opioids for severe pain<br>Being willing to take opioids at the end stage of cancer | **Higher score of 'tolerate'** | Pain medication should be 'saved' in case of pain | Confirmed and deepened |

| Focus group findings (QUAL) | | | | S-BQT (qual) | | Convergence label |
|---|---|---|---|---|---|---|
| Themes | Sub-themes | Key elements extracted from themes/subthemes | Consequence | Results of Subscale | Item descriptions* | |
| **Cultural values and beliefs influence how Chinese people respond to their cancer pain** | Cancer pain is inevitable | Pain is an inevitable part of cancer treatment<br>Cancer treatment taking precedent over pain management<br>Survival more important than the pain relief | Rejection/delay in receiving pain treatment<br>Acceptance of pain<br>Normalisation of pain | **Higher score of 'fatalism'** | Pain medication cannot really control the pain | Confirmed and deepened |
| | | Cancer pain the indication of cancer recurrence | Eager to find the cause of pain but rejecting pain medications | **Moderate score of 'disease progress'** | The experience of pain is a sign that illness has become worse | Contradicted |
| | Chinese people express their pain differently compared to local people | More reserved<br>High expectation of bearing pain | Unwilling to ask for help for pain<br>Normalisation of pain<br>Endurance of pain | **Higher score of 'a desire to be good '** | Doctors and nurses might find it annoying to be told about pain | Confirmed and deepened |
| | | | | **Moderated score 'fear of distracting physicians'** | The patients often complain to doctors about the pain, which might distract the doctor's attention from curing the disease | Confirmed and deepened |
| **Philosophical health beliefs' shape Chinese people's perceptions of cancer pain** | Cancer pain is self-provoked | Deserving of the pain as cancer is self-provoked<br>Acceptance of pain can relieve psychological distress | Acceptance of cancer and cancer pain<br>Endurance of pain | **Lower score of 'religious fatalism'** | I am predestined to bear pain | Contradicted |
| | The body can self-heal | Human being's body can self-heal<br>Strong-willed in self-control of the pain | Preference for using a healthy regimen to promote self-healing and avoid harm of opioids<br>Normalisation of pain | **Not applicable** | | Complemented and extended |

### *5.6.1 Cultural beliefs underpinning higher barriers to using opioids*

The integration of the qualitative findings and the results of the S-BQT further confirmed that the themes of 'conflicting views on using opioids for cancer pain' identified in the focus group findings are related to participants' higher barriers to using opioids, which are associated with following subthemes.

**'Culture-related negative medications beliefs' and 'side-effects'**

This integrated finding indicates that participants' extreme resistance to opioids was most likely associated with their strong 'culture-related negative medications beliefs', which was confirmed by the highest scores of 'side-effects'. The main reason was because participants were afraid that using opioids, especially when they were receiving cancer treatment, can cause damage to their body system, particularly their vital organs.

**'Western biomedical model-related opioid fears' and 'side-effects', 'addiction' and 'as needed'**

Participants' belief that opioids should be avoided during cancer treatment was also another important contributor to higher barriers in using opioids, which was confirmed by their higher scores of 'side-effects', 'addiction' and 'as needed'.

Their extreme concern about side-effects and fears of addiction to the opioids resulted in rejection of taking opioids and enduring the pain, or denying about using opioids. Because of a misconception that taking too much medication can cause dependence and tolerance, they would only take weak analgesics when they were in pain.

**'Opioids extend life for people with terminal cancer pain' and 'tolerate'**

Participants' belief that 'opioids extend life for people with terminal cancer' was associated with their higher score of 'tolerate', but its impact on participants' attitudes of using opioids for their cancer pain was contradicted.

While participants had a perception that opioids should be saved for severe pain often occurring at the end stage of cancer, they would bear their pain and reject opioids as long as they felt that they were able to control their pain. Nevertheless, their willingness to save the opioids to extend their life and to be free of extreme pain is a predictor of opioid use at the end stage of their life.

### *5.6.2 Cultural beliefs underpinning pain reporting and help-seeking behaviours*

The theme ‘cultural values and beliefs influence how Chinese people respond to their cancer pain’ affecting participants’ pain reporting and help-seeking behaviours perceived by the participants was consistent with their higher score of ‘fatalism’ and ‘disease progress’, and moderate mean scores of ‘fear of distracting physicians’ and ‘a desire to be good’. Three subthemes were respectively related to these moderate or higher mean scores with different consequences.

**‘Cancer pain is inevitable’ and ‘fatalism’**

The participants’ higher score of ‘fatalism’ reflected their strong belief that ‘cancer pain is inevitable’, whereby they believed that having cancer pain during their cancer treatment is normal. Based on participants’ personal experiences, their cancer pain was often triggered when they were receiving chemotherapy or radiotherapy. Taking pain medication was impractical, since the cancer treatment and the process of recovery from their cancer treatment could last for months or years. Instead of receiving pain treatment, they would rather accept the pain and might tell health professionals that they have no pain during a pain assessment.

**‘Cancer pain is inevitable’ and ‘disease progress’**

The participants’ belief that ‘cancer pain is inevitable’ and the higher score of ‘disease progress’ had a contradictory impact on their help-seeking behaviours. While the participants were eager to consult health professionals about their pain to discover the causes, they often rejected analgesics because they assumed that continuing with their cancer treatment saving their life and living longer was more important than being comfortable. In addition, well managed pain may conceal signs of cancer progressing or recurrence.

**‘Chinese people express their pain differently compared to local people’ and ‘fear of distracting physicians’ and ‘a desire to be good’**

The participants’ perception that ‘Chinese people expressing their pain differently compared to local people’ had a negative impact on their pain reporting and help-seeking behaviours.

Their unwillingness to bother others and high level of expectation of enduring the pain prevented them from asking for help for their pain. This was evidenced by the moderate mean scores of 'fear of distracting physicians' and 'a desire to be good'. They hence would endure and normalise their pain.

### *5.6.3 Complicated role of religious and philosophical health beliefs on pharmacological pain management practice*

The theme 'Religious and philosophical health beliefs shape Chinese people's view of cancer pain' on participants' pharmacological pain management practice was inconsistent.

**'The body can self-heal' – an indirect barrier to using analgesics**

The subtheme of 'the body can self-heal' is not associated with any S-BQT subscale but provided a complementary and extended view on the influences of philosophical health beliefs on participants' pain management practice.

Participants' belief in self-healing and their desire to self-control pain using non-pharmacological approaches and/ or TCM can indirectly act as a barrier for them to use analgesics.

**'Cancer pain is self-provoked' and 'religious fatalism'**

The lower mean survey score of 'religious fatalism' suggests that these participants' religious beliefs are not a major contributing factor to participants' reluctance to using analgesics. However, this is somewhat contradictory to the qualitative findings, which suggest that participants believed that they deserved getting cancer and having cancer pain because of their prior lifestyle and personality. They therefore tended to endure the pain and found that acceptance of the pain can relieve their psychological distress.

## 5.7 Discussion

The integrated data presented in this chapter suggested that Chinese migrant cancer patients living in Australia experience uncontrolled chronic cancer pain, which has negative physical, psychological and social impacts on their daily life. Similar to non-Chinese patients (Jacobsen, Møldrup, Christrup, & Sjøgren, 2009) and Chinese people living in China (Xu, Luckett, Wang, Lovell, & Phillips, 2018), one of the main reasons why Chinese migrant cancer patients in this study experienced poorly controlled chronic cancer pain was related to their resistance to opioids and other analgesics. The opioid fears (e.g. concerns about addiction, side-effects, resistance and dependence) and poor adherence to regular opioid use are also widely reported by other populations

(Flemming, 2010 ; Odenmenger, Smitt, Dooren, Gerrit, & Rijit, 2009; Yates et al., 2002) as well as by Chinese people living in China (Xu et al, 2018).

However, the drivers leading to Chinese migrant cancer patients' higher barrier to using opioids for cancer pain in this study were somewhat different. Their cancer pain experiences and perceptions of cancer pain and its pharmacological management were influenced by a range of cultural and social factors which fall within three domains of Leininger's 'Semi-Structured Inquiry Guide', namely: 'Ethnohistory'; 'Cultural Values, Beliefs, and Lifeways' and 'Religious/Spiritual/Philosophical Factors' (Wehbe-Alamah & McFarland, 2015).

### *5.7.1 'Ethnohistory'*

An individual's cultural heritage shapes the way they conceptualise the meaning of their life and their health and in turn characterises their care needs and experiences (Leininger, 2002).

The findings reported in this chapter provided a cultural lens on how chronic cancer pain affected the quality of life of Chinese migrants living with cancer and highlighted the impact of social distress associated with their poorly managed cancer pain. Regardless of location, Chinese people with poorly controlled chronic cancer pain experience physical, psychological functioning and serious sleeping problems (Deng et al., 2012; Liang, Li, Wu, Wang, & Tsay, 2011).

Similar to the findings from this study, Chinese migrants living with cancer pain highly value the support received from their family and friends and want to continue their contributions to family life for as long as possible (Lin, 2008). They are eager to maintain a normal life and to find joy and peace through daily activities while coping with the difficulties associated with their cancer treatment and living with this chronic illness (Lin, 2008). They often go to great lengths to maintain these activities, so as not to be a burden to their family. Their inability to manage their housework, other daily activities or return to work can destroy their confidence in dealing with their everyday life and increases their fears of being a burden.

The sense of vulnerability was exacerbated when the Chinese migrants in this study felt that they did not belong to Australian society. Feeling like an 'outsider' in Australia was reflected in the way they referred to themselves as 'Chinese' and to Australians as the 'local people' or 'the locals' during the focus groups. Despite most having lived in Australia for more than 20 years, these Chinese migrants living with cancer pain strongly associated with being Chinese. This strong cultural identity united them as members of the Chinese diaspora whilst isolated them from mainstream Australian society.

The cultural isolation and its influences on the health care outcomes of Chinese migrant cancer patients living in Australia were first reported in a qualitative study involving non-English-speaking immigrants living in Australia (Butow et al., 2010). According to Butow et al. (2010), compared to people from other cultures, Chinese migrant cancer patients expressed more concerns about cultural isolation, which delayed them receiving cancer treatment and compromised their cancer care outcome. The feelings of cultural isolation reduces people's ability to deal with their pain and adversely impacts on their physical and psychological functioning (Mackey, Karayannis, Baumann, Melloh, & Sturgeon, 2018).

Addressing this gap requires cancer care services to proactively provide social and medical support to ensure that Chinese migrants living with cancer pain have access to culturally appropriate resources and information that enables them to better manage their cancer pain and provides strategies to help them to regain their physical, psychological and social functioning. This type of care is critical to enabling Chinese migrants to regain or maintain their independence and confidence, so they can re-establish their self-esteem and find meanings in their life (Lin, 2008).

### *5.7.2 'Cultural Values, Beliefs and Lifeways'*

Understanding the influence of cultural values, beliefs and lifeways on health perspectives is another essential component of culturally congruent care (Leininger, 2002). People from diverse cultural groups conceptualise their pain differently, which affects their pain management decision-making (Narayan, 2010).

While opioid fears are similar within and between people from the same and different cultural backgrounds (Jacobsen et al., 2009; Xu et al., 2018), Chinese migrants' 'culture-related negative medication beliefs' deepened this fear. The findings of this study suggests that Chinese migrants' belief about being poisoned by cancer therapy drugs and the harm of strong medications to their vital organs resulted in their extreme resistance to using opioids for their cancer pain. They even rejected weak analgesics when they were receiving cancer treatment. These culture-related negative medication beliefs are likely rooted in the ancient theory of TCM. Chinese people have an old saying that "a medication has three-point of poison components" (Wang, 2018, np)This saying warns Chinese people about the side-effects of medications and addresses the importance of medication safety. Yet, some Chinese people may be very cautious about medication use if they over-interpret the side-effects as being toxic (Wang, 2018).

While the Chinese migrants living with cancer pain in this study were overly concerned about the side-effects of opioids, similar concerns have been expressed by other cancer populations, making chronic cancer pain management more complex and challenging (Mackey et al., 2018). As a result of early cancer diagnosis and advances in treatment, the proportion of cancer patients living with chronic cancer pain and receiving opioids for their pain has increased. Adverse consequences associated with the chronic use of opioids, such as escalating use, abuse and related deaths, have in recent years become a growing problem for cancer survivors (Mackey et al., 2018).

It becomes difficult to convince Chinese migrants to take opioids when they have experienced adverse opioid side-effects, such as hallucinations or confusion, or have heard other people's opioid-side-effects stories. Early educational interventions addressing Chinese migrant cancer patients' potential negative medication beliefs, combined with close monitoring to minimise opioids side-effects, will assist them overcoming these barriers.

Health professionals also need to be aware that Chinese migrant cancer patients' attitudes to opioids may change over time, especially as their cancer progresses and they are near the end of life. This change occurs because Chinese migrants' fear of living with such severe cancer pain becomes greater than their fear of opioids and negative medication beliefs. Being cognisant of the potential for this change in Chinese migrants' acceptance of opioids is important for health professionals, so they can adjust the focus of their consultations and interventions accordingly to introduce opioids towards the end of life.

People's traditions and cultural values shape their reaction to pain as well as their preference about handling and communicating their cancer pain (Al-Atiyyat, 2009; McFarland & Webbe-Alamab, 2015). An individual's interpretation of the meaning of pain determines their pain tolerance and endurance (Al-Atiyyat, 2009). The findings of this study suggests that Chinese migrants' belief that their cancer pain is inevitable embodies their strong capability for pain endurance. Enduring cancer pain and finding its cause via medical consultations is likely to be Chinese migrants' first response to the sudden onset of pain. This action is shaped by the belief that pain is an unavoidable part of their cancer journey, and that while analgesics can only temporarily relieve their physical symptoms but it cannot cure the underlying cause of the pain and may actually be a sign of cancer reoccurrence.

In this study, Chinese migrant cancer patients' pain expression and responses to pain were grounded in the cultural context of where they were born and spent their formative years. Their desire to be a good person and their fear of distracting physicians are derived from traditional Chinese family education. These cultural norms and social expectations can, however, act as barriers to the optimisation of pain care outcomes(Luckett et al., 2013). Chinese people's high expectations about their ability to overcome their difficulties themselves and the importance they place on retaining a sense of control over their life and pain increased their level of pain endurance, and affected their pain reporting and help-seeking behaviours. However, the influences may differ between young and older Chinese migrants. Compared to the younger generation, older people born in China who have grown up in a traditional Chinese family and society were more reluctant to seek help to manage their cancer pain. For these Chinese migrants, enduring pain in silence may help them retain respect whilst being unwell and allow them to retain their social identity. Maintaining their social identity may also require older Chinese migrants to hide or normalise their pain from health professionals.

### *5.7.3 'Religious/Spiritual/Philosophical Factors'*

As people's religious, spiritual and philosophical views assist them to overcome difficulties associated with their illness, understanding and incorporating these beliefs into health care is an essential component of culturally congruent care (Leininger, 2002). This was very evident in this study, in which Chinese migrant cancer patients' philosophical health beliefs about the body's ability to self-heal and unhealthy lifestyles inducing cancer and cancer pain influenced their perception of their pain and their pain management practices.

While these health beliefs were an obstacle to using opioids, they helped to ease Chinese migrants' psychological pain, and enabled them to identify other means of strengthening their body and controlling their pain. A strong willingness to self-control pain reflects cancer patients' desire to regain a sense of control over their life (Narayan, 2010), which is important to Chinese migrant cancer patients (particular the males) when they are living in a host country.

When the Chinese migrants living with cancer pain in this study sought a healthy and safe way to promote self-healing and to minimise the harm of opioids to their body systems, they wanted to receive non-pharmacological therapies and/or TCM. This preference is in keeping with the value of Chinese people place on harmony, which is a philosophical idea originating from ancient Chinese culture (Chen & Yan, 2010; Ip, 2014). Harmony is a key concept in Chinese people's social wellbeing, which brings joy and happiness that can be conveyed by peaceful, satisfied and positive emotions (Ip, 2014). Harmony is also a core component of the concept of wellbeing in TCM, which address the importance of keeping a balance between mind, body and lifestyle. By using natural and alternative means to promote the body's capacity to adapt to and resist the external environment, and optimise health(Chen & Yan, 2010), TCM contributes to the healing process that is necessary to achieving harmony(Chen & Yan, 2010).

## 5.8 Summary

This chapter reported influences of 'Ethnohistory', 'Religious/Spiritual/Philosophical Beliefs', and 'Cultural Values, Beliefs and Lifeways' on Chinese migrants' perceptions and responses to their cancer pain and pharmacological management practice. Barriers to using opioids or weak analgesics were high, resulting in chronic cancer pain. The contradiction of Chines migrants' willingness to consult health professionals about their pain with their extreme resistance to opioids makes cancer pain management even more challenging. The strategies acknowledging these contradictions and addressing this population's barriers of using opioids and pain reporting during a pain assessment are required to help them achieve optimal cancer pain management.

The next chapter reports on the focus group Part 2 findings about cultural and social factors shaping Chinese migrants' non-pharmacological management practice and use of TCM and other complementary approaches for their cancer pain.

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# Chapter 6 ‘Cultural and Social Structure Dimensions’: The influence of ‘cultural and social structural factors’ on Chinese migrants’ perceptions and needs for non-pharmacological approaches and traditional Chinese medicine for cancer pain

## 6.1 Introduction

Chapter 5 reported on focus group Part 1 findings with reference to Leininger’s ‘Semi-Structured Interview Guide’, and considered ‘Ethnohistory’, ‘Cultural Values, Beliefs, and Lifeways’ and ‘Religious/Spiritual/Philosophical Factors’ influencing Chinese migrants’ perceptions and response to their cancer pain, their pain-reporting practices, and adherence to prescribed opioids.

Chapter 6 continues the report on the focus group Part 2 findings, with an emphasis on influence of ‘cultural and social structural factors’ influencing Chinese migrants’ perceptions and needs in relation to using non-pharmacological methods and TCM to manage their cancer pain. The findings are generated in reference to ‘Cultural and Social Structure Dimensions’ in Leininger’s ‘Sunrise Enabler’ and discussed in line with Leininger’s ‘Semi-Structure Interview Guide’ (Wehbe-Alamah & McFarland, 2015).

## 6.2 Findings of focus group: Part 2

The three themes and their relevant sub-themes that emerged in the analysis are summarised below:

1) Desire to access non-pharmacological pain care:
    i) Exercise helps to reduce pain severity
    ii) Desire for greater access to physiotherapy
    iii) Desire for more psycho-oncological support
2) Beliefs and barriers related to the use of TCM for cancer pain:
    i) Benefits of TCM
    ii) Concerns about the qualifications of TCM practitioners
    iii) Concerns regarding the quality of Chinese herbal medicines
    iv) Fear of contradictions between western medicine and TCM
3) Financial difficulties and policy constraints:
    i) Unaffordability of TCM and other pain treatments

ii) Ineligibility for financial assistance.

### 6.2.1 *Desire to access non-pharmacological pain care*

All participants preferred to use non-pharmacological methods and suggested that *“there are a lot of non-drug methods which may be used to help control of pain” (P14, female, 59 years old and breast cancer)*, such as exercise, physiotherapy or psycho-oncological therapies. However, unmet care needs associated with the lack of access to physiological and psycho-oncological support or referral were identified as holding them back from receiving quality non-pharmacological pain management.

#### Exercise helps to reduce pain severity

Regular exercise and movement was considered to be one of the most highly valued non-pharmacological methods for relieving participant’s cancer pain and improving their overall feelings of wellbeing.

> *People want to live. To be alive means you need to be active and doing exercise. When you start to move around, the pain would be eased, and the bad things would be reduced even though it may not be reduced 100%. It would be fine even it just reduced a little bit. (P24, male, 89 years old and pancreatic cancer)*

Participants reported that regular physical exercise also helped to decrease the pain caused by muscle stiffness or limb numbness.

> *Perhaps doing exercise twice a day for 90 minutes at a time may help, because my hands will be stiff if I don’t do exercises. (P8, female, 73 years old and lung cancer)*
>
> *I use elastic ball to stop pain … I did myself because my hand was numb … I felt comfortable after squeezing it. (P19, male, 67 years old and colorectal cancer)*

They thought that walking around and repositioning or knocking on their shoulder could activate blood circulation and ease pain.

> *I have my own approach. My case is that I cannot stay at one position for several hours, so I have to change my position from time to time. So, I would go out to buy a green onion – just going out and walking around. The pain would be reduced after I walk down the street. I use this method to reduce my pain. (P3, female, 55 years old and breast cancer)*
>
> *I did exercises myself. People said that knocking on the shoulder in this way may help the blood flow and reduce the pain. I felt much better after I did it for two or three years. I do the exercises every day. (P21, female, 53 years old and breast cancer)*

Participants also reported that exercising helped minimise the impact their cancer pain had on their sleep. For example, some suggested that yoga combined with music is an effective pain management strategy because it helps relax the body and assists with sleep.

> *Sometimes when I cannot sleep at night because of pain, I would stand up doing some exercise, such as shaking hands and moving around, which seems to reduce a little bit of pain. (P24, male, 89 years old and pancreatic cancer)*

> *I did yoga before when I was in Hong Kong, listening to the music and closing eyes which is very comfortable. I would gradually fall sleep and relax … I did this to treat the pain. (P14, female, 59 years old and breast cancer)*

In addition, participants suggested that listening to music, watching TV/video or chatting on the phone can help people self-adjust their mood and distract them from the pain.

> *I think we need to self-adjust our own mood. When pain occurs, we do not have to be over concerned about it. We should listen to music or do other activities to help distract us from the pain. Besides, we should discuss with our doctors and see if they have some methods to help us manage our pain – talk with specialists. (P15, female, 49 years old and lung cancer)*

> *Almost the same. Watching TV and listening to music could distract me from pain which may make me feel a little bit better and relaxed. (P14, female, 59 years old and breast cancer)*

### Desire for greater access to physiotherapy

While exercising is seen as a healthy way of managing cancer pain, some participants experienced difficulties and needed guidance to do it properly as they were afraid they would be injured.

> *Because I really do not know how to exercise and I have not had any experience. (P8, female, 73 years old and lung cancer)*

> *The exercises are different after the operation. When I was doing exercise, the physician told me that I had to stop if I felt pain. So how can I dare to move? (P3, female, 55 years old and breast cancer)*

Some participants appreciated that physiotherapists are available for free at hospitals to provide regular training to cancer patients about physical exercise.

> *The hospital has physiotherapists. The hospital provided me with the service and asked me to do it regularly. So, it was recommended by the hospital, and it was free. (P16, female, 48 years old and nasopharyngeal cancer)*

> *They did tell me how to do the exercises. At that time – the second day of surgery, they asked me to get up and move my arm. A physiotherapist directly visited me. (P7, female, 70 years old and lung cancer)*

Regular physiotherapy helped these participants manage their cancer pain and restored their physical function after their cancer treatment was completed.

> *Physiotherapy helps me manage the pain. (P16, female, 48 years old and nasopharyngeal cancer)*

> *A physiotherapist was recommended by the oncology doctor. When I went to the physiotherapist, he taught me some gymnastics which I practiced at home. (P21, female, 53 years old and breast cancer)*

However, some were unaware of the physiotherapy service, or found it difficult to access these services.

> *I did not have a physiotherapist. (P8, female, 73 years old and lung cancer)*

> *No one taught me how to do the exercise. (P5, female, 55 years old and ovarian cancer)*

They were very disappointed that when they made a request to see a physiotherapist to facilitate them exercising properly, they could not get a referral from the GP or the oncologist. They suggested that there is a need to increase cancer patients' accessibility to physiotherapy services.

> *I'm mostly confused that I have asked my GP many times if he can refer me to try physiotherapy; he told me that I do not need it and I would be fine if I just do exercise at home. I was wondering how I could do exercises properly without any experience. I spoke to my doctor directly about my concerns. But he told me that it will be fine if you go home and do some exercise. Do not waste money! (P8, female, 73 years old and lung cancer)*

> *I applied but the doctor did not get back to me … I think he (the oncologist) just did not care. I said to him I had very bad pain … My joints were very painful and it was hard for me to walk. He said he may add an exercise program for me, but he did not do it. I did not want to see him anymore. It is pointless. (P13, female, 45 years old and breast cancer)*

**Desire for more psycho-oncological support**

Most participants were frustrated and felt that health professionals barely understood cancer patients' concerns, experiences or fears.

> *Not many people would be able to understand us when we speak out our concerns. (P1, female, 62 years old and breast cancer)*
>
> *Healthy people can hardly understand what we are experiencing mentally and emotionally. (P8, female, 73 years old and lung cancer)*
>
> *You cannot understand the fear inside of us. (P3, female, 55 years old and breast cancer)*

Participants suggested that *"psychological support is important – it is more important than pain treatment" (P17, female, 54 years old and breast cancer)*. One participant suggested that a referral to a psychologist was also helpful as they provided guidance and support when she felt depressed as a result of her cancer pain.

> *Sometimes when a GP sees you depressed, he will ask you to see a psychologist and let the psychologist give you some guidance. Because at that time my doctor suggested me to see the psychologist and I have seen psychologist for one year … At that time, it helped me. I needed to find someone for a chat. So, for people who like chatting, actually it is good … Things that you do not understand, he will point it out. (P4, female, 61 years old and breast cancer)*

However, participants were surprised that not every health care setting provides pain management or psychological support to cancer patients.

> *We … neither received support for pain management nor psychological support … I raised this issue when I went to an activity held in [name removed] hospital and asked why [name removed] − such a big hospital did not have this kind of service; and then they explained to me that they were under-funded. However, the [name removed] hospital organised a lot of activities to raise the funding. I do not know where this money had gone to … it is a very big cancer care centre ... There was nothing about pain management or psychological support. (P17, female, 54 years old and breast cancer)*

Another critical issue was that general psychologists could only help from the psychological point of view, but they were not able to understand and address participants' distress and concerns associated with their cancer diagnosis and cancer pain, since the psychologists did not understand cancer patients' health conditions.

> *I also had seen the psychologist. However, the downside was that he did not understand what the cancer is … How he could help me release my stress when he didn't even*

> *know about the cancer … My experience was that they were unable to help me and made me even more upset … The psychologist can only help me from the psychological point of view. I felt sad because I was diagnosed with the cancer. It seemed that I have to re-plan my life, and I was confused. But he could not help me resolve my problems. When he answered my questions, he did not address my problems and concerns which irritated me a lot. That is why I would never visit him again. (P3, female, 55 years old and breast cancer)*

Since none of participants were seen by the psycho-oncologist, the participants suggested that a psycho-oncological department needs to be established and employ psychologists with experiences and skills in cancer treatment, to provide ongoing support to people living cancer and cancer pain.

> *They must establish an independent department; and having psychologists who have experience and knowledge in treating cancer patients. That is how we can be helped. (P5, female, 55 years old and ovarian cancer)*

When there was limited access to the hospital psychological care service, participants turned to a Chinese cancer support group for more support.

> *The hospitals do not provide psychological support. Instead, the [name removed] (Chinese cancer support group) provide us a lot of support. (P21, female, 53 years old and breast cancer)*

### 6.2.2 Beliefs and barriers related to the use of traditional Chinese medicine for cancer pain

There was general agreement that Chinese people prefer to use TCM to control pain and to help them recover from cancer treatment.

> *But as far as I know, while I do not use TCM, a lot of my friends from (Chinese cancer support group) used TCM for their health and fitness. They would consult with TCM practitioners after they undertook chemotherapy. The Chinese people usually do this. (P3, female, 55 years old and breast cancer)*

> *A lot of Chinese people would do massage or acupuncture (to control their pain). (P4, female, 61 years old and breast cancer)*

While most participants perceived that TCM was beneficial, their preference for TCM differed depending on the individual’s perception or experience about the use of TCM for cancer pain.

**Benefits of traditional Chinese medicine**

Most participants have a perception that TCM is good for cancer rehabilitation. It can be used as an adjunct therapy, to help their body recuperate from the side-effects of cancer treatment and restore physical functions, relieving physical discomfort.

> *I took Chinese herbal medicines to recuperate my body. I hope it may help me improve my health conditions holistically and make me feel better. (P16, female, 48 years old and nasopharyngeal cancer)*
>
> *In the future I might need to use TCM to help with my rehabilitation. Because I have taken too many medications, I want to use TCM to help me recuperate my body. (P10, female, 57 years old and breast cancer)*

They suggested that many TCM therapies can be used to control pain. For example, some found that acupuncture was not only effective for cancer pain, but was also helpful in relieving pain-related psychological distress.

> *Acupuncture can help relieve my pain because I used to have uterine fibroids that acupuncture can make me feel comfortable. So I think the TCM is reliable. (P10, female, 57 years old and breast cancer)*
>
> *I want to use acupuncture as soon as I have pain. I feel that acupuncture can help me. (P3, female, 55 years old and breast cancer)*
>
> *I used acupuncture when I had depression. I think the acupuncture is very effective. (P11, female, 62 years old and breast cancer)*

Self-administered TCMs became an option for participants to control their pain or to improve their health conditions when there were concerns about the quality of TCM or lack of accessibility to TCM in Australia. For example, some participants self-administered acupuncture, massage or moxibustion to reduce their pain.

> *I did acupuncture and massage myself to control my pain. I looked at the internet and found a lot of points can stop the pain. So, I did it myself at home. (P21, female, 53 years old and breast cancer)*
>
> *I did moxibustion myself. It was my own thoughts. I found the information from the internet. (P18, female, 45 years old and breast cancer).*

Foods such as Chinese herbal soups were commonly used by participants to improve their health conditions and treat their pain.

> *I use regular Chinese herbs − those may be used to cook soup. I put some barley, lily and this kind of stuff in the soup and cook slowly. This kind of stuff does not have contradiction with my medications. (P12, female, 62 years old and lung cancer)*

They explained that from the perspective of TCM, pain is caused by toxic accumulation in the body. Drinking a decoction of Chinese herbal medicine, or a using heat pack/hot water may detoxify toxins from the body, to reduce or stop the pain.

> *I drink herb soups to disperse the heat toxin from my body. (P6, female, 67 years old and breast cancer)*
>
> *Is it based on traditional Chinese medicine theory to detox? (The facilitator)*
>
> *Yes, I use the herb soup to detox. (P6, female, 67 years old and breast cancer)*
>
> *Yeah. I use some hot water to burn the toxin. (P1, female, 62 years old and breast cancer)*

Some also took Chinese medicine powder or pills as an adjuvant to their cancer treatment after receiving permission from western medical doctors.

> *When I was undertaking the chemo, I took Chinese herbal medicine Ganoderma lucidum. It was made by a local pharmacist. He said to me Ganoderma lucidum is very good for cancer patients. I took it to my doctor and ask him if I can take it. He said I can take it as long as I eat separately with other medications. The pharmacist suggested me to take some tonic to help me recover. I take Ganoderma powder. (P23, female, 60 years old and bowel cancer)*

A participant with palliative care needs used Chinese medicine pills to maintain his health after his anti-cancer medications were stopped. These kinds of Chinese medicine pills and powders are westernised and made in health science facilities, to meet the needs of people for using Chinese medicines to stop their pain or to improve their health conditions.

> *My current western medicine doctor has stopped my (cancer treatment) medications. My child is living in Hong Kong. He is a western medicine doctor. His friend works in a Chinese medicine shop who suggested me to take Ganoderma lucidum. I have been taking the Ganoderma pills. He sent to me from Hong Kong. I have taken it for 10 months. I did not use other TCMs. (P24, male, 89 years old and pancreatic cancer)*

### Concerns about the qualifications of traditional Chinese medicine practitioners

While TCM was reported as favourable, only a few participants had visited TCM practitioners, to assist them restore their physical function and reduce chronic pain from spasms.

> *My elbows become very painful when the spasm starts. It has been like this for two years. I have been seeing the TCM practitioner, so I feel it is better now. (P14, female, 59 years old and breast cancer)*

The majority of participants expressed hesitation in seeing TCM practitioners for cancer pain, as they worried about their qualifications.

> *I am very conservative and do not really trust TCM practitioners in Australia. I would not trust unless [it is] someone who is very famous. So, I have never seen them. If I have pain, TCM would not be my first or final choice. I would go to see my western medicine doctor (the oncologist). (P15, female, 49 years old and lung cancer)*

It was hard to find a GP or qualified TCM practitioner administering acupuncture near their homes.

> *Nobody referred that, so I had to find my own TCM practitioner myself. (P4, female, 61 years old and breast cancer)*
>
> *There is no GP who may do the acupuncture nearby. I could not find. (P22, female, 60 years old and lung cancer)*

Concerns about the qualifications and skills of acupuncturists and its safety were also raised.

> *But even with acupuncture, we would be concerned about whether the practitioner had reliable skills. What if they insert the needle into the wrong place? We are afraid of getting trouble from using different treatment − we are afraid of it. We do not know if those acupuncturists are recognised by the western medicine. (P3, female, 55 years old and breast cancer).*
>
> *What if your arms and legs become stiff after receiving the acupuncture? (P9, female, 69 years old and colorectal cancer)*

A participant rejected using acupuncture after she witnessed a horrific incident.

> *The doctor (the oncologist) asked me if I wanted to try acupuncture. But I was uncertain about that treatment, because I saw an old lady who was in her seventies or eighties receiving the acupuncture treatment. The blood was pouring out from the back of her head where the acupuncture needles were. I went in tears while watching her. I was not*

> *sure if it was a doctor or a nurse or an assistant that inserted the needle into the wrong point that caused the horrifying scene. (P20, female, 49 years old and breast cancer)*

A few lost interest in TCM because there were no obvious effects on pain based on their previous experiences.

> *I know a very good TCM practitioner who comes from China. At that time, I did not have cancer. I went to see him when I felt my body got inflamed or I felt discomfort. But I felt that it did not help much. So, I lost interest. (P13, female, 45 years old and breast cancer)*

### Fear of contradictions between western medicine and traditional Chinese medicine

There was a widespread fear of contradictions between anti-cancer medications and TCM. For this reason, some participants did not dare to see TCM practitioners or use TCM after they had cancer, especially when their oncologists warned them that they cannot mix the anti-cancer medications with other mediations due to potential interactions between drugs.

> *I took Chinese herbal medicines before I had cancer, but I do not dare to take it now. (P7, female, 70 years old and lung cancer)*
>
> *I would like to, but the medication I am taking for my cancer treatment does not allow me to see the TCM practitioner, because I cannot mix these medications with others. He (the oncologist) said if you have taken medication for cancer treatment, do not mix them with other kind of medications you have taken … the Chinese herbal medications would have contradiction with my targeting drugs of chemotherapy, so I cannot take it. I hence do not dare to see the TCM practitioner. I would use the common medications without contradictions. (P12, female, 62 years old and lung cancer)*

Most were worried that they would not be able to clearly explain to their oncologists about Chinese herbal medicines they had taken, especially in an emergency situation. If they are poisoned by Chinese herbal medicines, western medical doctors may not be able to save their life because these doctors do not know TCM well.

> *Because we are scared. If we take the medications that our doctors prescribed to us, they would know the medications very well. However, if something happens when we take the Chinese medicines, we would have problems that we do not how to explain to our surgeons what Chinese herbal medicines we have taken. The doctors would not know how to treat us. This is a very crucial question. (P3, female, 55 years old and breast cancer)*

> *In case you need first aid after taking the Chinese herbal medicines, you don't know what kind of medicines you took and how to get first aid. The western medicine physicians do not know what you have taken either. They won't be able to save your life even when you are poisoned because of taking the Chinese angelica (a kind of Chinese herb). (P3, female, 55 years old and breast cancer)*

Some were so scared that they did not even take regular herbs, such as lotus seeds used in Chinese food therapy, when they undertook chemotherapy.

> *I did not use dietary therapy when I was taking chemo medications. I did it after two years of the chemo. At the first two years, I only took western medications and drank nutritional milk. I ate anything which the nutritionist taught me. So, I did not dare to take the regular herbs such as lotus seeds. (P1, female, 62 years old and breast cancer)*

The time conflict between clinic appointments for cancer treatment and TCM treatment as well as physical conditions (e.g. fatigue) also restricted participants' use of TCM for cancer pain.

> *Because at that time I was undertaking the chemotherapy, I did not have the energy and time to take the acupuncture – that was it. (P21, female, 53 years old and breast cancer)*

A few suggested that they should trust western physicians and concentrate on western treatment, since they were seeing western medical doctors.

> *If acupuncture is helpful I would accept it, but I would not take it initially. Because I think that I have seen western medical doctors, I should focus on western medical treatment. Because I decided to see western medical doctor, I need to trust the doctor as a patient. (P23, female, 60 years old and bowel cancer)*

> *I have not considered or tried the acupuncture. I think we have to focus on one thing. The other thing is just let it go and resign yourself to your fate. (P24, male, 89 years old and pancreatic cancer)*

### Concerns regarding the quality of Chinese herbal medicines

Some participants were not keen on using Chinese herbal medications for their pain treatment, as they had heard that the effects of artificially planted Chinese herbs are very weak.

> *With regards to Chinese herbal medicines, I heard from the radio which said that the soil and weather is crucial in cultivation of the herbs which may have impact on the effects. Now Chinese herbs are planted but there are not much effects. Besides, I do not want to put a lot of stuff in the pot; spend a lot of time to watch the fire pot; and drink it; and find it*

> *does not have effects. So, I am not keen about it. (P13, female, 45 years old and breast cancer)*

Another main concern about artificially planted Chinese herbs was that pollution through the use of pesticides can change these herbs' medicinal effects. The polluted herbs are likely to be missed during a random test.

> *Now one of the biggest barriers is that because the natural herbs are not enough, many Chinese herbs are artificially planted with pesticides and chemical fertilisers which would result in changing the herbs' medicinal effects. We cannot believe the TCM now due to these reasons. Besides, after the herbs are dried, people have to spray the insecticide on the herbs for the purpose of preservation. So now I don't take any Chinese herbal medicines. (P3, female, 55 years old and breast cancer)*

> *The quarantine staff may not able to check everything. You do not know whether those unchecked stuff are qualified. Besides, most of the Chinese herbs have pesticides, so I don't believe them anymore. (P7, female, 70 years old and lung cancer)*

While some thought that imported Chinese herbal medicines are safe as they are tested at Australian customs, others disagreed because these herbs would be sprayed with insecticide at quarantine.

> *I have been taking the Chinese herbal medicines … All medications imported to Australia are tested, so you do not have to be afraid. This is how I feel. (P6, female, 67 years old and breast cancer)*

> *Do you know the test means that the herbs need to be sprayed with insecticide? Otherwise the herbs will be returned. Our company does this business. (P3, female, 55 years old and breast cancer)*

### *6.2.3 Financial difficulties and policy constraints*

Most participants struggled with cancer-related financial difficulties. They were frustrated with the situation.

> *Actually, sometimes the most financially dreadful thing is having cancer. It is terrible. (All participants in focus group 1), because when you are sick you would spend more money. (P7, female, 70 years old and lung cancer)*

#### Unaffordability of traditional Chinese medicine and other pain treatment

The biggest concern of participants was that medications were very expensive, affecting TCM and other pain treatment's affordability following discharge from hospital.

> *It was fine because the cancer treatment was free at the hospital. Now I have left hospital, so I have to buy the medications myself. Before, when I was in the hospital, the medications and treatment were free. (P15, female, 49 years old and lung cancer)*

> *The medications are very expensive. (P1, female, 62 years old and breast cancer)*

Eventually, they stopped taking analgesics after cancer pain persisted for a long time, as they felt that it was meaningless to spend so much money trying different types of analgesics without effects.

> *Every time I spent a lot of money buying the pain mediation, but the medication did not work so I had to change. It wasted money. The painkiller I was taking made my sleepy, but it would cost a lot of money if I changed to another one. (P17, female, 54 years old and breast cancer)*

> *I took Panadol at home. It was certainly a financial burden, if you have to take it for a long time. I have stopped it recently and started taking something like vitamins. Those are very expensive. I am considering if I should continue to take it. (P14, female, 59 years old and breast cancer)*

They considered seeing TCM practitioners and using Chinese medicines to save money. However, they found that TCM consultations and Chinese medications can also cause financial constraints, as these costs are expensive as well.

> *TCM were not cheap. (P2, female, 54 years old and lung cancer; and P6, female, 67 years old and breast cancer)*

> *I visited three TCM practitioners and I have to pay all the costs for the consultations and the medications … Also, it is not cheap to see a TCM practitioner. He would ask you to take 10 times of the medications and every time you need to pay more than 100 Australian dollars. (P4, female, 61 years old and breast cancer)*

Medicare only covered the cost of a limited number of acupuncture treatments, which was not enough for their pain treatment. TCM practitioners would charge them an extra consultation fee for acupuncture.

> *Medicare does not cover TCM. (P6, female, 67 years old and breast cancer)*

> *Medicare covers the acupuncture, but I need to find the GP who may do acupuncture. You need spent $35 or $40 to see a TCM practitioner. Other costs are more expensive. You need to find them by yourself. I felt that acupuncture was very helpful. However, Medicare has policy that people cannot do too many acupunctures. (P21, female, 53 years old and breast cancer)*

Private health insurance could be *"very expensive" (P9, female, 69 years old and colorectal cancer)*, and most insurance does not cover the cost of TCM consultations and Chinese medicines.

> *Most of us are covered by private insurance, but there is not much of the coverage. (P6, female, 67 years old and breast cancer)*
>
> *The gap does not cover the TCM practitioner, but only covers the massage and acupuncture. (P14, female, 59 years old and breast cancer)*
>
> *It does not cover the Chinese medicines. (P16, female, 48 years old and nasopharyngeal cancer)*

Some insurances did not even have coverage for Chinese massage or acupuncture though the insurances were expensive as well.

> *There are certainly financial difficulties. You have to pay when you do Chinese massage for your pain. (P6, female, 67 years old and breast cancer)*
>
> *The acupunctures cost money. (P17, female, 54 years old and breast cancer)*

A few of the participants had insurance that covered the costs of a TCM practitioner. However, it was not easy to find a qualified TCM practitioner as required by the insurance policy.

> *I used my health insurance to see the TCM practitioners … You cannot see those TCM practitioners without licences, because we used the health insurance to see them. (P23, female, 60 years old and bowel cancer)*
>
> *Yeah. It is not about the coverage of the insurance, but whether you can find a good doctor or not. (P6, female, 67 years old and breast cancer)*

The process of finding a good TCM practitioner was also expensive and frustrating, which made their life even harder. Some people ultimately had to give up the treatment.

> *You have to use your money to pay for other doctors to treat you if you do not want to receive the treatment that your own doctor suggested. (P3, female, 55 years old and breast cancer)*
>
> *When you were seeing a doctor, sometimes you would not know whether the doctor was good or not, even if you had already paid. You must try and pay a lot of money to find a good doctor. (P4, female, 61 years old and breast cancer)*
>
> *I heard that somebody did not go to see the doctor because they wanted to save money. (P23, female, 60 years old and bowel cancer)*

Participants found it difficult to cope with the situation. They were desperately in need of help to receive acupuncture and other TCMs to control their pain, so that it did not hold them up for their anti-cancer therapies.

> *It is affordable to take the train to see the doctor for acupuncture, but the acupuncture costs $60 which I cannot afford. However, when pain occurs, it needs to be treated on time, so that the pain won't affect the hormone treatment. (P20, female, 49 years old and breast cancer)*

### Ineligibility for financial assistance

Most participants desired financial assistance after long-term cancer treatment, especially when they were discharged from hospital. Participants found that the costs of regular oncology consultations and anti-cancer medications were expensive.

Although the medication concession card assists with medication costs, not everyone was eligible.

> *Centrelink has financial benefit for the disabled – provides the concession card, which makes the price for the medication cheaper. Concession card is very helpful, only need $2.50 to visit the hospital and $6 to buy the medication priced more than $70. (P21, female, 53 years old and breast cancer)*
>
> *It is hard to apply for. My husband has a job and I do not have a job, but I cannot get the concession card. I applied but it was rejected. (P22, female, 60 years old and lung cancer)*

On the other hand, living costs sharply increased as they needed to eat healthy nutritious food to help them recover from cancer treatment.

> *You need to eat nice food. (P4, female, 61 years old and breast cancer)*
>
> *You need to buy the fresh food. (P6, female, 67 years old and breast cancer)*
>
> *You would spend a lot of money. It is part of the pressure. (P3, female, 55 years old and breast cancer)*

While medical and living expenses became a huge burden, some participants lost income since they could not work, particularly when they suffered pain. They felt helpless as they were eager to return to work, but no one supported them.

> *You would not have money if you do not work. You won't be able to go to work when you feel pain. (P3, female, 55 years old and breast cancer)*
>
> *Before we can make a lot of money. Then suddenly, we have to stop our work. There is no income. It costs a lot of money when you go to see the doctor and eat nutritious …*

> *There is no help. We want to work but cannot. (P22, female, 60 years old and lung cancer)*

The financial difficulties were worse for single parents with cancer pain. One participant sold her property to support herself and her children after she was diagnosed with cancer, because the financial support from the government stopped after three months of unemployment.

> *I cannot work. Of course it affected me financially. Like myself, I have to support my family. My whole family would not have food if I do not work. Right now, we have to rely on the money I saved before … Centrelink would only give a little bit of allowance to you after you have lost all income for three months. I had to sell my investment property to support myself. Because I cannot work right now, and I do not have any other choices. (P16, female, 48 years old and nasopharyngeal cancer)*

When the participants were unemployed and lost income due to the pain, they were not able to apply for financial support from the government because they did not have a medical certificate since the pain cannot be detected.

> *Financially, it has a significant impact on us … We cannot work because of the pain. However, when we go to the government to seek help because we do not have income, the government won't care about us. The pain cannot be detected by film (X-ray) or ultrasound. Centrelink will not provide help to us if we do not have the medical certificate or evidence. (P21, female, 53 years old and breast cancer)*

They urged the government to provide more funding to support cancer patients and change policy so that Medicare may cover the cost of pain treatment.

> *Every patient who had lung cancer would have financial problems. Doctors should know about this problem and they should tell the government that money is not enough to cover the treatment. (P8, female, 73 years old and lung cancer)*

> *It would have already helped us if the government may let us use Medicare to treat our pain. (P1, female, 62 years old and breast cancer)*

## 6.3 Discussion

The Chinese migrants in this study perceived that non-pharmacological approaches including TCM and other complementary approaches are very helpful in the control of cancer pain, and are preferable to medication as a way to strengthen their body and help them restore their physical and psychological functions after receiving cancer treatment. However, unmet needs regarding physiotherapy and psycho-oncological care and financial difficulties and policy constraints all impacted on their capacity to access optimal non-pharmacological pain care. These factors are aligned with the following three domains of Leininger's 'Semi-Structured Inquiry Guide', namely: 'Professional and Generic (folk lay) Care Beliefs and Practices', 'Economic Factors' and 'Political and Legal Factors' (Wehbe-Alamah & McFarland, 2015).

### *6.3.1 'Professional and Generic (folk or lay) Care Beliefs and Practices'*

Individuals' beliefs and preferences toward professional standards of care and traditional (folk and lay) approaches are determined by their cultural views about health care, which influences their healing process and care outcome (Leininger, 2002).

Cancer pain is a multifaceted symptom with negative effects on people's physical, psychological, social and spiritual wellbeing (Brant, 2014). Evidence-based complementary therapies, psychological support and physiotherapy are vital elements of non-pharmacological care for people living with cancer pain (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

#### Traditional Chinese medicine and other complementary therapies

Since the 1980s complementary medicine (CM) including TCM has been utilised by a substantial proportion of the Australian population as an adjunct to mainstream medical care (Expert Committee on Complementary Medicines in the Health System, 2003; Steel et al., 2018). While the evidence is variable, complementary therapies are recommended to reduce cancer-related symptoms and improve quality of life for people living with cancer (Cancer Council NSW, 2018).

CM offers a holistic way of promoting healing, and is one of the main drivers for people living with cancer or other chronic diseases to integrate CM into their health care (Reid, Steel, Wardle, Trubody, & Adams, 2016). When western medicine does not resolve the problem, Chinese cancer patients turn to TCM and other alternative approaches to help reduce pain (Chung, Wong, & Yang, 2000).

Chinese people often say that 'life depends on motion'. Exercises are commonly reported by Chinese migrants in this study as an effective way of reducing cancer pain. A meta-analysis over 37 clinical trials involving adult cancer patients concluded that early exercise interventions during the period of active cancer treatment may significantly improve the patients' physical and social functioning at 12 weeks' follow-up (Mishra et al., 2012). Evidence-based guidelines for cancer patients on exercise have been developed by the Clinical Oncology Society of Australia (COSA) (COSA, 2018) to guide all health professionals from the multidisciplinary cancer care team, to promote physical activities as a part of standard cancer care that helps people neutralise the adverse effects of cancer and its treatment and return to their normal daily life. Even though the effect of exercise interventions on pain relief is not proven (Mishra et al., 2012), Chinese migrants may be likely to benefit psychologically from exercise more than some other groups.

Although heterogeneity of exercise programs in the current literature makes it difficult to distil the most important elements of exercise programs (e.g. type, intensity, and interval), walking by itself or together with strength training, yoga and Qigong have demonstrated potential as effective components of exercise interventions for cancer patients (Mishra et al., 2012). These exercise forms may be especially favourable to Chinese migrants. For example, vigorous-intensity aerobic exercises, such as walking or jogging at least 75 minutes per week would be beneficial (COSA, 2018). Importantly, patients should be referred to an accredited exercise physiologist or physiotherapist, so that they may set up an individualised training plain that is appropriate for the patient's health status and ability (COSA, 2018).

### Traditional Chinese medicine theory underpinning health beliefs

Chinese migrants' preferences to adopt exercise, TCM and other complementary therapies, and their eagerness to receive physiotherapy and psycho-oncological support to manage their pain are likely influenced by their health beliefs associated with TCM theory. Originating in ancient China, TCM has been evolving for thousands of years (Australian Traditional-Medicine Society, 2019), and has become an essential part of Asian culture, influencing many people's perception of health and healing (Xu et al., 2013).

Adhering to the principle of holistic medicine, TCM practices take into account interactions between the human body and environmental factors, addressing the importance of maintaining a harmonious relationship with nature and its forces (Chen, Miaskowski, Dodd, & Pantilat, 2008; Xu et al., 2013). Based on the principles of TCM, people with an illness should be treated as a whole person, with the aim of maintaining the health of the mind, body and spirit, not just curing the disease and its symptoms (Cancer Council NSW, 2018). Instead of recommending analgesics for temporary pain relief, TCM considers a person's overall health condition and focuses on causes underlying the cancer pain (Chen et al., 2008).

TCM is rooted in Chinese philosophies such as Taoism that consider Yin and Yang balance (Chen et al., 2008). According to TCM theory, the human body's system is supported by Qi − a vital energy flowing through meridians from internal organs to the surface of skin (Li et al., 2015). The flow of Qi is regulated through interactions between two contradictory but balanced forces − Yin and Yang (Li et al., 2015). The meridians are blocked when people have had cancer (Chen et al., 2008; Chung et al., 2000). The blockage breaks the Yin and Yang balance, hence destroying the harmonious environment in people's body and mind (Chung et al., 2000). Chinese people believe that pain may also be caused by heat, cold, and other toxins accumulated in the body (Chen et al., 2008). So, rather than taking analgesics, Chinese cancer patients prefer to use TCM and other complementary approaches to cure the meridians, unblocking Qi and blood circulation and correcting the Yin and Yang balance (Chen et al., 2008).

Consistent with the findings from this study, acupuncture is favoured as an adjunctive therapy for Chinese people with cancer pain living in China and other populations worldwide, particularly for those diagnosed with terminal cancer (Chiu, Hsieh, & Tsai, 2017). Acupuncture, moxibustion and other TCM techniques based on the theory that applying various forms of mechanical, electrical or Chinese medical stimulation to acupoints of the body may unclog Qi and promote blood circulation, restoring the body's function and reducing physical and emotional symptoms (Li et al., 2015). The effectiveness of acupuncture in reducing cancer pain intensity and sleep interference is evidenced via randomised controlled trials, and should be integrated into the multimodal approach of cancer pain management (Chiu et al., 2017; Tao et al., 2016).

### Safety of traditional Chinese medicine and other complementary therapies

The findings of this study confirm that Chinese migrants are eager to take an active role in the process of recovery from cancer treatment and pain management. Self-administered simple TCM techniques and dietary therapies were reportedly used by most of the participants. Like other general populations with cancer (Cancer Council NSW, 2018), Chinese migrants often adjust their diet with good nutrition to help their body gain energy and cope with the side-effects of cancer treatment.

They also would like to drink general Chinese herbal soups or to take Chinese herbal medicine pills, to strengthen their health and remove the toxins from cancer treatment in their body to stop the pain. However, although simple TCM techniques, dietary therapies or self-prescribed Chinese herbal medicines may be affordable and used without professional guidance, they may not always be safe (Cancer Council NSW, 2018).

People often assume that TCM and other complementary therapies are natural and do not have any risks (Cancer Council NSW, 2018; Xu et al., 2013). However, like western medicine, these therapies can also have adverse effects if they are not correctly administered (Expert Committee on Complementary Medicines in the Health System, 2003; Xu et al., 2013). They need to be provided to the public in a safe way in compliance with Australian national standards and regulations for health care (Chinese Medicine Board of Australia, 2019; Expert Committee on Complementary Medicines in the Health System, 2003). Importantly, there should be an awareness that some Chinese herbal medicines may interact with conventional western medicines, inducing negative effects on people's health (Xu et al., 2013). Some herbs or herbal products bought from overseas may not be made to the quality required by the regulations of Therapeutic Goods Administration (TGA) (Cancer Council NSW, 2018).

Health professionals play a vital role in providing reliable information and resources about complementary therapies to cancer patients for their pain management (Australian Adult Cancer Pain Management Guideline Working Party, 2016). A systematic review based on 41 randomised and 14 non-randomised controlled clinical trials in Chinese cancer patients suggested that a range of processed Chinese herbal medicines can be used effectively and safely via various routines (e.g. external application, oral administration and intravenous infusion), and have been used as alternative approaches to treat different types of cancer pain and lessen the side-effects of conventional analgesics (Xu et al., 2007). A lot of Chinese herbal medicines are approved by the TGA to be used in Australia, although this does not necessarily guarantee substantial evidence for effectiveness.

Health professionals need to respect cancer patients' decisions and encourage them to speak about their needs in relation to the use of complementary and alternative medicines (CAM) (COSA, 2013). In the meantime, they need to discuss with patients the benefits and potential harms of CAM, and adhere to the principles of risk management for CAM (COSA, 2013). Essentially, they need to open up to patients if they have an ethical concern or are not comfortable discussing a patient's needs for using CAM because of their lack of training, and refer patients to accredited CAM practitioners (COSA, 2013).

For instance, in the same way as other health practitioners, Australian and overseas trained TCM practitioners are assessed and registered with the Chinese Medicine Board of Australia, under the national registration and accreditation scheme of the Australian Health Practitioner Regulation Agency (Chinese Medicine Board of Australia, 2019). Depending on their qualification, registered TCM practitioners may practice via three divisions of acupuncture, Chinese herbal medicine or Chinese herbal dispensing, to deliver health care services as per the registration standards (Chinese Medicine Board of Australia, 2019).

Oncologists and other physicians involved in cancer treatment, nurses and other allied health professionals need to inform Chinese migrants of this information, discuss their concerns and needs with them, and refer them to registered TCM practitioners for consultation about options and potential risks of TCM techniques and Chinese herbal medicines in association with their cancer treatment.

### Psycho-oncological care and traditional Chinese medicine

Cancer pain is the most common cause for physical distress and is often interrelated with psychological disorders, such as emotional distress, depression, anxiety and hopelessness (Lang-Rollin & Berberich, 2018). Consistent with TCM principles about maintaining people’s mind and spirit health (Chung et al., 2000), psychological support is recommended as a critical component of non-pharmacological interventions for cancer pain (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

The Chinese migrants in this study highlighted the importance of psychological support to their wellbeing, considering it as the first priority for cancer pain management. However, they found that psychological counselling provided by general psychologists had little benefit for cancer patients, and only a few had access to psychological services. They suggested that psychologists with proficiency in both oncological and psychological care and psycho-oncology services are needed to support them overcome cancer and pain-related psychological burdens.

Psycho-oncology (also known as psychosocial-oncology) has emerged as a new discipline in response to increased attention on cancer diagnosis and treatment related to emotional pain and distress of patients and families (Bultz, 2016). In Australia, psycho-oncology services are delivered by multidisciplinary teams consisting of social workers and psychologists, or psychiatrists in integrated cancer centres (Butow, Dhillon, Shaw, & Price, 2017). However, while the majority of patients in this study indicated that they might have benefited from psycho-oncology treatment and psychosocial support, none had received a referral for this care.

Research on evidence-based psychological interventions (e.g. cognitive behavioral therapies, relaxation techniques, distraction techniques and guided imagery therapy) are effective in reducing cancer pain related to psychological symptoms (Brant, 2014; Jacobsen & Jim, 2008), and are recommended by the Australian Adult Cancer Pain Management Guideline Working Party (2016).

In addition, TCM and other complementary therapies have also demonstrated great potential in improving cancer patients' mental health (Cancer Council NSW, 2018). One of the participants in this study reported the efficacy of using acupuncture to treat depression. While the benefits of acupuncture in reducing the level of depression and anxiety need to be determined in clinical trials (Tao et al., 2016), there are many other TCM and complementary approaches that may be used to ease psychological burdens. For example, a systematic review and meta-synthesis suggested that TCM Five-Element Music Therapy and Chinese massage are effective in reducing cancer-related depression and anxiety (Tao et al., 2016). The booklet about complementary therapies for cancer patients developed by the Cancer Council NSW (2018) suggests that research on evidence-based exercise, Qigong, hypnotherapy, meditation, mindfulness, tai chi and yoga may also be considered for use in reducing cancer patients' stress and anxiety and improving their overall wellbeing (Cancer Council NSW, 2018).

While psycho-oncology services may be difficult to access due to limited availability, psychosocial care is supposed to be provided by the whole multidisciplinary team in which nurse specialists and care coordinators are positioned at the front line of the care (Butow et al., 2017). Routine screening for psychological problems should be implemented at all stages of cancer care (Lang-Rollin & Berberich, 2018). However, screening is still not routine at many cancer services and, even where it is, screening may not be translated to ensure screening of people from non-English-speaking backgrounds. Routine psychological screening and psychological support started at an early stage of cancer treatment may provide a good opportunity for Chinese migrants living with cancer pain to discuss their needs with their cancer treatment team and promote their psychosocial wellbeing.

### *6.3.2 'Economic Factors' and 'Political and Legal Factors'*

When economics, politics and political actions have an increasing impact on people's accessibility to health care, it is important to understand how these factors affect health care outcomes and the wellbeing of people from diverse cultural backgrounds (Leininger, 2002).

Most of the participants in this study faced financial hardship due to increased living and medical costs as well as unemployment associated with their cancer diagnosis, treatment and cancer pain. These factors affected them approach to TCM and other pain treatment. The findings of this study are supported by a retrospective study in an English-speaking population with chronic pain about the predictors of using CMs (Ndao-Brumblay & Green, 2010). Similar results are also found in a recent national survey of the general Australian population, in which employment and living with chronic diseases were found to be significant predictors ($p < 0.001$) of using CMs (Steel et al., 2018). However, in the current study, ineligibility for Medicare concession cards and other financial support and/or limited private insurance cover allegedly impeded Chinese migrants' use of TCM and other CM methods for easing cancer pain.

In contrast to the Australian health care system, both TCM and western medicine are important components of mainstream health care in China (Xu et al., 2013). The practice of integrative medicine (IM) in China began in the 1950s, in order to maximally take advantage of TCM and conventional western medicine promoting people's health and wellbeing (Lu & Chen, 2015). For seven decades, great effort by Chinese and western scientists, TCM practitioners and researchers has been made to bring the ancient practice of TCM in line with modern western medicine (Xu et al., 2013), in a collaborative way into all aspects of diagnosis, treatment, and prevention of diseases (Lu & Chen, 2015; Wang & Zhang, 2017). So far, hundreds of IM hospitals and institutes have been established in China delivering IM services to the Chinese public (Lu & Chen, 2015). TCM has also been extensively used in conjunction with other complementary approaches by Chinese and other cancer patients, to relieve pain and suffering associated with the adverse effects of conventional cancer treatment (Tao et al., 2016; Xu et al., 2007). When Chinese people move to Australia, it is not surprising that they would like to adopt TCM and other CM in addition to mainstream oncological medicines to control cancer pain and restore health.

However, like many other CM, TCM is neither covered or only partially covered by Medicare unless patients have a referral from their GP as part of a Chronic Disease

Management Plan (Cancer Council NSW, 2018). In 2018, the standard consultation fee for a private complementary practitioner ranged from $80 to $140 per hour, excluding costs of herbal medicines and other related products (Cancer Council NSW, 2018).

Besides TCM and other CM, cancer patients have to pay for conventional therapies after they are discharged from the hospital if they do not have a referral or private insurance; and conventional pain management services for cancer patients in hospitals are often limited as well. For example, in Australia, psycho-oncology services are free for patients admitted to public hospitals, but there is a long waiting list for the services and they are not available in private hospitals (Butow et al., 2017).

Traditionally, the biomedical approach informed cancer care with a sole focus on saving and extending the patient’s life (Bultz, 2016). In spite of robust research evidence demonstrating psycho-oncology as a must for good cancer care, transition from the biomedical model to the biopsychosocial model to include psycho-oncology in mainstream cancer care faces significant challenges (Bultz, 2016).

Psycho-oncological services and CMs progressively become important in cancer care and for people living with chronic conditions. It is crucial that health policy-makers, administrators, health care providers and researchers recognise the unmet needs and make changes in these areas to ensure optimal care is being provided to the public (Bultz, 2016; Butow et al., 2017; Steel et al., 2018), particularly for the Chinese migrant population who are at a disadvantage in receiving cancer care (Lim et al., 2019).

## 6.4 Summary

The findings reported in this chapter show that unmet physiological and psycho-oncological care needs are impeding Chinese migrants from achieving optimal non-pharmacological pain care. Majority of Chinese migrants living with cancer pain in this study described concerns about the qualifications of TCM practitioners, contradictions between western medicine and TCM, the quality of Chinese herbal medicines, financial difficulties and political issues as the main barriers to effective pain care.

Oncologists, nurses and other health professionals who are caring for Chinese migrants living with cancer pain need to foresee their needs and the barriers they face in using non-pharmacological, TCM and other CM approaches for cancer pain. Increasing accessibility to and affordability of evidence-based physio-oncological, TCM and other complementary services is key to meeting the needs for non-pharmacological pain management in this population.

The next chapter reports on ‘cultural and social structural factors’ that influence Chinese migrants’ capacity to manage their cancer pain at home.

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# Chapter 7 'Cultural and Social Structure Dimensions': The influence of 'cultural and social structural factors' on Chinese migrants' management of cancer pain at home

## 7.1 Introduction

The focus group undertaken with Chinese migrants living with cancer pain generated a significant amount of data, presented in Chapters 5 and 6, in accordance with Leininger's 'Sunrise Enablers' and 'Semi-Structure Interview Guide' (Wehbe-Alamah & McFarland, 2015). These chapters considered the findings in terms of the 'cultural and social structural factors' affecting Chinese migrants' pain experiences, their use of pharmacological and non-pharmacological cancer pain management strategies, and their access to TCM.

This chapter reports on the themes and subthemes that emerged from focus group Part 3 findings focusing on 'cultural and social structural factors' influencing Chinese migrants' cancer pain management at home in accordance with 'Cultural and Social Structure Dimensions' in Leininger's 'Sunrise Enabler'(Wehbe-Alamah & McFarland, 2015). It is discussed in line with Leininger's 'Semi-Structure Interview Guide' (Wehbe-Alamah & McFarland, 2015). Collectively the identified cultural and social factors influence this population's ability to self-manage cancer pain, effectively communicate their pain care needs, seek help and obtain support to manage their pain at home.

## 7.2 Findings of focus group: Part 3

The five themes that emerged in the analysis are summarised below:

1) Cancer pain education shapes Chinese migrants' capacity to self-manage their pain:
    i) Too little education and information makes it difficult for Chinese migrants to self-manage their cancer pain
    ii) Preferences for cancer pain information formats vary
2) Communication barriers and enablers:
    i) Poor communication discourages pain reporting
    ii) Medical jargon impedes expression and comprehension
    iii) Inappropriate translation causes confusion
    iv) Involvement of Chinese-speaking health professionals supports

    communication

  - v) Bilingual educational information as a communication tool promotes shared understanding

3) Physicians' and nurses' attitudes to cancer pain and its management:
   - i) 'Pain is normal'
   - ii) 'Take Panadol'
4) Barriers and enablers to navigating with health care services for cancer pain:
   - i) Uncertainty about where to seek help
   - ii) Difficulty accessing pain treatment services
   - iii) Need for continuing support
5) Family and social support:
   - i) Fear of being a burden
   - ii) Importance of peer support
   - iii) Role of Chinese cancer support groups.

The following sections describe these themes and subthemes.

### *7.2.1 Cancer pain education shapes Chinese migrants' capacity to self-manage their pain*

'Cancer pain management' was an unfamiliar term to the participants in this study, and they struggled to interpret it. Only one participant demonstrated a clear understanding.

> *It (cancer pain management) means to help you relieve the pain. (P11, female, 62 years old and breast cancer)*
>
> *When we are talking about management, I am not sure if I should manage my pain medication or I should manage myself. (P13, female, 45 years old and breast cancer)*
>
> *Is it about being healthy, doing exercises, losing weight or having fun? Is it about managing yourself? (P5, female, 55 years old and ovarian cancer)*

Some thought that cancer pain management was only for people suffering severe pain or those at the end of life.

> *We have never heard about it. I do not mean that the doctor does not have information about cancer pain management. Perhaps they think they don't need to tell us at this stage; and it may be better to do it progressively. Perhaps some doctors would tell the patients this information if they have had severe pain. However, we've never heard about it. (P9, female, 69 years old and colorectal cancer)*

> *In my understanding, pain management only applies to the patients who are at the final stage. Is it correct? Then he should need this help, so he would find someone to help. (P10, female, 57 years old and breast cancer)*

**Too little education and information makes it difficult for Chinese migrants to self-manage their cancer pain**

Participants claimed that they had not received any education or information about cancer pain management.

> *No one taught us about the pain management. (All participants in Focus Group 1, n = 8)*
>
> *We have very limited information of cancer pain management ... Nobody tells us this information. (P7, female, 70 years old and lung cancer)*

Participants wanted to learn more about how to assess their pain and what methods they could use to control their own pain. However, health professionals rarely took the time to teach them to self-manage their cancer pain at home.

> *They did not suggest any methods to deal with the pain. (P22, female, 60 years old and breast cancer)*

They had very limited knowledge about different types of analgesics and how to use these medications effectively. Lack of analgesic knowledge restricted their ability to discuss pain management options with their treating medical team and to make an informed decision about the best approach to manage their cancer pain.

> *Right now, we do not even know anything about what kind of medication may be used for pain treatment and do not know the names of the pain medications. Not to mention about what pain medication may be specifically used for. (P15, female, 49 years old and breast cancer)*
>
> *Because we do not have any general knowledge about the pain medications, we would not be able to discuss with them (about my pain treatment). (P13, female, 45 years old and breast cancer)*

Participants expressed frustration when they were prescribed analgesics with little understanding about their potential side-effects.

> *If we do not have the general knowledge (about pain medication), we have to force ourselves to take it. (P9, female, 69 years old and colorectal cancer)*

Participants described how there was often no printed cancer pain information at their treating cancer care centres or acute care hospitals.

> *When we go to the cancer care centre, they have a lot of information booklets about cancer. All these booklets are very detailed. They have booklets about radiotherapy and chemotherapy, but they lack a manual for pain. (P15, female, 49 years old and breast cancer)*
>
> *The Chinese booklets are incomplete and there is no Chinese booklet about the pain. (P18, female, 45 years old and breast cancer)*

A minority of participants had access to information or educational sessions about cancer care in their treating hospitals and communities, but it was not beneficial for Chinese patients because they were conducted in English.

> *After all, the information provided to us by the hospitals at [name removed] district about the post-operative care are all in English; and all the lectures are delivered in English. (P20, female, 47 years old and breast cancer)*
>
> *There are a lot of lectures about diseases and symptoms held in [name removed] Library. However, we cannot understand because they speak English. So even if we know they are holding the seminars, it is useless for us. (P2, female, 54 years old and lung cancer)*

Participants unanimously agreed that, *"We would like to know any information about pain management" (P7, female, 70 years old and lung cancer).* They also believed that having better cancer pain knowledge would enable them to more readily differentiate between acute and chronic pain so they could take appropriate action to manage their own pain.

> *I would like to know why I have pain. So, we may distinguish when we should see a doctor; and (ask doctors) give us some suggestions about the methods we can use to relieve (the pain) ourselves. (P21, female, 53 years old and breast cancer)*
>
> *There should be information about what kind of pain is dangerous (acute) and what kind of pain does not matter (chronic) I think this is very important, because we cannot distinguish it. (P22, female, 60 years old and breast cancer)*

Despite having limited access, participants were aware of the benefits of education and information, including its potential to help them gain a sense of control over their life.

> *Be prepared before you go to the clinic. Because you don't know what is behind. When we have this kind of disease − it is very serious. I feel helpless and do not know what the next step is. If you may find information first, you would be much calmer when you ask doctor the questions. Your quality of life would be improved. Some people were scared to death because they did not have any information. (P13, female, 45 years old and breast cancer)*

Participants were also eager to learn appropriate methods to control their pain and restore physical functions. They were interested to learn about pain assessment, so they could take the right dose of pain medication according to their level of pain, which would save time at the clinic visit.

> *The most important thing we would like to know is what method we can use and what medication we can take to solve (the problem of pain). (P6, female, 67 years old and breast cancer)*
>
> *We also need someone to teach us what we can do to recover. (P8, female, 73 years old and lung cancer)*
>
> *I do not mind if someone can teach us (to assess the level of pain). I would like to try, because it is not a solution to see the GPs every time when we have pain. For example, if someone can teach you to take two tablets when you have pain level of six and one tablet when you have pain level of three, I would listen to him and do as he teaches. So, we do not have to ask the GPs every time. This is how I think. (P2, female, 54 years old and lung cancer)*

In addition, participants perceived that general knowledge about pain medications, such as the effects and strength of different ones, would enable them to take medication with a better understanding, guiding them to take appropriate pain medications for their pain.

> *I think we need the general information about the painkillers. We are reluctant to use the painkillers. If we have some general knowledge about the painkillers, we would take them with peace of mind … I think it is necessary to learn the knowledge about the pain medications. (P9, female, 69 years old and colorectal cancer)*
>
> *We need information about strength of different pain medications – how strong they could be and what risk factors the medications may cause, which may be described one by one … It may tell us what medications we may choose upon the level of pain. (P15, female, 49 years old and breast cancer)*

They also suggested that knowledge about the side-effects of pain medication could help relieve their fear of analgesics.

> *There should be clear information about the medication – benefits, after-effects and side-effects, so that the Chinese cancer patients would not be afraid about the medications. (P17, female, 54 years old and breast cancer)*

### Preference for cancer pain information formats vary

While participants were keen to have better access to opportunities to learn about cancer pain, most were less enthusiastic about technological learning solutions, such as ‘apps’ due to suspicions about the security of the app as well as the challenges of using novel technology.

> *You would not know who made the app. You know the world is messy. (P5, female, 55 years old and ovarian cancer)*

> *We’re not interested in apps and we have not had much education. (P2, female, 54 years old and lung cancer)*

Participants did not like to use smart phones to access information for cancer pain management, as they did want to become addicted to them, using a Chinese slang term referring to people addicted to smart phones.

> *I do not like the smart phone very much. Because I am not the ‘low-down-head-family’ (P12, female, 65 years old and lung cancer)*

Another problem with apps on mobile phones perceived by the participants was that it was hard for them to concentrate on reading, because reading information on mobile devices was not easy.

> *You would feel like as if the clouds fly over your eyes after you read the information on the phone. (P10, female, 57 years old and breast cancer)*

In addition, most participants were unaware of the kinds of modern technologies that could be used for pain relief. Some participants found that there were pain relief devices in hospitals, but they refused to use them because they did not know the effects of the medications in the device and were afraid of overdosing.

> *We do not know what modern technology may be used to control the pain. If there’s a device or a machine that can relieve pain, I guess we’ll use it. But we don’t know it at all. (P2, female, 54 years old and lung cancer)*

While participants might on occasions search for information on the internet, they were concerned that the information available was often confusing and at times incorrect.

> *Online information cannot be trusted … On YouTube, every doctor said differently. (P18, female, 45 years old and breast cancer).*

> *It is hard to tell. Sometimes the information is correct; sometimes incorrect. We need to be careful. (P21, female, 53 years old and breast cancer).*

They felt it was often difficult to make a judgement about the accuracy of online resources, and perceived that a booklet using the same format of those for cancer treatment with detailed information such as side-effects and immediate actions would be very helpful.

> *Because we do not have capabilities in making judgement. If you let patients search the information online themselves, they would be very scared. Or sometimes you would feel too optimistic. It is hard to sort out more accurate opinions … When I did chemo, they did very well because they have information booklet. Basically, it would tell you some information about side-effects; what would happen when a side-effect occurred ... I think they did very well. (P23, female, 63 years old and bowel cancer)*

A small number of participants thought that the internet was more convenient, but these participants only trusted the information available from government websites.

> *Online information is preferred … We all use internet. When I was sick, the first thing was to search information online … We only trust the government websites. I would not look at other websites or use WeChat. One of the traditional Chinese medicine practitioners said to us, you could believe a little bit but do not believe everything from WeChat. (P13, female, 45 years old and breast cancer)*

These participants on occasions used the internet to check correct medical terms (e.g. medication names) and their pronunciation so they could frame questions for their doctors.

> *The reason I think the internet is better is because sometimes when we go to see the doctor, our English is not that accurate. If I find information online, I can prepare myself and think about what questions I am going to ask. When I see the doctor, I can ask the questions, because I have checked the meaning of English terms. So, this is what I mean. (P13, female, 45 years old and breast cancer).*

While some participants would like to search for certain types of resources online, most preferred written information (e.g. booklets, pamphlets or information sheets) because this type of information was perceived to be more effective, safe and easier to access.

> *I would like to read the (cancer pain management) booklets. Because when you have a booklet, you may take it out and read if sometimes you forget about something. The booklet would last longer. (P9, female, 69 years old and colorectal cancer)*

However, written information was only helpful if it was up-to-date.

> *The most hilarious thing was the (English) cancer book I mentioned which is quite thick. When I found a phone number in this book, I made a call to ask for help. He told me that*

> *I called the wrong number. I said I wanted to ask questions about the cancer. But he replied that he only does the translation. (P4, female, 61 years old and breast cancer)*

Participants suggested that educational resources related to cancer pain need to be available in various forms to meet people's individual needs and preferences. While online educational resources were popular with young people, written information was perceived to be more suitable for the elderly.

> *I think that the resources should to be developed in many ways, but not just focus on the internet. I do not mean it does not help, but just feel that it should be in a range of styles … Just like me, usually the cancer patients are elderly. We would be very tired when we have pain. We do not have much time to search information online like young people. We only need some general information and we should reduce the time surfing on internet. (P15, female, 49 years old and breast cancer)*

They also suggested that cancer care services or acute care hospitals ought to have real-time online clinical consultation for people living at home.

> *You need to consider that patients are everywhere. It is impossible to set up an official network where you live. It takes time. If you put it on the internet, the IT staff may link it to the department of the hospital which they can respond to and help you find solutions. Because you are sick, you have to go to the hospital anyway. So that you would not just find someone randomly to explain it. (P13 female, 45 years old and breast cancer).*

### 7.2.2 Communication barriers and enablers

Participants unanimously agreed that poor communication with their physicians or nurses, medical jargon and suboptimal interpreter services all affected their confidence in conveying their pain experience, discussing different pain treatment options and concerns about analgesics with their physicians or nurses. These language and communication barriers hindered the reporting of their pain, receiving appropriate pain care and adhering to taking analgesics.

#### Poor communication discourages pain reporting

Participants were keen to report their pain during their regular clinic visits to oncology specialists or their GPs. However, most were disappointed that these health professionals failed to respond to their pain concerns.

> *I went to see the doctor for solution whenever the pain struck, but the doctor did not explain to me anything. (P1, female, 62 years old and breast cancer)*

Some found that their physicians did not have time to listen to their concerns about cancer pain or explain the effects of pain medications to them during clinic visits.

> *Every time when I went to see the oncologist, they were always short of time and only met me for a little while. (P21, female, 53 years old and breast cancer)*

The cost implications of extending a consultation with oncologists to talk about pain medications posed a barrier.

> *Doctors do not have time to tell you about the pain medication. They would charge you more if they spend more time to talk to you. Some specialists do this. The cost would be different – the cost for 30 or 45 minutes is different. (P12, female, 65 years old and lung cancer)*

There was a perception that physicians and nurses did not explain pain control any better than information readily available in the public domain or through friends with knowledge and experience.

> *As I know, I find that in the hospital, doctors and nurses are not willing to talk about the effects of the medication. They won't use their medical knowledge to tell you about what medications may treat what kind of pain. However, in fact I think every medication has its own details. One of my friends knows about the pain medications very well. He provides me with a lot of information. He would say this kind medication may cause less pain in women than men. He would also tell you when you should take which kind of medications. (P9, female, 69 years old and colorectal cancer)*

In turn, ineffective communication about cancer pain treatment influenced participants' adherence to pain medications or led them to reject strong pain medications such as opioids.

> *They (doctors and nurses) would not tell you whether you should take the pain medication when you did not have pain. They did not tell me anything, so I did not take any even if they gave me several pain medications. (P3, female, 55 years old and breast cancer)*

Participants were very dissatisfied about the situation and some felt that, *"It is useless talking to the doctors."* (P18, female, 45 years old and breast cancer; P20, female, 47 years old and breast cancer)

A few who had received appropriate explanations about pain medications prior to discharge had better pain control at home.

> *I did not run into any difficulties after I was discharged. It was explained clearly when they gave me the medications. (P23, female, 63 years old and bowel cancer)*

### Medical jargon impedes expression and comprehension

For most participants language posed the biggest barrier to effective communication, even for those who had a good command of English.

> *Language is a big barrier. (P5, female, 55 years old and ovarian cancer)*

Many were afraid that they might not be able to seek help and receive appropriate pain care, as they were unable to clearly and precisely describe their pain.

> *There may be problems with ourselves. For example, we may not able to communicate or speak out our question precisely. If we cannot make ourselves clear, when you want people to help you, it would be hard for you to make the request. If you say the pain lightly, he would say to you that is normal. If you say it seriously, he would make it as a big deal, using the whole set of instrument or tests which make the things complicated (P19, male, 67 years old and bowel cancer)*

Although most participants had no problem with conversational English when dealing with daily life, they had difficulty in correctly pronouncing medical terms due to a lack of medical knowledge. They hence lost confidence in initiating conversation with their physicians and other health professionals about options for pain treatment and their concerns about analgesics.

> *Sometimes when we go to see the doctor, our English is not that accurate. We do not have problems when we are talking about daily life. However, we are not only sick but also have to take the medications. So far, I still cannot pronounce the names of these medications, because I need to remember the spelling and also need to be able to speak. (P13, female, 45 years old and breast cancer)*

> *Yes, this is a problem. We could not make ourselves clear because all of us do not understand general medical knowledge. (P21, female, 53 years old and breast cancer)*

### Inappropriate translation causes confusion

While there was an interpreter service available, sometimes participants could not understand the words the interpreters translated, because the interpreters may come from different Chinese backgrounds.

> *The interpreter cannot help you at all. (P4, female, 61 years old and breast cancer)*

> *Sometimes I cannot understand the words interpreters translated. Because there are slight differences in interpreters' languages which depends on their backgrounds − whether they come from Malaysia, mainland China or Hong Kong. Also, there are slight differences in both Chinese and English. For example, in Malaysia people say 'baxian',*

> *but here we would say 'percentage'. This is very basic vocabulary, but it can be interpreted differently. (P15, female, 49 years old and breast cancer)*

Geographical differences also caused confusion when English was translated into Chinese, as people from different locations within China speak different dialects.

> *There are also deviations in Chinese, even though we all speak Chinese. (P15, female, 49 years old and breast cancer)*

> *Perhaps it is because of the local difference. It won't have much difference when we speak Mandarin which it is easy to understand. But we are from southern China. (P16, female, 48 years old and nasopharyngeal cancer)*

For example, the Cantonese-speaking participants were confused about the term cancer pain management even when it was translated into Chinese. They suggested that this term, *"Should be in the Mandarin which is different from the Cantonese (term)" (P14, female, 59 years old and breast cancer).* In Cantonese, the word 'management' was often related to executive administration. So, it was hard for Cantonese-speaking participants to link the term cancer pain management to the management of their own pain.

> *(Cancer pain management) sounds like managing a company (P13, female, 45 years old and breast cancer)*

> *We are Cantonese. We barely use this kind of formal term to talk about pain. Usually we would say 'manage people'. (P15, female, 49 years old and breast cancer)*

The quality of online telephone interpreter services was not ideal either. Participants were disappointed with the bad attitudes and inadequate translation of many telephone interpreters.

> *Nowadays the telephone interpreters have very bad attitudes. (P5, female, 55 years old and ovarian cancer)*

> *She (telephone interpreter) did not even know the word 'breast' when we were talking about breast cancer. (P1, female, 62 years old and breast cancer)*

Given concerns about the quality of interpreter services, participants suggested that involving both a Chinese−English speaking family member and interpreter into the care (e.g. clinic visits) may lead to a better mutual understanding between health professionals and patients.

> *Basically my English is OK. But my husband or the interpreter would be beneficial, as they can ensure that I won't misunderstand what doctor said to me. This is very*

> *important. The misunderstanding between me and my doctor is not good. So it is helpful. (P23, female, 63 years old and bowel cancer)*

### Involvement of Chinese-speaking health professionals supports communication

Participants found that Chinese-speaking health professionals were very helpful in providing continual support to them for their pain management after discharge.

> *A Chinese-speaking nurse worked there who may help. There is no problem with the communication … I did find this was helpful because we often contact each other via emails and keep in touch for many years. She always reminds me of upcoming activities. (P20, female, 47 years old and breast cancer)*

They suggested that it was convenient when hospitals had health professionals speaking different languages, as it was much easier to describe their pain and consult about their pain care needs with health professionals from the same cultural background.

> *If you have had severe pain and need go to the ED (emergency department), he would ask you what language you speak, because there is a doctor who speaks Cantonese. So communication is not a problem. Nowadays, there are lot of doctors at the hospital who may speak different languages. There are a lot of Chinese doctors. (P12, female, 65 years old and lung cancer)*

Even though some participants or their family can speak good English, sometimes they would have difficulty clearly expressing their meaning or explaining the Chinese medications they were taking. Talking to a Chinese-speaking health professional may promote interaction and strengthen mutual understanding about their pain and needs.

> *Because we cannot express our meaning precisely, the doctors cannot accurately understand what and how our pain is about. We cannot speak English fluently and clearly like we did in Chinese. The Chinese-speaking doctor may understand us – they have already known what we would say next even though we have not said anything. English is different – After all, it is not the mother tongue. (P21, female, 53 years old and breast cancer)*

### Bilingual educational information as a communication tool promotes mutual understanding

Participants suggested that Chinese-English educational information materials may be used as a means of communication, to enable them to actively interact with clinicians during their clinic visit for better understanding about cancer pain and its management.

Those who spoke English well in daily life but had limited knowledge about medical terms would like to learn English medical terminology by reading English against Chinese texts to help them understand doctors’ words during clinic visits.

> *You do not know some medical terms, but you may learn, so you would be able to speak out when you talk to the doctors next time. The English and Chinese together would be much better. You may communicate with the doctors. (P22, female, 60 years old and breast cancer)*

For those who spoke limited English, they may use the Chinese−English booklet as a useful communication tool to describe their pain to their doctors.

> *Sometimes when I told doctors about my pain, they asked me to speak English, but I cannot speak English. So it would be much clearer if I let them look at the booklet. (P12, female, 65 years old and lung cancer)*

The Chinese−English information materials can also help participants clarify the meaning of Chinese translated by interpreters from diverse Chinese backgrounds.

> *Sometimes the Chinese translation is not good, so if it is made in both Chinese and English, at least we may check the meaning of the English. (P9, female, 69 years old and colorectal cancer).*
>
> *Chinese−English information are very important. Sometimes I cannot understand the words interpreters translated. Because there are slight differences in interpreters’ languages which depends on their backgrounds … We may read the English and then we will know its original meaning when we do not understand the Chinese translation. (P15, female, 49 years old and breast cancer)*

### 7.2.3 Physicians’ and nurses’ attitudes to cancer pain and its management

Participants claimed that physicians’ and nurses’ attitudes to cancer pain and its treatment during their clinic visits or receiving cancer pain treatment in hospitals shaped their help-seeking behaviours.

**‘Pain is normal’**

Most participants would like to seek medical help from their oncologists or other physicians involved in their cancer treatment, assuming that they should follow these physicians’ instructions about pain treatment.

> *In short, we would listen to the doctors. I do not have such kind of experiences. We would all follow the doctor's words. (P9, female, 69 years old and colorectal cancer in focus group 2)*

> *We have to listen to anything doctors said. If doctors tell you do not take something, then you should not take it. (other participants in focus group 2)*

However, participants reported that sometimes these physicians' attitudes to cancer pain unintentionally discouraged them to take action. This was especially the case when physicians advised participants that the pain was normal, and the pain only occurred between their clinic visits.

> *When I said to the doctor that I felt pain, the doctor said to me it was normal. I only met the doctor fortnightly, and the pain disappeared when I went to see the doctor. So only I knew what kind of pain I was suffering at home. (P19, male, 67 years old and bowel cancer)*

Participants felt upset when some physicians advised them that they had to accept pain, because the pain was the after-effect of cancer treatment and cannot be stopped.

> *The pain started after half a year since my first visit. The doctor explained to me and told me that I must accept it. After another half year, I went back to the doctor and asked him about my pain. He told me that the pain was not caused by the operation, but it was the after-effects of hormonal therapy which I need to receive for many years. (P4, female, 61 years old and breast cancer)*

> *It was really difficult. I did not have enough energy to walk. Then I told my doctor about my situation. But doctor said there was no solution, and those experiences were not the result from chemotherapy. (P2, female, 54 years old and lung cancer)*

### 'Take Panadol'

Most of participants thought that it was pointless to visit oncologists or GPs when they were in pain, because they had always been told to take Panadol.

> *In short, you do not need to see the doctor when you have pain, because they would tell you to take the Panadol. (P7, female, 70 years old and lung cancer)*

Participants suggested that they would be willing to follow instructions to take opioids if their physicians asked them to. However, very few participants were advised by their physicians to use opioids. They found that if the physicians' advice encouraged them to adhere to taking opioids, it helped them achieve good pain control.

> *I was doing better than her. I took pain medications three times a day as doctor suggested. It should be morphine – the strong pain medication. I had to take it every day. The doctor said to me that I must take it. Otherwise, I would be suffering. I was afraid of the pain and took the dose as recommended. The pain was well controlled, (P16, female, 48 years old and nasopharyngeal cancer)*

Participants were advised that taking too many opioids is not good and they should only take them as needed. The physicians' words deepened their fear of opioids and resulted in rejection.

> *The doctor prescribed those painkillers (opioids) for me, but he suggested that I should not consume too much and I should take it according to my situation. (P1, female, 62 years old and breast cancer)*

Some participants had been put off talking to their physicians about their pain or medication side-effects because the physicians had previously advised that the side-effects are normal.

> *If I said to the doctor about these hallucinations (after using the pain killers), he would say to me it was normal which was useless. So, I did not say anything but endured the pain by dragging the railing of the bed hard. (P19, male, 67 years old and bowel cancer)*

In addition, hospital staff attitudes to pain treatment can also discourage patients from ahering to alagesics after discharge. The majority of participants described how, when they were inpatients, they were disappointed that their physicians paid so little attention to their pain and its management. This experience negatively affected the participants' capacity to manage their cancer pain at home.

> *If the medications are used for chemo or radiotherapy, they would tell you in detail. However, if you have had pain in hospital, they would give you Panadol or other medications, but they would not tell you about the side-effects. You just need to take the medication when you feel pain. (P9, female, 69 years old and colorectal cancer)*

Some participants found that no one care about their pain even after they underwent major surgery. Regardless of intensity or cause of pain, physicians or nurses only asked participants to take Panadol.

> *No one cared about my pain when I had a major surgery. (P8, female, 73 years old and lung cancer)*

> *No one has asked me about my pain level. After I had surgery, those nurses came to my room and placed a cup on the table. I did not know what it was. After a while, the nurse came in and asked me why I did not take it. I asked the nurse why I had to take it. The*

> *nurse said to me it was the pain medication. I asked the nurse 'I do not have pain. Do I need to take it?' … She walked away and did not pay attention to me. (P7, female, 70 years old and lung cancer)*

Most participants agreed that not only the physicians and nurses in the hospitals, but also GPs at the primary care centres, would ask them to take Panadol without assessing their pain.

> *This (the physician and nurse offering the participant Panadol without assessing her pain) happened not only in the hospital, but also when I went to see the GP. The GP would only ask you what your pain level is and then tell you to take Panadol − they do not really care but ask you to take Panadol. (P3, female, 55 years old and breast cancer)*

Some participants claimed that their physicians or GPs always told them that their pain would get better after a period of time. In fact, the pain was persistent. Inconsistent messages and ineffective pain treatment led many participants to perceive that their physicians or GPs were ineffective at managing their pain.

> *I feel the doctor is perfunctory. Every time when I went to see the doctor, I told him that I had pain and my joints were like robots ... He said to me it would take two or three months to recover. After two or three months, I went to see him, he said to me it would take five or six months. This is perfunctory – Yes, it is 'foo you' (Chinese slang means irresponsible). I do not know if he is short of time. (P13, female, 45 years old and breast cancer)*

A smaller number of participants were very satisfied with their pain care, because they perceived that their physicians and nurses were suitably educated and provided care that met their cancer pain management needs.

> *I think doctors and nurses in the hospitals have all received professional training … In my opinion, people here who oversee cancer pain management are very caring which is very important to patients and may reduce patient's sense of terror. (P24, male, 87 years old and pancreatic cancer)*

### 7.2.4 Barriers and enablers to navigating with health care services for cancer pain

Participants reported that a range of system-related barriers affected their ability to manage their cancer pain at home, with too little support provided post-discharge from acute care.

### Uncertainty about where to seek help

One of the main system-related barriers expressed by participants was that they were uncertain about where to seek help for their cancer pain post-discharge.

> *I do not know which one (health professionals) I should ask when I have pain. Besides, they will shift the responsibilities to each other. After the treatment is finished, they will not care about you anymore. You have to resolve the problems and find the answers yourself. (P2, female, 54 years old and lung cancer)*

After being discharged from acute care, some participants felt a sense of frustration as they perceived that no health professionals took overall responsibility to manage their cancer pain. They were often very confused and did not know who they should go to for their pain treatment. Many, eventually, presented to the ED, especially if their GP was not available or was unable to assist.

> *The GP would not necessarily tell you. If you have a cancer doctor, the GP will shift his responsibility to your cancer doctor. (P7, female, 70 years old and lung cancer)*

> *That is right. You need initially to call them. If the GP cannot help, you can only go to emergency room. (P17, female, 54 years old and breast cancer)*

Participants who did not receive discharge follow-up or did not have access to a cancer support group had to go to the ED or consult their oncologists for advice, which for many was a costly exercise.

> *I did not have experience about the home visit. No nurse has called me. Every time I had pain I went to the hospital. The pain started one or two weeks after I had the surgery. They did not contact me. (P9, female, 69 years old and colorectal cancer)*

> *Either you have to spend extra 100 to 200 dollars to see the specialist; or you may go to [name removed] (Chinese cancer support group) to ask other patients ... Actually, if you are outside of the Chinese cancer support groups, you would have to go back to your surgeon. (P21, female, 53 years old and breast cancer)*

In addition, participants claimed that there were no local community-based services available to assist them to manage their cancer pain, except for the Chinese cancer support groups.

> *There was no resource for pain management in my area. In my experience, there was nothing associated with the community. (P19, male, 67 years old and bowel cancer)*

> *No. There were not any community services helping us. For us, only [name removed] (Chinese cancer support group) is helpful. (P21, female, 53 years old and breast cancer)*

As a result, most participants claimed that they had little idea of how to deal with their pain at home and felt that the process of managing pain at home was tough since they had no one to call on to guide them. They saw this as a major gap in care provision that should be urgently addressed.

> *Everyone has similar experiences and complains about this problem, because no one can help us. Everyone is like this, but we are not willing to continue like this forever. (P1, female, 62 years old and breast cancer)*

### Difficulty accessing pain treatment services

Another main system-related barrier preventing participants from better managing their cancer pain at home was the inconvenience of accessing pain treatment services, especially for unrelieved pain that developed after hours.

> *The barrier would be the inconvenience. When I have pain, I have to find a doctor (GP) before I may go to the hospital. This is a barrier. When I had pain in the evening at home, I would bear it and did not go to see the doctor (GP) until dawn … I wish I would stand the pain for several hours. You would have to wait even when you went to the emergency room. They would ask you to wait. The pain was still there. (P9, female, 69 years old and colorectal cancer)*

Participants had a perception that the Chinese health care system was more convenient because in China patients do not need a referral to see the specialist and they are able to visit several specialists in one day.

> *When I was in Taiwan, it was very convenient to see a doctor. We may choose to see specialists by ourselves and we may see four or five doctors in one day. In Australia, I find it very hard as you have to see the GP first. After you see the GP, you will be referred to see the specialist … I was afraid there would be a lot of inconvenience in relation to see the doctor and to do the surgery in the hospital, since I have gotten used to the medical treatment in Taiwan. (P23, female, 63 years old and bowel cancer)*

### Need for continuing support

Most participants stated that no one took care of them after they were discharged from either private or public hospitals.

> *There are no nurses taking care of patients in private hospital after discharge home ... Fortunately, I have several friends who are nurses. They come to help me out. (P17, female, 54 years old and breast cancer)*

> *I went to public hospital but there were no nurses taking care of me after I was discharged. (P19, male, 67 years old and bowel cancer)*

The home visit service was only provided to cancer patients who had undergone major surgery, and there was no continued support provided at home to cancer survivors.

> *You said the visit from the nurses at home is likely because you went to a different hospital. For the hospital I went to, I know they have the nurse visit to follow-up those patients who had breast total resection. For people like me who did not have the total resection but only had the tumor removed, they would not visit you for the follow-up. (P22, female, 60 years old and breast cancer)*

Very a few participants received nurse follow-up services post-discharge, but some found that when they consulted the nurse about their pain, they were often unable to assist, but instead asked them to see the GP.

> *Actually, we have nurses (follow-up) too. However, when you were suffering and calling them, they did not help sometimes. They let you go to see your GP. I feel that those nurses seem have difficulty communicating with the cancer specialists. They did not want to ask the specialists but perfunctorily dealt with you. (P22, female, 60 years old and breast cancer)*

While the majority of participants were dissatisfied with their pain care, two recipients of follow-up visits from community nurses found these visits to be very helpful.

> *A nurse visited me after I was discharged … They taught us a special arm gymnastics to stretch the muscles − stretching the chest and arm muscles. They also taught us to massage wounds with hot water when taking bath. I felt that it was very effective ... They were very helpful. I gradually got better and better after each visit … thought that other hospitals in Sydney should provide this kind of services – the home visit, because the breast cancer surgery-related pain was particularly easy to treat. (P20, female, 47 years old and breast cancer)*

Essentially, visits by the community nurses and follow-up calls to address their pain and analgesic-related issues increased participants' confidence and ability to deal with their cancer pain and daily life.

> *Currently, I have a community nurse visit me at home. Sometimes they call me every week and ask me about my daily living … They taught me how to use pain medications. They paid attention to my pain. They asked me about my treatment and my pain. They need to know … Of course, it was helpful. Sometimes, we had a chat together which was very happy. (P24, male, 87 years old and pancreatic cancer)*

Apart from the nurse home visit/phone call follow-up services, paticipants suggested that there should be a department at hospitals continually providing specific services, to facilitate patients dealing with their pain and to speed their process of recovery from cancer treatment.

> *I hope there is a department where it provides specific support and help people like us to resolve the problems, no matter what the problems are, after-effects of the surgery or the chemotherapy. Sometimes we have pain as well as other distress. If there is a specific department where we can ask the questions directly and they can help us to resolve the problems. It would be more helpful. So we do not have to wonder if we should ask our specialists or GPs or chemotherapists. (P2, female, 54 years old and lung cancer)*

> *If there is no such department, the process of recovery will be very difficult, and the progress would be very slow. (P4, female, 61 years old and breast cancer)*

The department should be able to help cancer patients resolve the problems associated with the after-effects of cancer treatment and pain, so they do not have to wonder which doctor they should talk to about their concerns.

> *In other words, no matter it is pain or other after-effects, we can go to there and get help directly. So we do not have to go to see those GPs. Sometimes GPs are not responsible, and they do not want to pay any attention to you but just tell you go home and take Panadol. That is it. (P5, female, 55 years old and ovarian cancer)*

The ideal service was considered to be a cancer rehabilitation department or a cancer recovery centre providing services to assist cancer patients dealing with the pain.

> *It would be beneficial for all cancer patients if there is a cancer rehabilitation department to specifically deal with the pain. (P8, female, 73 years old and lung cancer)*

> *It means that she wants to have a cancer recovery centre, to assist those who need the support. It will really make the difference if there is a cancer recovery centre. (P7, female, 70 years old and lung cancer)*

There also should be a telephone hotline to the department for cancer patients to consult about the causes of their pain to help them cope with their pain. The hotline should be in Chinese and other languages.

> *I think they should at least have a hotline for us to ask the questions. For example, if it was for sure that the chemotherapy can cause my sore knees, then the doctor should demonstrate to me how certain he was, but he didn't. So if there is a special department, they would at least have a hotline which I can call for a consultation. Or they may at least tell me whether my sore knees are because of my age or the chemotherapy. If I can*

*know the reason, I will not have to mix two things together. Otherwise, it will affect me and make my health conditions worse. When you blame cancer for everything, it may affect your emotions. So they should at least have a hotline for us to consult. The hotline should be in Chinese as well as in other languages. (P2, female, 54 years old and lung cancer)*

### *7.2.5 Family and peer support*

Participants' perceptions about the influences of family on their pain management varied depending on individual experiences. While most participants perceived that family support was important in assisting them to cope with the tough journey of their cancer and cancer pain treatment, they were afraid of becoming a burden to their family. They were eager to seek help from the physicians in order to resolve the problem themselves. They also perceived that peer support was more important than family support in helping them to relieve psychological burdens and restore social functioning.

#### Fear of being a burden

Most participants perceived that family support was very important for them being able to cope with their pain, as the family provided direct care to them and supported them go through a lot of difficulties by:

1) Taking participants' mind off their pain and enriching their life in general

   *The family would make you happy. For example, every day when my daughter comes back home after work, she will tell me what happened at work and, she will tell me some interesting things. She makes me feel very happy which it is helpful. (P3, female, 55 years old and breast cancer)*

2) Encouraging them to look for medical help and assisting them with translation when they went to hospital

   *He (husband) did not go to work after I had the disease (cancer), he sent and pick up me (from the hospital) which it was very convenient. Besides, my daughter would help me with the translation, so did my son. Because our English was not good, we had to rely on our son and daughter. (P12, female, 65 years old and lung cancer)*

3) Providing practical assistance during their daily life

   *We are sitting at home like a queen. The family would not ask us to do anything when we have pain. My husband was so nice. He did all the housework before he went to work. He also asked for a day off when I had the operation, chemotherapy etc. So, I felt good*

> *at that time and thought that it was not too bad to be sick. (P13, female, 45 years old and breast cancer)*

4) Providing them with financial support

> *They would take you to the hospital and pay the cost for you – this is also a kind of support. (P9, female, 69 years old and colorectal cancer)*

However, while participants recognised the importance of family support, some highlighted that the family cannot really help with their pain because the pain was their own problem.

> *They would ask you to go to bed and help you do the housework. This is the only way. What else can they do for you? Can you give some pain to them? No, it is impossible. (P2, female, 54 years old and lung cancer).*

A few participants claimed that their family did not care about them. They were the best person to help themselves.

> *I do not usually talk about my pain. Whenever I speak out, my daughter would respond immediately, 'Mum, why you are so negative all the time? You should not continue like this,' and so on. Then she would not say anything. I do want to talk about it and would never start the conversation again. No one can help you. The most important person is you who can help yourself! Your friends may listen to you but that is it. The most important thing is to take care of yourself and treat by yourself. (P8, female, 73 years old and lung cancer)*

Regardless of whether or not patients received support from their families, participants preferred to ask for help from their physicians or other health professionals involving in their cancer treatment to find solutions themselves, as they did not want to become a family burden.

> *Because the disease is my own, they are not able to understand how much I was suffering. I would make them worry; and everyone's feelings are not the same, so they may not be able to help us. I feel like this. I would like to do my best to resolve my own problems. It is nice if the family care about you. However, it would become a burden, if they could not understand you. For example, if I woke up my family that night, I would feel very embarrassed and feel very uncomfortable. (P9, female, 69 years old and colorectal cancer)*

Instead of bothering their family, participants would rather suffer pain quietly, particularly when the pain occurred at night.

> *I would make judgement and bear the pain myself, if the pain did not relieve when dawn came. If it was painful, I would ask them to help me. However, midnight was not a right time to wake them up. It would be different if the pain occurred in the morning, we could drive to the hospital. But the pain occurred at night when they were asleep. I would suffer more if I had to wake them up. I would vomit and have diarrhoea. I felt that it was too much to ask them to get up and change the clothes. It was better to lie in the bed and wish for no pain and relax myself. (P9, female, 69 years old and colorectal cancer)*

**Importance of peer support**

Apart from finding solutions themselves for their pain, most participants perceived that peer support – the support from those who spoke the same language and had the same diseases and problems as them was more important for them, because they found that peers had a better understanding of their feelings compared to their family.

> *Because everyone has experienced the pain; it would make us feel better knowing that everyone is on the same boat. I do not need to explain to them about my feeling. Sometimes it is hard for healthy people to understand our situation. When I told my husband I had pain here and there, what he would tell me is to stop taking the medication for my treatment if the medications make me feel pain. But the consequence would be terrible once you stop. The doctor would ask you to continue taking the medications for a few years. My husband's suggestion does not help much. (P1, female, 62 years old and breast cancer)*

Participants felt that sharing experiences with others cheered them up and enabled them to face reality.

> *Yes. I feel very happy. Everyone can share about their experiences. (P4, female, 61 years old and breast cancer)*
>
> *After the talk, I would go home cooking and dancing. (P2, female, 54 years old and lung cancer)*
>
> *I feel that if other people can face this, so do I. (P7, female, 70 years old and lung cancer)*

Being a member of a peer group enabled participants to overcome social barriers and openly express their concerns.

> *Certainly. I lived in this area for more than 10 years. After I lost my hair because of the cancer, I have barely come to this area because I am afraid to run into my friends … However, this group (the Chinese support group) is very good, because everyone has cancer. I may open my heart and speak frankly. If I meet someone outside, I would say*

> *nothing. You can say it is also a good will, because usually people would be afraid of cancer. They could be scared if they know I have cancer. Cancer patients often died because they were frightened to death by the cancer. (P13, female, 45 years old and breast cancer)*

In addition, support from friends, colleagues and relatives was important to help them go through the tough times and relieve their psychological burden.

> *I was touched deeply. I am a sole parent. My children have to study. I cannot do anything when I was sick. I had to reply on my friends, colleagues and relatives. They did cooking, shopping and other things for me; and supported me going through the difficulties … otherwise, I would be worried too much. At that time … I felt as if I was in hell. I worried about my cancer and worried who was going to help me. I felt that my life was to be collapsed. The feeling was terrible. Then my colleagues and my friends helped me. (P16, female, 48 years old and nasopharyngeal cancer)*

### The role of Chinese cancer support groups

The majority of the participants in the focus groups attended one of the Chinese cancer support groups run by a Chinese community cancer support organisation in cooperation with study sites. They said that Chinese cancer support groups played a remarkable role in supporting people from Chinese background to overcome the hardship of the cancer journey and deal with their pain at home.

> *Because we are all Chinese, the scope of the service is very limited for us. So far, I think that [name removed] (Chinese cancer support group) is the one who has done the best job. So it can attract a group of people with Chinese background to come here, like us. (P15, female, 49 years old and breast cancer)*

The Chinese cancer support groups provided support to assist participants cope with their cancer treatment and manage their pain via providing a series of lectures and other education resources (e.g. radiation for cancer, pain management, TCM in cancer treatment, nutrition, and rehabilitation).

> *We come here to listen to the lectures. Here we meet some friends who had cancer and exchange ideas. Besides, all volunteers and other people at Chinese cancer support groups are very nice. They provide us information and support which are not available from the community or other place. (P21, female, 53 years old and breast cancer)*

> *We attend the [name removed] (Chinese cancer support group). They provide lectures. For example, every Wednesday, they run the group and totally did four times about*

> *radiation for cancer, how to manage pain, traditional Chinese medicine in cancer treatment etc. (P21, female, 53 years old and breast cancer)*

Participants also found the peer educational programs run by the Chinese cancer support groups were very helpful. While participating in the educational program, Chinese-speaker cancer patients diagnosed with the same kind of cancer can chat and exchange experiences about cancer treatment and pain.

> *The [name removed] (Chinese cancer support group) now had a new term called 'peer education.' For example, I had bowel cancer. I could not join the conversation when other people who were diagnosed with other kinds of cancer were talking. However, there was a person who also had bowel cancer. I may talk to him. He also told me a lot of precautions which played the role of warnings … So, the peer education is very effective. (P19, male, 67 years old and bowel cancer)*

In addition, staff at the Chinese cancer support group liaised with physiotherapists and organised physiotherapy for Chinese cancer patients to help them restore their physical functioning.

> *They should contact [name removed] (Chinese cancer support group). [Name removed] organised us − the people who had breast cancer − to do the spa therapy for several times. It was the hot water spa, which was organised by the physiotherapists and [name removed]. (P14, female, 59 years old and breast cancer)*

They run group activities such as yoga and exercises to help participants control their pain.

> *Thanks for [name removed] (Chinese support group), because it provides us a way to treat the pain. Yoga is actually a kind of help. When your body has pain, you may do yoga to relieve the pain. It (Chinese support group) has a lot of courses for us to explore. So [name removed] is very helpful for us. If you go to watch those videotapes or read the book yourself, there would not be much motivation for you to do it. Then if there is a group, the group will be able to help us and will make us − everyone would feel that the pain can be relieved. Attending the groups is a social activity. (P10, female, 57 years old and breast cancer)*

Participants suggested that there should be more community resources like the Chinese cancer support group to assist cancer patients manage their pain at home.

> *There are needs for more resources for cancer pain management − the community resources. (P15, female, 49 years old and breast cancer)*

> *Like [name removed] Chinese cancer support group. (P14, female, 59 years old and breast cancer)*

## 7.3 Discussion

The findings of this chapter identified that a range of education, language, communication, professional and system-related barriers may compromise Chinese migrant cancer patients' capacity to self-monitor pain, communicate pain-related concerns, make informed decisions, navigate the health care system, and take appropriate actions to manage their cancer pain at home. Importantly, the findings also highlight that Chinese migrants living with cancer pain are eager to receive education and support for cancer pain management if available.

The barriers and enablers perceived by the Chinese migrants in relation to managing cancer pain at home are connected to the five domains of Leininger's 'Semi-Structured Inquiry Guide', including: 'Educational Factors', 'Technological Factors', 'Language and Communication Factors', 'General and Specific Care Factors', and 'Kinship and Social Factors'(Wehbe-Alamah & McFarland, 2015).

### *7.3.1 'Educational Factors' and 'Technological Factors'*

People from diverse cultural backgrounds have different views on the role of health education and information in relation to their health care (Leininger, 2002; Wehbe-Alamah & McFarland, 2015). Health education has shown great potential in the enhancement of chronically ill patients' self-efficacy and coping skills and increasing their awareness about how to obtain social support to self-manage chronic conditions (Adams, 2010).

Self-management is a core component of cancer pain management (Adams, 2010; Australian Adult Cancer Pain Management Guideline Working Party, 2016). Findings from this study suggest that these Chinese migrants recognised the importance of cancer pain education for enabling pain self-management. All participants had very positive attitudes towards using knowledge and skills to self-manage cancer pain and regain control of their life.

Health-related knowledge and skills assist people with chronic illness to independently make health decisions (Rubinelli, Schulz, & Nakamoto, 2009). A qualitative meta-synthesis over 52 studies conducted in 20 countries involving people with chronic illness from diverse cultural backgrounds suggested that knowledge about the role of medications and methods of self-care is a vital element of successful self-management practice (Schulman-Green, Jaser, Park, & Whittemore, 2016).

Patient-based educational interventions are effective in improving cancer patients' knowledge and attitudes towards pain management and analgesics (Bennett, Bagnall, & José Closs, 2009). The effectiveness of patient-based educational intervention consisting of a booklet/video about the improvement of adult cancer patients' knowledge and attitudes, as well as the outcome of cancer pain management, has been established via a randomised controlled trial in an Australian English-speaking population (Lovell et al., 2010).

It is recommended that health professionals deliver cancer pain management-related education at each patient's encounter (Australian Adult Cancer Pain Management Guideline Working Party, 2016). Unfortunately, the Chinese migrants in this study reported receiving almost no education on cancer pain management, and were frustrated that their limited cancer pain management skills hindered their ability to make informed decisions and to actively control their pain.

Similar to the education needs of cancer patients from western cultures (Bender et al., 2008), all the participants in this study would like to know about the nature, types and cause of cancer pain, options for pain treatment, where to find help and how to communicate their pain. In addition, they expressed strong interest in obtaining knowledge about the effects of analgesics, and would like to build up their skills in self-monitoring pain. Knowledge and skills about these matters are fundamental for people living with cancer pain to solve pain-related problems through the process of self-management (Yamanaka, 2018).

However, most participants claimed that nobody taught them the knowledge and skills they needed, which disempowered them from making informed decisions, seeking help and adhering to recommended analgesic use. Cancer pain management becomes even more difficult when patients are not able to differentiate between types of pain (Luckett et al., 2013; Marie, Luckett, Davidson, Lovell, & Lal, 2013). Distress and anxiety associated with uncertainty about the causes of pain may increase a patient's psychological burden. Cancer pain educational interventions should be integrated into daily clinical practice and adapted to serve cancer patients from different cultures throughout the cancer control continuum (Martin, Pisu, Kvale, & Johns, 2012).

Another significant educational barrier reported in this study was the lack of information supporting Chinese migrants to self-manage cancer pain. In Australia, multiple educational resources are well established and recommended for cancer patients, families and health professionals to facilitate self-pain care (Australian Adult Cancer

Pain Management Guideline Working Party, 2016). For example, booklets, videos, online training packages developed by the Cancer Council NSW (2018) with comprehensive information about cancer pain, options for pain treatment, effects and side-effects of analgesics, questions check list, helplines and so on support patients in taking an active role to manage cancer pain.

The National Institute for Health and Care Excellence's (2012) online educational guideline provides useful information for patients, families and health professionals about prescriptions and the use of strong opioids for cancer pain relief. It is recommended that health professionals deliver educational information about cancer pain and its management to all patients experiencing pain (Australian Adult Cancer Pain Management Guideline Working Party, 2016).

However, most of the participants in this study expressed concern that they had never received any information assisting them to deal with their pain. Compared to the English-speaking population who find it easy to obtain useful and updated health information related their health problem from a wide range of sources (Australian Bureau of Statistics [ABS], 2019), Chinese migrant cancer patients are at disadvantage in receiving sufficient information for cancer care (Cancer Council NSW, 2017). These disparities became evident in a recent systematic review (Lim, Butow, Mills, Miller, & Goldstein, 2017), and in qualitative studies conducted in Australia about exploring Chinese migrant cancer patients' information needs (Butow et al., 2010; Lim et al., 2019).

Unmet information needs for cancer pain management are broadly reported by Chinese migrants living in English countries (Lim et al., 2019). In Australia, Chinese migrants experience difficulties in receiving quality information and support for cancer care due to language-, culture- and health literacy-related barriers (Lim et al., 2019). Like other migrant populations living in Australia, Chinese migrant cancer patients often feel excluded from health decisions and health care, as they barely receive information from their health care providers (Butow et al., 2010). They perceive that the poor information provision is associated with health professionals' prejudice about their ethnic backgrounds (Butow et al., 2010). Researchers have appealed for information to be delivered in a culturally sensitive manner to promote optimum cancer care for people from ethnic minority groups living in Australia (Huang, Butow, Meiser, & Goldstein, 1999). Culturally targeted resources need to be developed to support

Chinese migrant cancer patients in order to improve the quality of life of this vulnerable population (Lim et al., 2017; Lim et al., 2019).

Apart from language-, culture-, professional- and health care system-related barriers, people's ability to evaluate and select relevant and appropriate health information can be a barrier to receiving optimal health care (Australian Commission on Safety and Quality in Health Care, 2014). According to a recent National Health Survey with 5,790 English-speaking Australian adults, most Australians (83%) felt able to compare health information from different sources, to identify the best health information for their situation and consult with health professionals about their information needs (ABS, 2019). These results are very different to the perception of the Chinese migrants in this study, who appeared to have inadequate health literacy to retrieve, understand and make an informed judgement about the quality of the health information they had access to.

Health literacy is associated with a person's health-related knowledge (Adams, 2010). It refers to an individual's cognitive and social skills that motivates and enables them to acquire access to, comprehend, assess and utilise health-related information and other resources, to engage with health care and to act for good health (Kanj & Mitic, 2009; World Health Organization, 2009).

Health literacy is a critical element affecting the outcome of self-managing chronic health conditions (Adams, 2010), and is a key element that enables outpatients with chronic pain to adopt adequate strategies to dealt with their pain (Köppen, Dorner, Stein, Simon, & Crevenna, 2018). People with low health literacy often struggle to cope with their health problems, and have difficulty accessing health services and making informed decisions about their health care (Australian Commission on Safety and Quality in Health Care, 2014; Kanj & Mitic, 2009).

In this study, participants attributed their limited ability to appraise health information to their age, the fatigue associated with living with unrelieved pain, cancer treatment and lack of education. Most preferred written information rather than electronic information on the internet. Similarly, an Australian study found that the internet was not a favourable information source for most people living with chronic pain (Corcoran, Haigh, Seabrook, & Schug, 2010). In their quantitative study education level, age and accessibility to a home computer were significant factors associated with internet usage (Corcoran et al., 2010). Individuals with higher educational levels ($p < 0.05$) were more likely to search for pain-related information via the internet; and having access to a computer at home was a significant predictor ($p < 0.05$) of internet usage (Corcoran et al., 2010).

A significant factor influencing internet usage identified in this study was concern about internet fraud and the quality of information published a via non-government websites. When people with chronic pain have concerns about the quality of online information and are confused about the information obtained, they are unwilling to consult with their physicians about the pain-related information and to use the information to help them manage pain (de Boer, Versteegen, & van Wijhe, 2007). The hesitation may cause a delay for Chinese migrants to actively find health information and discuss their cancer pain-related information needs with their health care providers.

Noticeably, while only a few participants in this study preferred to access online information, most of the Chinese migrant cancer patients in another qualitative study conducted in Australia found that the internet was a good source of educational information and support for cancer care (Lim et al., 2019). Since associated factors underpinning those patients' opinions were not explicated in this study, it is unclear whether the differences were related to participants' birth countries and/or their physical status. Both written and online information should be offered as options to Chinese migrants living with cancer pain, to meet individual needs.

In addition to educational factors, people's attitudes towards using high-technology to access health information and manage health conditions also varies in different cultures, which has an impact on health care accessibility (Leininger, 2002; Wehbe-Alamah & McFarland, 2015). The participants in this study raised concerns about the safety of electronic devices and their negative impact on people's health, and their fear of addiction to electronic devices in addition to their lack of skills in operating them; all acted as barriers to adopting modern technologies for pain care.

Chinese migrants need education and technological support to help them overcome barriers they encounter for self-managing cancer pain. When providing cancer pain management-related education and information to these patients, health professionals need to consider factors that may potentially impact their educational outcomes.

Importantly, health professionals need to be aware that providing verbal and written information to migrant cancer patients in their own language is critical to eliminate their frustration associated with misunderstanding of health information, and to improve their medication adherence and capability for self-care (Butow et al., 2010).

At present, most recommended educational resources about cancer pain and its management are delivered/prepared in English or only accessible via the internet, such as the self-management tools displayed on the website of the Cancer Council NSW (Cancer Council NSW, 2019a), or published by Cancer Council Australia (Cancer Council NSW, 2018) and the National Breast Cancer Foundation (2019). It would be valuable if these educational tools/information resources could be translated into Chinese−English versions and modified in response to Chinese migrants' cultural needs. To enable Chinese migrants to fully take advantage of educational resources, educational information materials need to be prepared in both simplified and traditional Chinese styles, as well as written and electronic versions targeting different generations and diverse Chinese migrant groups.

### *7.3.2 'Language and Communication Factors'*

Factors related to language and communication influence people from different cultures to seek help and access care to maintain their health (Leininger, 2002; Wehbe-Alamah & McFarland, 2015). Implementing culturally appropriate communication strategies addressing health care needs and the barriers people face from culturally and linguistically diverse backgrounds is essential to reduce health disparities in Australian society (Australian Commission on Safety and Quality in Health Care, 2014). Effective communication between patients, families and health professionals is an essential 'enablement approach' to self-management strategies that motivate cancer patients to actively take action in relation to their own pain (ElMokhallalati, Mulvey, & Bennett, 2018).

The Chinese migrants in this study considered language as one of the biggest obstructions to communicating their concerns and needs about cancer pain. The adverse effects of language and communication barriers on Chinese migrants' cancer care experiences, needs and outcomes have also been well documented in the systematic review and previous qualitative studies in Australia (Butow et al., 2010; Lim et al., 2017; Lim et al., 2019).

While the majority of the English-speaking population have no problems asking questions to clarify their concerns and actively interacting with their health care providers (ABS, 2019), Chinese migrants face extra challenges in dealing with cancer care as they experience language difficulties when communicating their care needs and understanding verbal and written information (Butow et al., 2010; Lim et al., 2019). Consistent with previous qualitative studies (Huang et al., 1999; Lim et al., 2019), medical jargon amplified the language barrier for the participants in this study, even for those who spoke good English.

Health-related information materials should be prepared in plain language, congruent with the reading skills of intended audiences, to encourage them to actively interact with health professionals (Australian Commission on Safety and Quality in Health Care, 2014; Kanj & Mitic, 2009). However, many health-related resources are barely understood because of the use of medical jargon and technical language (Kanj & Mitic, 2009). Migrant cancer patients often withdraw their attention and shut off when health professionals use English materials explaining medical procedures (Butow et al., 2010). Professionally trained interpreters are needed, regardless of patients' proficiency in speaking English (Huang et al., 1999).

Even though a standard interpreter service is set up to aid non-English-speaking patients understand health-related information and communicate their care needs during a clinic visit, concerns on its quality were not only raised by participants in this study, but also reported by Chinese and other migrant cancer patients in previous studies (Butow et al., 2011; Lim et al., 2019). Incorrect translations of medical and cultural concepts, as well as time limitations, reportedly affected Chinese migrants in receiving optimal cancer care (Lim et al., 2019). Compared to Anglo-Australian cancer patients, migrants (including Chinese) with interpreters received less responses/information from their oncologists during a same-length clinic consultation, and 20% of cues were not interpreted ($p < 0.05$) (Butow et al., 2011).

Lack of attention and being unsympathetic to patients' concerns and questions about pain during clinic visits were also reported by most of participants in this study. The communication disparities may lead to inappropriate decisions and poor care outcomes (Butow et al., 2011). Adopting a caring communication style when attending to patients' concerns and the use of culturally appropriate written materials during a medical conversation may reduce Chinese and other migrant cancer patients' psychological distress associated with confusion and uncertainty, and promote informed treatment decisions (Butow et al., 2010).

Health professionals need to assess Chinese migrant cancer patients' understanding, using plain language and allowing sufficient time for patients to express their concerns (Huang et al., 1999). Implementation of educational tools such as a question prompt list, dairies with pain rating scales, and cue cards to aid cancer patients describe their pain and pain experiences may help them to effectively communicate their care needs, and build up confidence in self-managing pain (ElMokhallalati et al., 2018; Marie et al., 2013). Ideally, as suggested by the participants in this study, these educational tools should be provided in Chinese-English versions to help them overcome language barriers. Involving family members in communication and directly speaking to a Chinese−English-speaking health professional (Huang et al., 1999) may also promote better understanding and interaction between patients and health professionals to effectively manage cancer pain.

### *7.3.3 ‘General and Specific Care Factors’*

The domain of ‘General and Specific Care Factors’ explores people’s expectations for good care when they are ill, for example, how nurses and other health professionals may assist them regain health, and what general and specific care factors influence them to access community resources or receive good care at home (Leininger, 2002; Wehbe-Alamah & McFarland, 2015).

Successful self-management of cancer pain requires health professionals’ support with sincerity (Yamanaka, 2018). Chinese migrant cancer patients, particularly those with lower educational levels, tended to rely on physicians with expertise to foresee care outcomes and make the right decision for their treatment, since they had difficulties understanding their own situation (Huang et al., 1999). They greatly valued physicians’ (particular their oncologist) proficiency and skills, and anticipated receiving clear recommendations about their treatment (Huang et al., 1999). However, most of the participants in this study perceived that they were not offered useful advice when they reported their pain to their physicians, GPs or nurses. Like other Chinese migrant cancer patients (Huang et al., 1999), they lost trust in their physicians and other health professionals when unclear instructions were provided, because they thought that these health professionals were incompetent and did not care about them. Physicians’ and nurses’ negative attitudes towards cancer pain and its treatment discouraged them from seeking help when their pain occurred.

Physicians and nurses are the key personnel to provide education to cancer patients, to help them enhance their capability and self-efficacy of self-managing pain (ElMokhallalati et al., 2018). It is critical that they establish a good relationship with cancer patients, assessing their pain and offering adequate pain treatment as per the World Health Organization’s guidelines about using analgesics for pain relief, to support them throughout the process of self-management (Yamanaka, 2018).

However, the literature review found that health professionals' deficient knowledge and negative attitudes towards pain assessment and management are mostly reported as contributory factors to ineffective cancer pain management (Ger, Ho, & Wang, 2000; Kasasbeh, McCabe, & Payne, 2017). It is not unusual that health professionals do not understand the nature and severity of cancer pain, the anxiety and depression associated with the pain, and the lack of confidence in administering analgesia (Kasasbeh et al., 2017). When physicians are overstressed about opioid-related addiction and respiratory depression, they often underrate patients' pain intensity and prescribe inadequate amounts and types of analgesics to patients (Ger et al., 2000). Some health professionals expect their patients to have pain, as a result, the patients' needs for analgesia was often overlooked (Kasasbeh et al., 2017).

Lack of time to assess pain, limited clinic consultation time, and lack of access and awareness of using pain management guidelines are also reported by physicians as the main barriers to effective cancer pain management (Luckett et al., 2014; Luckett et al., 2013). Educational interventions targeting health professionals should be implemented to improve their knowledge about cancer pain and its management, promote the use of validated pain assessment scales, increase awareness of patient education and adhere to cancer pain management guidelines (Luckett et al., 2014; Yamanaka, 2018). Health professionals should be aware of the benefits that providing cancer pain education to enable self-management of pain may eventually save health professionals' time and improve pain management outcomes(Luckett et al., 2013).

In addition to profession-related barriers, lack of access to pain treatment services and continuing support were also reported by the participants in this study as significant care factors affecting their ability to manage their cancer pain at home. The literature suggests that Chinese migrant cancer patients' inadequate health literacy impedes them from receiving optimal cancer care (Lim et al., 2019). People's level of health literacy shapes their capability of finding the right health services or health care providers for their health needs, and their ability to advocate for themselves when consuming those services (Australian Commission on Safety and Quality in Health Care, 2014).

Even though the majority of the participants in this study had lived in Australia for more than 20 years, they experienced difficulties in finding help and access to cancer pain treatment services; whereas the majority of the English-speaking population find it easier to navigate the Australian health care system (ABS, 2019). The findings of this study are supported by a previous study that found that Chinese migrant cancer patients felt vulnerable because they did not have the capacity to access standard cancer care, or received a lower standard of care compared to Australian-born people due to difficulties in communication or prejudice against non-citizens (Huang et al., 1999).

One of the reasons the participants in this study commented on their difficulty in accessing cancer pain treatment services was because of differences between the Chinese and Australian health care system. Health care in China is mainly provided via public hospitals, and Chinese patients may access a drop-in pain clinic at a hospital or arrange a consultation by directly contacting their oncologist, nurses and other health professionals who are in charge of their cancer treatment. Confusion may occur when Chinese migrants move to Australia and find that most cancer patients need to wait for an appointment, or have to get a referral to see an oncologist or other physician for a cancer pain-related consultation. Follow-up services provided by nurses may help them cope with the situation.

People’s health literacy is not only determined by individual health literacy, but is also influenced by the health literacy environment (Australian Commission on Safety and Quality in Health Care, 2014). The health literacy environment, such as the organisation, policies, procedures, resources, health care providers and interrelationships that constitute the health system, influences how people access, grasp, evaluate and adopt health-related information and services (Australian Commission on Safety and Quality in Health Care, 2014). Self-management of cancer pain is a process whereby cancer patients solve cancer-related problems, not just control the symptoms (Yamanaka, 2018). Successful self-management of cancer pain for people at home can only be achieved with ongoing support from the health care system for patients, families and health professionals (ElMokhallalati et al., 2018). The patient−practitioner consultation-based organisational approaches (e.g. regular review and follow-up services) are effective in supporting self-care for people living with chronic conditions (Rees & Williams, 2009).

Since Chinese migrant cancer patients expect to receive continuing support from oncologists following cancer treatment, dissatisfaction occurs when their oncologists decrease commitment to them upon completion of cancer treatment (Huang et al., 1999). Psychological and spiritual support from health professionals, family and the community are required to support them go through their tough cancer journey (Huang et al., 1999).

Nursing professionals are the key people in the implementation of self-management supporting strategies, providing ongoing evaluation, education and assistance to patients and families and liaising with multidiscipline teams, and enhancing patients' self-efficacy to manage their own pain and cope with their daily life at home (Hochstenbach et al., 2017; Yamanaka, 2018). This kind of service should start as soon as the patients' cancer treatment commences at clinics or before they are discharged. Early self-management supporting interventions beginning with oncological inpatients during the transition from hospital to home are ideal to help patients develop knowledge and skills to effectively manage cancer pain at home (Koller, Miaskowski, De Geest, Opitz, & Spichiger, 2012).

Importantly, more follow-up services by Chinese−English-speaking nurses should be funded to provide support to Chinese migrants living with cancer pain. Having a 'bilingual cultural advocate' representing Chinese migrant cancer patients to navigate with the health care system and to liaise with health professionals about their care needs with insights into their Cultural values and beliefs, to provide appropriate information, and to guide and support them would be beneficial (Butow et al., 2010; Lim et al., 2017).

### *7.3.4 'Kinship and Social Factors'*

People's perspectives about the role of family and friends in relation to supporting them with their health care vary in different cultures (Leininger, 2002; Wehbe-Alamah & McFarland, 2015). Social support from family is an essential element for cancer patients to successful manage their own pain at home (Yamanaka, 2018).

'The family remains a central organising structure of life in the Chinese migrant community' (Huang et al., 1999, pp.212). Most of the participants in this study highly valued the importance of their families in providing physical, psychological and social support to help them overcome difficulties throughout the tough cancer journey. Health professionals need to be cautious about Chinese migrant cancer patients' preference to involve their families in the information and care process, as it is divergent from usual western practice (Huang et al., 1999; Hume & Malpas, 2016). However, that does not mean that the Chinese migrants in this study expressed their pain-related concerns to their family, or relied on their family to make decisions about their pain treatment; rather, a peer support group or Chinese cancer support group were preferred.

Some researchers suggest that support groups and peer support are useful resources that improve the capability of people to self-manage their pain at home (Koller et al., 2012). However, a systematic review suggests that peer support programs (e.g. one-on-one face-to-face, group face-to-face, and group internet) demonstrate potential in improving cancer patients' care experience; however, its benefit in relieving psychosocial distress is yet to be confirmed via further research as these programs only involved sharing experiences without other interventions (Hoey, Ieropoli, White, & Jefford, 2008).

The findings of this study suggest that the Chinese cancer support groups played an essential role in providing continued assistance to Chinese migrants, helping them build up coping and pain management skills to manage their cancer pain at home. This kind of cancer support group offers a supportive and caring environment for people living with cancer to share their true feelings and experiences without disturbing their families and friends, as well as learning from others (Cancer Council NSW, 2019b). The cancer support groups also offer ongoing education and information sessions delivered by physicians, nurses and other allied health professionals (Cancer Council NSW, 2019b). Attending cancer support groups may empower patients to actively interact with family members and health professionals to regain a sense of control over their life, which may reduce psychological burdens and enhance coping skills (Cancer Council NSW, 2019b). Health professionals should screen the pain of Chinese migrant cancer patients and address their cancer pain-related concerns at each clinic visit, referring them to community-based cancer support groups where available.

However, this kind of community-based migrant service is often under-funded and poorly connected with hospitals and outpatient services (Butow et al., 2010). More funds are needed to support these community services. Most of the participants in this study attended one of the Chinese cancer support groups. This sample may have been more proactive than the average in terms of receiving education and information about cancer pain and its management, as they benefited from the cancer care education and information they obtained via the Chinese cancer support groups that helped them cope with their cancer. The limitations of convenient sampling as used in this study is discussed in Chapter 9.

## 7.4 Summary

The findings from focus group Part 3 highlighted that a range of 'cultural and social structural factors' impeded Chinese migrants' capability of managing and accessing optimal pain care at home. Self-management supporting strategies involving the efforts of cancer patients, carers, health professionals and health care system need to be implementedm to assist patients and their carers manage cancer pain at home, in order to improve quality of life for cancer patients and their carers (ElMokhallalati et al., 2018).

Comprehensive educational interventions targeting knowledge deficits in patients, their carers and health professionals and addressing multifactorial aspects of cancer pain management and individual's needs may have great potential to improve the quality of cancer pain management (ElMokhallalati et al., 2018; Luckett et al., 2013). Involving bilingual staff and families in the process of informed decision-making during clinic visits, providing continual support via follow-up services and a dedicated pain service, and increasing access to community-based Chinese cancer support services may be useful in enabling Chinese migrants to effectively manage their own cancer pain at home.

The next chapter reports on the 'cultural and social structural factors' affecting Chinese migrants' cancer pain management from a nursing perspective.

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# Chapter 8 'Cultural and social structural factors' affecting Chinese migrants' cancer pain management from a nursing perspective: Cross-sectional survey

## 8.1 Introduction

Chapters 5−7 reported on the 'cultural and social structural factors' shaping Chinese migrant cancer patients' perceptions and approaches to managing their cancer pain, in accordance with Leininger's 'Sunrise Enabler' and' Semi-Structure Interview Guide' (Wehbe-Alamah & McFarland, 2015).

This chapter reports on health professionals' experiences and perspectives of caring for Chinese migrants living with cancer pain. It presents the results of the cross-sectional survey regarding Australian cancer and palliative care nurses' experiences of caring for these patients. It details their perceptions about the role of cultural influences on cancer pain management practices, as well as the resources that would assist them to better meet this population's pain management needs.

The methodology considerations and methods related to this cross-sectional survey were described in Chapter 4. The following sections report the survey results.

## 8.2 Demographic characteristics

One hundred and thirty-three eligible respondents completed the *'Survey of Cancer and Palliative Care Nurses'.* The mean age of respondents was 45.8 years (*SD* ±9.8), and most were female (*n* = 123, 92.5%). Table 8.1 outlines other demographic data, such as language, work area, location, and training.

The majority spoke English as their first language (*n = 104,* 78.2%). A small number spoke Mandarin (*n* = 6, 4.5%), Cantonese (*n* = 4, 3%) or another language (*n* = 19, 14.3%) at home.

On average, respondents had been a registered nurse for 21.1 years (*SD* ±11.6). Just over half worked in palliative care (*n* = 70, 52.6%), while the remainder worked in cancer care (*n* = 62, 46.6%), with one person working across both services.

The respondents who answered the question about the postcode of their workplace (*n* = 130, 97.7%) worked within 47 different public health services across four Australian states. The majority worked in NSW (*n* = 112, 84.2%), while a smaller number worked in Victoria (*n* = 7, 5.3%), Queensland (*n* = 6, 4.5%) or Western Australia (*n* = 5, 3.8%).

**Table 8.1 Characteristics of the nurses**

| Characteristics | *N* | % |
|---|---|---|
| Language spoken at home | | |
| English | 104 | 78.2 |
| Mandarin | 6 | 4.5 |
| Cantonese | 4 | 3.0 |
| Others | 19 | 14.3 |
| Work area | | |
| Cancer care | 62 | 46.6 |
| Palliative care | 70 | 52.6 |
| Both states | 1 | 0.8 |
| New South wales | 112 | 84.2 |
| Victoria | 7 | 5.3 |
| Queensland | 6 | 4.5 |
| Western Australia | 5 | 3.8 |
| Cancer pain training | | |
| Compulsory training at work | 42 | 31.6 |
| Elective training | 60 | 45.1 |
| Both | 25 | 18.8 |
| None | 6 | 4.5 |
| Cultural care training | | |
| Compulsory training at work | 37 | 27.8 |
| Elective training | 24 | 18.0 |
| Both | 21 | 15.8 |
| None | 32 | 24.1 |
| Missing | 19 | 14.3 |
| Cultural influence | | |
| Very much | 71 | 53.4 |
| Somewhat | 51 | 38.3 |
| Not at all or hardly | 11 | 8.3 |

Nearly all respondents (*n* = 127, 95.5%) had received training on cancer pain management. However, less than two-thirds (*n* = 82, 61.7%) had received training on culturally congruent or culturally competent care.

Most respondents (*n* = 122, 91.7%) were of the opinion that cultural background influenced Chinese cancer patients' pain management needs 'substantially' or 'to a certain degree', while a small number of respondents (*n = 11, 8.3%*) thought that cultural background did not or hardly influenced these patients' needs.

While 93% ( *n* = 114) of respondents who considered cultural background influenced patient needs answered the question about *'In which ways does culture influence Chinese patients' cancer pain management needs?'* , twelve comments (10.5%) were excluded from analysis. The reasons of the exclusion were because these respondents provided very limited information (e.g. one or two words), or were uncertain about the influence of culture due to their limited knowledge and experience in cultural care or cancer pain. The following comment provides an example:

> *I do feel that as my expertise is limited, I am not sure if these characteristics were due to personalities of the few (Chinese migrant) patients that I looked after, rather than culturally based behaviours. (R6, female, 43 years old, cancer care, RN)*

Of those (*n* = 107, 87.7 %) who answered *'What (if any) education or resources do you think would be useful in helping to meet the pain management needs of Chinese patients?',* fifteen comments (14%) were excluded from analysis. The reasons for the exclusion were because either the respondents provided limited information (e.g. one or two words, such as 'while board'); or were unsure what resources would be helpful (e.g. some commented 'unsure' or 'NA').

The following sections report on the results of the thematic content analysis.

## 8.3 Nurses' perceptions of cultural influences on Chinese migrants' cancer pain management

Five themes and 10 sub-themes emerged from the thematic content analysis of Question 11a: *'In which ways does culture influence Chinese patients' cancer pain management needs?* (refer to Table 8.2). These themes disclosed that respondents perceived a range of 'cultural and social structural factors' informing Chinese migrant cancer patients' responses to their cancer pain and pain treatment needs, as described below:

**Table 8.2 Cultural factors affecting Chinese migrants' cancer pain management**

| Themes | Sub-themes | Example quotes | Respondents (*N* = 102) |
|---|---|---|---|
| **Chinese cultural beliefs about pain, cancer, and death shaped their expression of and response to pain** | Acceptance of pain reduces suffering | • *"Cultural beliefs influence patients' acceptance of receiving analgesic to relieve pain." (R54[1], 62 years old, palliative care nurse)*<br>• *"They have very strong beliefs that pain is a sign of weakness. Mind over matter – if you think you're not in pain, pain will not exist. So managing pain with their beliefs makes it harder, they will usually refuse treatment." (R104, 57 years old, palliative care nurse)*<br>• *"I find a lot of Chinese migrant cancer patients are quite passive in their (pain) treatment." (R17, 47 years old, cancer care nurse)*<br>• *"Suffering is part of disease." (R98, 58 years old, cancer care nurse)*<br>• *"Some Chinese patients have a different perception of the 'healing' of their pain and may under-report and put up with it." (R38, 40 years old, palliative care nurse)* | 17 |
| | Expression of pain is unacceptable | • *"Chinese patients in my experience are extremely strong and display great stoicism with regards to their pain. They do not like to draw attention to themselves, preferring to suffer with great dignity. They rarely cry out in pain for example. That behaviour seems to represent poor self-control and social etiquette. Loss of face. They sometimes will tell the specialist when prompted but on the whole they appear to not want to bother me with their complaints." (R52, 55 years old, palliative care nurse)*<br>• *"Very stoic. Don't seem to like admitting that they have pain." (R17, 47 years old, palliative care nurse)*<br>• *"Denying they have pain." (R9, 56 years old, cancer care nurse)*<br>• *"Find that Chinese cancer patients tend to be more stoic and do not want to take opioids." (R64, 50 years old, palliative care nurse)*<br>• *"More stoic about pain than Anglo-Saxon patients − sometimes will under-report." (R116, 55 years old, cancer care nurse)* | 49 |

| Themes | Sub-themes | Example quotes | Respondents (*N* = 102) |
|---|---|---|---|
| | Unwilling to discuss cancer and death | • *"Because Chinese migrant cancer patients often don't want to talk about death or dying, there seems to be some lack of understanding of patients' situation." (R82, 50 years old, palliative care nurse)*<br>• *"Chinese migrant cancer patients do not want to discuss cancer, so it can be difficult to persuade them to use opioids." (R40, 65 years old, palliative care nurse)*<br>• *"Focus is on curative treatment rather than palliation." (R84, 61 years old, palliative care nurse)* | 7 |
| **Religious beliefs contribute to suffering** | | • *"No religions. No hope makes them depressed which worsens their threshold of pain." (R85, Mandarin-speaker[2], palliative care nurse)*<br>• *"Cultural needs of Buddhist to have their body 'free' of medications prior to death." (R114, 36 years old, palliative care nurse)* | 2 |
| **Traditional pathways versus western medicine** | Believing in traditional pathways rather than western medicine | • *"The differences between Chinese medicine and western medicine are quite vast and therefore that creates a divide in ideas about treatment." (R131, 28 years old, cancer care nurse)*<br>• *"Reliance on traditional Chinese medicine, rather than western medications or safe use of both." (R45, 57 years old, palliative care nurse)*<br>• *"Chinese migrant cancer patients have a strong difficulty (in pain management) with their traditional pathways in attending to symptom control." (R41, 28 years old, palliative care nurse)*<br>• *"Use of alternative therapies without informing physician/nurses. Declining services for fear of treatment with western medicine." (R9, 59 years old, palliative care nurse)*<br>• *"Distrust of some pain care/comfort methods; wanting to use traditional methods alone." (R89, 55 years old, cancer care nurse)* | 44 |

| Themes | Sub-themes | Example quotes | Respondents (*N* = 102) |
|---|---|---|---|
|  | Myths around opioids and other analgesics | • *"Heavy stigma around more use of pain relief the worse and more severe of the illness. Misunderstanding or complete lack of knowledge on pain ladder." (R39, 38 years old, palliative care nurse)*<br>• *"It seems that they see pain relief as a 'weakness', and an inevitable passage to death; they often blame the medication for the patient's deterioration." (R51, 55 years old, palliative care nurse)*<br>• *"Fear that taking morphine means that death is imminent." (R50, 48 years old, palliative care nurse)*<br>• *"Noticed that Chinese migrant cancer patients have refused to take opioids/analgesia if they are able to tolerate the pain." (R76, 35 years old, Mandarin-speaker, cancer care nurse)* | 57 |
| **Dependence on family for decision-making about pain care** | Family rejecting analgesics for the patient | • *"Family members make decisions on behalf of the patient and sometimes deciding whether the patient needs pain management or not; thereby interfering with care needs." (R47, 48 years old, palliative care nurse)*<br>• *"Strong family involvement. Patient rarely able to make their own decisions. Patient is rarely alone." (R105, 62 years old, palliative care nurse)*<br>• *"Sometimes this reluctance (to take analgesia) is expressed by family members and it can be difficult to ascertain if it is coming from patient or family." (R6, 43 years old, cancer care nurse)*<br>• *"Most patients I have come in contact with are older people. So there is a generational issue … they are quiet and stoic in response to care and symptoms; they prefer to rely on family rather staff to assist them." (R50, 57 years old, palliative care nurse)*<br>• *"All families like to collaborate but sometimes it seems some Chinese families prefer the patient to be more awake and express concerns about drug addiction and encourage the patient not to take too much pain relief." (R82, 50 years old, palliative care nurse)*<br>• *"Families don't want their loved one to 'get hooked onto morphine' and many think 'morphine will kill them'." (R62, 55 years old, palliative care nurse)* | 57 |

| Themes | Sub-themes | Example quotes | Respondents (*N* = 102) |
|---|---|---|---|
| | Family withholding information about diagnosis and prognosis from the patient | • *"Concealing of information by family members protecting patients etc." (R99, 55 years old, cancer care nurse)*<br>• *"Family requesting patient not be told they have cancer." (R95, 55 years old, cancer care nurse)*<br>• *"Diagnosis is often not discussed with patient." (R55, 60 years old, palliative care nurse)*<br>• *"Family not wanting patient to know about their condition." (R83, 49 years old, palliative care nurse)*<br>• *"Many families do not want their loved on to have the word 'cancer' or 'palliative' used around them." (R62, 55 years old, palliative care nurse)* | 9 |
| **Difficulty conveying their pain experience to others** | Unable to clearly describe pain and treatment needs | • *"Language barrier makes it difficult for them to verbalise pain and their needs." (R60, 27 years old, palliative care nurse)*<br>• *"In my experiences Chinese patients often only want to speak to nurses who speak their language." (R104, 57 years old, palliative care nurse)*<br>• *"There are language difficulties. Unable to articulate pain." (R2, 65 years old, palliative care nurse)*<br>• *"Most patients I have come in contact with are older people. So there is a generational issue; communication of feelings, pain and other intangible aspects are often difficult to describe …They prefer to rely on family rather staff to assist them; Much of this is related to language as well." (R52, 55 years old, palliative care nurse)*<br>• *"Patients that are from NESB (non-English speaking background) are difficult to treat, especially pain management because they are unable to express and communicate their needs or whenever they are in pain." (R80, 29 years old, male[3], palliative care nurse)* | 17 |
| | Challenge of using interpreter service | • *"Use of interpreter can be challenging." (R83, 49 years old, palliative care nurse)*<br>• *"Need to have good interpreter available to discuss in depth about pain types, frequency, duration and response to analgesia." (R118, 55 years old, cancer care nurse)*<br>• *"Getting interpreters after hours is always a challenge − phone is never good." (R114, 36 years old, palliative care nurse)* | 6 |

[1] Respondents' identification
[2] Unless specified, the examples are quotes from English-speakers
[3] Unless specified, respondents are female

1) Chinese cultural beliefs about pain, cancer and death shape Chinese migrants' expression of and response to cancer pain:
    i) Acceptance of pain reduces suffering
    ii) Expression of pain is unacceptable
    iii) Unwilling to discuss cancer and death
2) Religious beliefs contribute to suffering
3) Traditional pathways versus western medicine
    i) Believing in traditional pathways rather than western medicine
    ii) Myths around opioids and other analgesics
4) Dependence on family for decision-making about pain care:
    i) Family rejecting analgesics for the patient
    ii) Family withholding information about diagnosis and prognosis from the patient
5) Difficulty conveying their pain experience to others:
    i) Unable to clearly describe pain and treatment needs
    ii) Challenge of using interpreter service.

### *8.3.1 Chinese cultural beliefs about pain, cancer and death shape Chinese migrants' expression of and response to cancer pain*

Respondents perceived that culture shaped the way in which Chinese migrants conceptualised the healing processes associated with their cancer pain, the cancer itself, and their death. Respondents said that these cultural responses often acted as a barrier to effective management of their cancer pain.

#### Acceptance of pain reduces suffering

Respondents suggested that Chinese migrants often believed that pain was a normal part of having cancer and that this conviction shaped their pain management expectations. They also perceived that Chinese migrants were often passive in seeking help to manage their pain, which may have been influenced by their powerful convictions that cancer pain indicated that their body and mind were not strong. Respondents perceived that this belief influenced their patients' acceptance of recommended pain treatments, with many preferring to accept the presence of pain and using mindfulness to reduce their sensation of pain, rather than using recommended analgesics. Adopting these non-pharmacological approaches assisted patients to overcome their fears, and reduce the distress associated with their cancer diagnosis and pain, enabling them feel less pain.

#### Expression of pain is unacceptable

Respondents perceived that Chinese migrants often expressed their cancer pain quite differently to other cancer populations, because they were fearful of causing trouble for others. Their overwhelming desire ‘not to be a bother’ was perceived by respondents as contributing to patients presenting as being stoic and unwilling to ask for pain relief, often suffering in silence as they endured their cancer pain.

#### Unwilling to discuss cancer and death

Respondents found that Chinese migrant cancer patients’ general unwillingness to discuss their cancer, or death, led them to focus on active treatment rather than palliative care, which created an additional barrier to effective pain management. For these reasons, respondents suggested that it was sometimes hard to help their patients to understand the underlying cause of their cancer pain and to receive appropriate analgesics, especially opioids associated with end-of-life care.

### *8.3.2 Religious beliefs contribute to suffering*

A small number of respondents (*n* = 2) perceived that religious factors sometimes worsened suffering in Chinese migrant cancer patients either because their Buddhist beliefs led them to reject using pain medication as they wanted to eliminate medications from their body prior to the death or, on the other hand, because a lack of religion made them depressed.

### *8.3.3 Traditional pathways versus western medicine*

Respondents found that there were widespread beliefs about TCM and other alternative approaches, as well as myths around opioids and other analgesics in Chinese migrant cancer patients, leading to rejection of opioids and other analgesics.

#### Believing in traditional pathways rather than western medicine

Respondents observed that Chinese migrant cancer patients believed in TCM and other alternative therapies to manage their pain. They believed this belief contributed to a lack of trust in western medicine, which often led patients to obtain health care information from unofficial sources. This belief influenced their decision-making about cancer pain treatment, as well as their reluctance to inform their usual health care provider(s)/teams. Their reluctance to use western medicine often led patients to decline pain treatments because of safety concerns. These divergent beliefs made it difficult for health professionals to effectively manage their patients' pain.

**Myths around opioids and other analgesics**

Respondents also suggested that intertwined with beliefs in TCM pathways, Chinese migrant cancer patients had concerns about opioid-related addiction, unwanted side-effects, and dependence. Respondents observed that their patients often misunderstood or underestimated the efficiency of opioids and other analgesics, and were extremely worried that opioids could harm their body and aggravate their health conditions. These myths were perceived as contributing factors to many patients enduring cancer pain and rejecting the use of recommended strong analgesics, especially opioids.

### *8.3.4 Dependence on family for decision-making about pain care*

Respondents observed that Chinese migrant cancer patients, especially the older generation, relied on their family to communicate with health professionals and to make decisions about their pain care. While family support was important, family involvement could sometimes impede patient access to optimal pain management, due to a range of social structure factors, as described below.

**Family rejecting analgesics for the patient**

Respondents found that as patients were dependent on their families for decision-making, they might not report their pain or other concerns to health professionals, but rather confide only in their family. In addition, families' concerns about side-effects and the safety of pain relief led to some families being reluctant to let patients take analgesics. There was also a perception that some families rejected the use of opioids as they wanted to keep the patient awake or believed that opioids could worsen their health condition(s).

**Family withholding information about diagnosis and prognosis from the patient**

Respondents observed that since families were unwilling to inform patients of their health conditions, they often withheld information (e.g. cancer diagnosis, advanced stage of cancer or end-of-life care) from the patients to protect them. These patients often were not aware of their own health condition, and could not therefore make decisions about pain management, particularly as their cancer advanced. It was hard for nurses to know whether the patients understood their own health condition and whether rejecting opioids was their own decision.

### *8.3.5 Difficulty conveying their pain experience to others*

The participants in this study commented that Chinese migrants have difficulty in communicating their pain experiences with others because of language barriers and inadequate interpreter services.

**Unable to clearly describe pain and treatment needs**

Respondents suggested that language barriers made it difficult for Chinese migrants to articulate their cancer pain and pain treatment needs. These patients, especially older ones, often needed translation assistance from an interpreter or a family member to understand how to manage their pain. Respondents suggested that while the use of interpreters was recommended, many patients actually preferred talking to Chinese-speaking health professionals about their pain and care needs, probably because it was easier for them to communicate their concerns directly to the health professionals in their mother tongue.

**Challenge of using interpreter service**

Respondents acknowledged the importance of interpreters in helping them communicate with Chinese migrants about their pain. However, sometimes the meanings of their words were lost via the translation/interpretation process. Respondents also claimed that accessing after-hour interpreting services was challenging and that there were not enough trained interpreters to provide services to a Chinese population who speak different dialects, especially older people who are less fluent Mandarin speakers. When this occurred, it was particularly challenging to communicate with the patients to ensure they had adequate understanding of their pain, the proposed pain management regimen, and the confidence to talk about the presence of unrelieved pain.

## 8.4 Strategies for culturally congruent pain care

The thematic content analysis of Question 11b: '*What (if any) education or resources do you think would be useful in helping to meet the pain management needs of Chinese patients?*' identified three main strategies (refer to Table 8.3) to improve Chinese migrants' cancer pain management and meet their needs:

1) Integrating culturally congruent care to cancer pain management practice by:
    i) Promoting culturally congruent pain care using a collaborative approach
    ii) Promoting culturally appropriate communication using simple, translated tools

    iii) Better access to interpreter services

2) Culturally appropriate education delivered in Chinese languages to the patients:
    i) Education to eliminate misunderstanding around cancer pain management
    ii) Increasing access to Chinese educational resources and pain assessment tools
    iii) Providing information on interaction between Chinese and western medicine
    iv) Involving family and interpreter in the education
3) Strengthening nurses' understanding of Chinese cultural beliefs and medicine in relation to pain management:
    i) Providing education about influences of Chinese cultural beliefs on patients' pain care
    ii) Providing education on Chinese traditional pathways in pain management
    iii) Compulsory cultural education in various formats

### *8.4.1 Integrating culturally congruent care with cancer pain management practice*

Respondents suggested that integrating the following interventions into clinical practice was likely to better meet Chinese migrants' cancer pain management needs.

**Promoting culturally congruent pain care using a collaborative approach**

Respondents suggested that it was important to consider Chinese migrants' cultural beliefs, values, and preferences when co-developing their cancer pain treatment plan. They also suggested that there is a need to promote culturally congruent care by establishing a collaborative approach involving relevant Chinese cancer support groups, Chinese-speaking health professionals, and multi-disciplinary teams into Chinese migrant cancer patients' pain management. Establishing a more culturally collaborative approach to manage pain would help patients better understand the importance and effectiveness of analgesics (including opioids) in their pain treatment. Until these systems were established, respondents perceived that promoting more collaborative approaches involving Chinese-speaking health professionals in patient care would enable nurses and other health professionals to understand patients' cultural beliefs and traditional pathways in relation to their pain management. This collaborative approach would help to integrate cultural understanding into pain care and offer pain management options (e.g. TCM and non-pharmacological interventions) to meet their pain management needs.

**Table 8.3 Culturally appropriate interventions addressing Chinese migrant cancer patients' pain management barriers and needs**

| Themes | Sub-themes | Example of the quotes | Respondents (*n* = 98) |
|---|---|---|---|
| **Integrating culturally congruent care with cancer pain management practice** | Promoting culturally congruent pain care using a collaborative approach | • *"Understanding their traditional pathways and how it can be incorporated into our day-to-day care. Giving the patients the option and voice to have such methods to be incorporated. Bringing into discussion and communication with the health team." (R79[1], 23 years old, palliative care nurse)*<br>• *"Chinese-speaking nurses to have on board would help to make them understand about the opioid and its efficiency" (R35, 28 years old, Nepali-speaker[2], palliative care nurse)*<br>• *"Respecting their cultural background is the main core of providing good pain management." (R83, 49 years old, palliative care nurse)* | 24 |
| | Promoting culturally appropriate communication using simple and translated communication tools | • *"Providing an opportunity for the patient and their family to discuss their needs and working with them to ensure they receive the required information." (R112, 41 years old, palliative care nurse)*<br>• *"Using simple English and explained in definition about our resources like available medications and how we use like PRN (as required) medications." (R70, 32 years old, Nepali-speaker, palliative care nurse)*<br>• *"Translation of main Chinese words into English making it easy to communicate." (R60, 27, Nepali-speaker, palliative care nurse)*<br>• *"Communication tools around pain scores − location/sites, duration, alleviating factors, pain characters." (R113, 48 years old, palliative care nurse)* | 22 |
| | Better access to interpreter services | • *"More interpreter services availability − not just at initial diagnosis /or end of life but at each visit." (R4, 57 years old, cancer care nurse)*<br>• *"Have available interpreter service to speak to families and patients with medical, nursing and allied health." (R52, 55 years old, palliative care nurse)* | 13 |

| Themes | Sub-themes | Example of the quotes | Respondents (*n* = 98) |
|---|---|---|---|
| **Culturally appropriate education delivered in Chinese languages to the patients** | Education to eliminate misunderstanding around cancer pain management | • *“Education focused on demystifying pain management in patients with cancer; Supporting patients and families to explore feelings of guilt around diagnosis and use of pain medicine.” (R50, 57 years old, palliative care nurse)*<br>• *“Adjust good education booklets that encompass the importance of Chinese patients telling the health care provider the accurate level and duration of pain. Explaining the role of the health professional is to minimise the pain symptoms. Education that it is not stoic to put up with pain.” (R17, 47 years old, cancer care nurse)*<br>• *“Patients’ greater awareness of how pain management can improve their quality of life and enable them to enjoy time with family pain free.” (R119, 60 years old, cancer care nurse)*<br>• *“Guide that explains simple analgesics and benefits of taking regularly and also how slow-acting analgesics work.” (R17, 47 years old, cancer care nurse)*<br>• *“Patient-information brochures explaining the different types of medication used.” (R129, 29 years old, palliative care nurse)*<br>• *“Myths about morphine from Palliative Care Australia.” (R47, 48 years old, palliative care nurse)*<br>• *“Facts about pain management and opioid use in palliative care.” (R58)*<br>• *“Explanation to myths of opioid use.” (R4, 57 years, cancer care nurse)*<br>• *“Difficult to comment as I am not sure what brochures we have in Chinese language – but patients from all backgrounds would benefit from a simple brochure on opioid treatment (use, side-effects … addiction, signs of toxicity etc.)” (R82, 50 years old, palliative care nurse)* | 35 |
|  | Increasing access to Chinese educational resources and pain assessment tools | • *“Pain management seminar (free, trusted source) by Chinese-speaking health professional.” (R39, 38 years old, palliative care nurse)*<br>• *“Pictures/pamphlets or any literature in Chinese to support pain management.” (R24, 49 years old, Filipino speaker, cancer care nurse)*<br>• *“Resources in their own language would be beneficial to each patient, e.g. end-of-life care, understanding pain medication, and provide online resources to patient and family.” (R83, 49 years old, palliative care nurse)*<br>• *“Brochures in their own language about the cultural belief of Chinese people and how these can be incorporated with western pain relief.” (R51, 55 years old, palliative care nurse)*<br>• *“Materials from official Chinese organisations (credibility).” (R14, 47 years old, cancer care nurse)*<br>• *“A tool in their own language asking them to tick their pain scale and to reflect on normal ADL's (activities of daily living) that a Chinese person may complete.” (R18, 32 years old, Spanish-speaker, cancer care nurse)* | 22 |

| Themes | Sub-themes | Example of the quotes | Respondents (*n* = 98) |
|---|---|---|---|
| | Providing information on interaction between Chinese and western medicine | • *"(Provide) information on reactions between western medicine and Chinese medicine and what is OK." (R23, 47 years old, cancer care nurse)*<br>• *"Also about importance of telling staff about herbal medications." (R41, 28 years old, palliative care nurse)* | 8 |
| | Involving family and interpreter in the education | • *"Family or close friends can spend time with this kind of patient (during the education) as they might have psychological pain rather than physical pain, e.g. stress, anxiety from disease." (R23, 47 years old, cancer care nurse)*<br>• *"(Including) interpreter service for education." (R20, 30 years old, cancer care nurse)*<br>• *"Use of interpreter to fully explain pain medication." (R3, 65 years old, male[3], palliative care)* | 21 |
| **Strengthening nurses' understanding of Chinese cultural beliefs and medicine in relation to pain management** | Providing education about influences of Chinese cultural beliefs on patients' pain care | • *Education session to educate nurses to understand how cultural background may affect Chinese migrant cancer patients' feelings and beliefs around pain relief. (R6, 43 years old, cancer care nurse)*<br>• *"Education regarding how Chinese people perceive and describe pain. How Chinese people view and treat pain." (R88, 44 years old, cancer care nurse)*<br>• *"Cultural understanding of reasons for refusing analgesia." (R37, 63 years old, palliative care)*<br>• *"Culturally specific education on what may drive patients and families' views of cancer, morphine and other opioid medications." (R50, 57 years old, palliative care nurse)*<br>• *"Exploration as to how and why Chinese are reluctant to discuss pain and pain management." (R17, 47 years old, cancer care nurse)*<br>• *"Education on the cultural needs that these patients have and how to best manage them within the hospital polices/procedures." (R7, 33 years old, cancer care nurse)*<br>• *"[Initial] cultural sensitivity 'champion' in each ward (taken on by a current ward registered nurse with training and/or Chinese background)]." (R82, 50 years old, palliative care nurse)*<br>• *"Cultural awareness training; Cultural respect; Family engagement; Family roles and responsibilities in Chinese culture." (R4, 57 years old, cancer care nurse)* | 25 |
| | Providing education on Chinese traditional pathways in pain management | • *"Information for nurses on Chinese methods of pain measurement and how they can be implemented in the health care setting." (R5, 36 years old, cancer care nurse)*<br>• *"Education on Chinese medicine and specific drugs to be aware of." (R23, 47 years old, cancer care nurse)*<br>• *"Nurse-cultural in-service, explanations of alternative therapies." (R129, 29 years old, palliative care nurse)* | 30 |

| Themes | Sub-themes | Example of the quotes | Respondents (*n* = 98) |
|---|---|---|---|
| | Compulsory cultural education in various formats | • *"Compulsory training with CPD (Continuing Professional Training) points if working in Cancer Care." (R124, 59 years old, cancer care nurse)*<br>• *"Lectures/resources about their belief and concerns, duties to their families for staff. How we can work will them. Also how they can work will us." (R54, 62 years old, palliative care nurse)*<br>• *"To access current journals via academic resources; Education through COSA (Clinical Oncology Society of Australia), CNSA (Cancer Nurses Society of Australia), Cancer Institute." (R14, 47 years old, palliative care nurse)*<br>• *"General cultural training that then links into specific training and tools to support patients with a Chinese background." (R 112, 41 years old, palliative care nurse)*<br>• *"Key words in Mandarin/Cantonese for worker education." (R32, 25 years old, Cantonese-speaker, cancer care nurse)*<br>• *"In-service; booklets − English/Chinese; Picture dictionary." (R9, 56 years old, cancer care nurse)*<br>• *"Nurses-online training because of time restraints in the workplace." (R127, 66 years old, cancer nurse)* | 33 |

1 Respondents' identification number
2 Unless specified, the examples are quoted by English-speakers
3 Unless specified, the respondents are female

### Promoting culturally appropriate communication using simple and translated communication tools

Respondents advised that nurses and other health professionals need to be encouraged to listen to their Chinese patients and the families' concerns related to opioids and other analgesics, and to use simple language to explain the effects of pain medication to alleviate their fears. They also need to encourage their patients to ask for help for their pain and to actively contribute to their pain management plan. Visual/written resources, such as communication books and translated cards with simple English−Chinese words about cancer pain and options for pain management would be beneficial in promoting culturally appropriate communication between patients and their health care teams.

### Better access to interpreter services

Respondents suggested that increasing accessibility to after-hour interpreter and telephone interpreter services, and offering an interpreter service at each clinic visit are essential to promote mutual understanding between patients/family and health professionals.

## *8.4.2 Culturally appropriate education delivered in Chinese languages to the patients*

Respondents urged that culturally appropriate education interventions in either Mandarin or Cantonese be available to encourage pain reporting and help-seeking behaviours.

### Education to eliminate misunderstanding around cancer pain management

Respondents outlined the type of pain education that would be helpful for Chinese migrants to manage their own pain, including topics such as pain, types of pain medication and side-effects, pain management options, and integrating TCM. They also stressed the importance of this education being available and delivered regularly, and in a culturally appropriate format that would encourage pain reporting and dispel the many opioid myths, and thus reduce misunderstanding and opioid-related concerns. Another important aspect of this education according to respondents would be to clarify health professionals' role in pain management and address the benefits of pain relief in improving patients' quality of life.

Providing education and information about pain, pain management, and palliative care in Chinese may support the patients and their families make decisions for their pain care with better understanding. The information provided to the patients should be consistent and repeated to reinforce the importance of accurate pain reporting and pain relief for their cancer and/or palliative care.

#### Increasing access to Chinese education resources and pain assessment tools

Respondents suggested that developing and implementing Chinese pain assessment tools in clinical practice might enable their patients to accurately assess and appropriately manage their cancer pain themselves. Various types of educational tools (e.g. visual aids and information booklets) and online official resources (e.g. the eviQ website) should be available to help address their educational needs. Access to Chinese educational resources and pain assessment tools would help patients cope with their cancer pain and actively engage with their pain treatment.

#### Providing information about the interaction between Chinese and western medicine

Respondents suggested that having health professionals on the team who are qualified in both TCM and western medicine would be ideal. Dual trained health professionals would be in a good position to educate Chinese migrants with cancer pain about the complementary aspects of Chinese and western medicine, as well as the unintended interactions that can occur and the importance of informing the medical team when they are taking Chinese medicine/herbs. The respondents also highlighted the importance of all health professionals encouraging their patients to discuss their Chinese medicine use and needs with the medical team.

#### Involving family and an interpreter into patient education

Respondents recommended that involving Chinese migrant cancer patients' families and interpreters into their education would be beneficial to relieve patients' psychological distress and help them fully understand the effectiveness of pain medications and the importance of cancer pain management.

### *8.4.3 Strengthening nurses' understanding of Chinese cultural beliefs and medicine in relation to pain management*

Apart from providing education to Chinese migrant cancer patients, respondents urged that in order to improve pain care to this population, education should be provided to the nurses and other health professionals to help them understand Chinese cultural beliefs and medicine and how these factors impact on pain management.

**Providing education about influences of Chinese cultural beliefs on pain care**

Respondents suggested that a cultural awareness campaign should be initiated at health care settings to help nurses and other health professionals better understand Chinese migrant cancer patients' cultural care needs as well as the family's role in their pain management.

Education on what and how Chinese cultural beliefs have shaped the patients' perceptions and responses to cancer pain and pain management would enable the nurses and other health professionals to obtain a better understanding about their pain reporting and help-seeking behaviours.

Understanding the cultural care needs of patients and their families, and the reasons for rejecting analgesics, is essential to promoting mutual understanding and respect and avoiding any potential conflict between patients and staff.

**Providing education on Chinese traditional pathways in pain management**

Respondents acknowledged that education/information about Chinese traditional pathways in pain management is critical to enable nurses and other health professionals to integrate these pathways in clinical practice to improve pain care outcomes.

**Compulsory cultural education in various formats**

Respondents also suggested that cultural education in relation to Chinese migrants' cancer pain management should be compulsory as an important component of nurses annual continued professional training for those who working in cancer care.

Access to various training and academic education resources about cultural care and access to Chinese-language tools may help nurses enhance their competences in managing Chinese migrants' cancer pain. The training could be delivered via face-to-face formal education (lectures/workshops), in-service or via online training programs, to suit nurses' needs and schedules.

## 8.5 Discussion

This nurse survey found that cancer and palliative care nurses perceive that culture influences Chinese migrants' perceptions and responses to cancer pain and its management. These nurses reported that Chinese migrants with cancer pain often under-reported or were unwilling to bother others with details about their cancer pain, and rejected opioids and other analgesics for pain treatment. These barriers are consistent with the literature related to cancer pain management of Chinese people living in China (Xu, Luckett, Wang, Lovell, & Phillips, 2018; Zeng, Li, Lin, & Mizuno, 2019). While these concerns have also been reported by other cancer populations (Luckett et al., 2014), the reasons for under-reporting cancer pain and not using opioids are somewhat different in Chinese migrants, and much more likely to be influenced by cultural factors. Australian cancer and palliative care nurses encountered challenges providing culturally appropriate care to Chinese migrants with cancer pain, especially at their end-of-life stage of advanced cancer, but desired to provide better care to this population.

### *8.5.1 'cultural and social structural factors'*

The 'cultural and social structural factors' identified in this study align with five domains of Leininger's 'Semi-Structured Inquiry Guide': 'Cultural Values, Beliefs, and Lifeways'; 'Religious/Spiritual/Philosophical Factors'; 'Kinship and Social Factors'; 'Language and Communication Factors'; and 'Professional and Generic (folk lay) Care Beliefs and Practices', as detailed below.

#### Domain of Leininger's 'Semi-Structured Inquiry Guide': 'Cultural Value, Beliefs and Lifeways'

In this survey, the nurses reported a perception that Chinese migrants' beliefs about cancer, cancer pain, and death shaped their expression and responses to cancer pain.

The nurses perceived that the cultural belief underpinning Chinese migrants' perception about acceptance of pain reducing suffering as that they assumed their pain was an inevitable part of having cancer. Previous research suggests that Chinese migrants are not alone in assuming that pain is an unavoidable part of cancer, with many other population groups making the same assumption (Bender et al., 2008; Luckett et al., 2013). In the case of Chinese migrants, their lifeways and customs underpinned their beliefs about cancer, pain, and its management, leading to a culture-specific passive acceptance of pain resulting in misunderstanding about their pain and rejection of recommended pain care.

The nurses' perception that expression of pain was unacceptable for Chinese migrants was a significant barrier to them seeking help for their cancer pain. This cultural norm was consistent with a 'desire to be good' and 'pain endurance beliefs', which have been reported by cancer patients living in China (Xu et al., 2018) as well as by people from other cultures (Oldenmenger, Sillevis Smitt, van Dooren, Stoter, & van der Rijt, 2009). In the case of Chinese migrants, the nurses in this survey found that they appeared more stoic than cancer patients from other cultures, and often denied having pain and rejected opioids.

The cultural construct, ‘unwilling to discuss cancer and death’, emerged in this survey was perceived to be related to the patients’ rejection of opioids and analgesics. The nurses observed that Chinese migrant cancer patients and their families were reluctant to talk about cancer and death. It hence was hard for the nurses to assess the patients’ pain management needs. The likely reason for a reluctance to engage in these sensitive conversations is because of their or their families’ perception that cancer is incurable and related to death (Huang, Butow, Meiser, & Goldstein, 1999).

‘Cancer’ in Chinese sounds like a death sentence (Mak, 2001). To some Chinese migrants living with cancer pain and their families, active cancer treatment is more important than pain treatment or palliative care, because it conveys hope that the person will survive. Focusing on active cancer treatment helps to reduce the hopelessness and distress associated with uncertainties that the patient may die, which it is often expressed by Chinese cancer patients and their families (Huang et al., 1999).

Chinese people believe that talking about death brings bad luck (Xing et al., 2017). Therefore, talking about death/dying in front of the patients may be very disrespectful and disappointing for Chinese patients and their family. So, in Chinese culture, it is not unusual that even medical practitioners are reluctant to talk about cancer and death (Mak, 2001). Communicating ‘bad news’ about cancer or dying to Chinese patients is challenging, as it may have negative psychological consequence for the patients and their families (Mak, 2001; Xing et al., 2017). For this reason, Chinese medical practitioners and patients’ families often try to conceal information about the patients’ cancer diagnosis and advanced prognosis (Mak, 2001). While this is confronting to the patients and their family, it can create ethical dilemmas for health professionals (Mak, 2001).

These ethical dilemmas may cause frustration and conflict between western health professionals, Chinese migrant cancer patients and their families (Hume & Malpas, 2016). When health professionals are obliged to inform Chinese migrant patients about their cancer diagnosis and treatment, their families do not want the information being directly disclosed to patients (Hume & Malpas, 2016).

While Chinese families tend to conceal information from the patients to protect them, the patients may have different thoughts in relation to knowing the truth of their health conditions. A qualitative study conducted in Hong Kong suggests that unlike what is commonly believed, older Chinese with terminal cancer are not afraid to know or talk about their prognosis (Ho et al., 2013b). In fact they see death as a natural part of their life and accept it calmly, especially if they perceive they have lived a long and fulfilling life (Ho et al., 2013b).

Chinese cancer patients, particularly the elderly, often prefer to be informed about the truth of their diagnosis, and to be aware of their dying (Ho et al., 2013b; Mak, 2001). This knowledge enables them regain control of their life and plan for the future (Ho et al., 2013b). Despite wanting this knowledge, like other populations, they may need psychological support after receiving bad news (Mak, 2001). In addition, the need for information in relation to a cancer diagnosis and prognosis should be individualised, as most Chinese cancer patients believe that not everyone could cope with the truth and they may die quickly after knowing the diagnosis (Huang et al., 1999).

Chinese cancer patients prefer to involve both their physicians and their families in the process of disclosure of the cancer diagnosis (Cao, Qi, Yao, Han, & Feng, 2017; Huang et al., 1999). During these conversations, they also expect physicians to offer options for cancer treatments, and outline benefits and side-effects (Cao et al., 2017). The emotional support and individualised disclosure process helps to increase their hope for life, and to establish a trusting relationship between them and health professionals (Cao et al., 2017). The trust relationship may promote effective communication and mutual understanding between Chinese migrant cancer patients, their families and health professionals, so that pain care can meet patients' needs.

These factors suggest that health professionals need to understand the cultural factors affecting Chinese migrants' willingness to acknowledge their cancer, the presence of pain, and to provide them with an opportunity to discuss their concerns and encourage them to seek help for their cancer pain treatment that is congruent with their cultural beliefs and practices.

### Domain of Leininger's 'Semi-Structured Inquiry Guide': 'Religious/ Spiritual/ Philosophical Factors'

A small number of nurses in this survey identified that religious beliefs contribute to Chinese migrant cancer patients' unnecessary suffering. These nurses perceived that religious beliefs affected their decisions about using opioids and other analgesics for pain at the end-stage of cancer. Assessing and managing cultural expectations relating to pain care is important for those who wish to have their body free of pain medication before death due to the influences of their religious beliefs. Knowledge of dying is essential for Chinese cancer patients to find inner peace and comfort to achieve a 'good death' with dignity (Ho et al., 2013b; Mak, 2001).

Health professionals need to be aware that the concept of maintaining dignity towards the end of life is conceptualised differently by Chinese populations, making it difficult for them to accept palliative care (Li, Richardson, Speck, & Armes, 2014). Older Chinese cancer patients' views of dignity at the end of life are often defined by traditional Chinese morality, their moral life and social roles (Li et al., 2014). Similar to other patients, Chinese patients with advanced cancer desire to live a normal life and maintain their social function as long as possible (Li et al., 2014). 'Living life in full' is meaningful for Chinese people with a terminal illness, as it enables them to find a sense of existence as an individual (Li et al., 2014). Maintaining their self-esteem and feeling valued by their children and others often helps Chinese cancer patients find inner peace and maintain their dignity at the end of life (Li et al., 2014).

However, the nurses in this survey observed that for many Chinese migrant cancer patients, their move to a new country meant that they had lost their social networks, hope, and traditional support. In addition, if these patients did not speak English, they were dependent on their adult children for making treatment decisions about their cancer and pain care. This loss of independence contributes to humiliation and feelings of worthlessness that often worsens their psychological pain and health conditions (Ho et al., 2013b).

Health professionals need to consider providing psychosocial interventions to Chinese cancer patients in a culturally sensitive manner, to improve the relationship between patients and their adult children and to help patients to regain or maintain a sense of dignity (Li et al., 2014). Psychotherapeutic interventions such as dignity therapy administrated by palliative care nurses and psychologists has helped patients with terminal illness (e.g. cancers) find meaning of life, significantly reduce their symptoms of suffering and distress ($p < 0.050$), and increase their will to live ($p < 0.001$) (Chochinov et al., 2005). This type of psychological interventions may also be relevant to Chinese migrants with cancer pain.

### Domain of Leininger's 'Semi-Structured Inquiry Guide': 'Kinship and Social Factors'

A notable factor related to the importance of kinship observed by the nurses was Chinese migrant cancer patients' dependence on family decision-making for their pain management. The nurses surprisingly noticed that the patients were committed to upholding their families' decisions, even if their families did not inform them of their cancer diagnosis, or did not consult them about their cancer treatment and rejection of recommended pain treatments.

While medical decisions are made in accordance with patient preferences in western cultures (Huang et al., 1999; Xing et al., 2017), in Chinese culture they are usually made via a family consensus process (Huang et al., 1999; Xu et al., 2018). Chinese cancer patients are rarely involved in decision-making for their own treatment or care plan (Xing et al., 2017). However, sometimes the medical decisions made by Chinese families for cancer patients may not always reflect the patient’s preferences (Xing et al., 2017).

Another notable cultural norm that needs to be considered in relation to decision-making is that in Chinese society, parents have long made sacrifices for their adult children. Older Chinese parents with terminal cancer would prefer to sign an advance care directive consenting to forgo active cancer treatment and invasive resuscitation, so that their children do not have to make this difficult decision (Ho et al., 2013b). Similar to other cultures, elderly Chinese cancer patients want to be able to manage their pain in order to enjoy everyday life and to be independent, which is more important than living a longer, less comfortable life (Ho et al., 2013b; Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016).

Chinese cancer patients’ acceptance of their advanced disease and their adult children’s desire to prolong their parents’ life through active treatment(s) may cause distress for the patients and worsen their pain. Managing these conflicting beliefs is an important but complex element of culturally competent care, which is essential to minimise patient and family distress and suffering, and eliminating cultural tensions between the patient, the family, and the health professionals.

Health professionals also need to be cognisant that Chinese cancer patients may not be able to make decisions based on their own wishes when they rely on their family to communicate their diagnosis and care plan with their medical teams, and find that their families have different thoughts about their treatment (Au et al., 2011). In contrast to medical practitioners and families’ good intentions over hiding the bad news from patients, Chinese cancer patients were eager to be informed of their diagnosis and health conditions in order to make plans for the future and to maintain a sense of control over their life (Ho et al., 2013a; Ho et al., 2013b; Mak, 2001). They felt frustrated and angry due to uncertainty on their diagnosis and health conditions with the medical practitioners and their family, and become less interested in their life and treatment, which may worsen their health conditions (Ho et al., 2013a; Mak, 2001).

For Chinese cancer patients, making an informed decision together with their treating doctor and family is critical to securing a sense of autonomy (Ho et al., 2013b). Open communication between health professionals, families, and Chinese cancer patients about the care plan helps minimise patient fear of being a burden to others and any ambiguity about the goals of care (Ho et al., 2013b).

However, balancing the cultural tensions between Chinese migrant cancer patients and families' needs can be challenging. Health professionals need to assess pain care needs and encourage patients to participate in decision-making about their pain treatment. Health professionals are also encouraged to inform families about the importance of involving patients in treatment decision-making and care planning. They need to build a trusting relationship with their patients and advocate that they take control of their own pain care, so they can have a better quality of life.

### Domain of Leininger's 'Semi-Structured Inquiry Guide': 'Language and Communication Factors'

The nurses in this survey also identified that language and communication difficulties affected Chinese migrants' capacity to actively contribute to decision-making about their cancer pain treatment. A recent Australian study found that older Chinese migrant cancer patients with limited English proficiency are more likely to be passive decision-makers who rely on their families and medical physicians to make treatment decision for them (Kwok & Koo, 2017). These Chinese migrant cancer patients were unlikely to question their doctor's professional ability in making a treatment plan for them (Kwok & Koo, 2017). The nurses also reported that their patients, particularly those in the older generation, were unable to discuss their pain treatment needs with others. Their lack of input into decision-making has led to poor pain outcomes, as the pain management plan may not address the patients' cultural and individual needs. Health professionals need to encourage Chinese migrants' to be active partners in their pain management care planning process. Effective communication between health professionals and patients in a culturally sensitive manner is key to empowering them to be more actively involved in their treatment decisions, and thus improve their care outcomes (Kwok & Koo, 2017).

When language was a barrier, the nurses faced the challenge of arranging an interpreter in order to understand the Chinese migrants' cancer pain needs. Previous studies suggest that using professional interpreters during the discussion about diagnosis and prognosis is critical to improving quality of life and relieving pain and anxiety for cancer patients and families with limited English proficiency (Silva et al., 2016). However, the nurses in this survey had concerns about the accessibility and quality of Chinese interpreter services. They suggested that more qualified interpreters with proficiency in Mandarin, Cantonese, and other Chinese dialects are required to optimise care for the increasingly diverse Chinese migrant population now residing in Australia.

### Domain of Leininger's 'Semi-Structured Inquiry Guide' 'Professional and Generic (folk or lay) Care Beliefs and Practices'

The nurses' perceptions of Chinese migrants' beliefs in traditional pathways for cancer pain is related to the domain of *'Professional and Generic (folk lay) Care Beliefs and Practices'.*

The nurses in this study observed that Chinese migrant cancer patients often hid their use of TCM or other alternative therapies from health professionals. This deception was likely because patients did not want to affect their harmonious relationships with their health care team. Traditionally, Chinese people regard the doctor as the authority, not wanting to ask questions or challenge their doctor's judgement on their treatment (Kwok & Koo, 2017). Unless doctors asked or recommended TCM or other alternatives for cancer pain, Chinese migrants were perceived to be reluctant to talk with doctors and other health professionals about their needs and preferences in this area.

This scenario is very similar to the reported barriers around the use of medical cannabis for pain (Crowell, 2016; Ko, Bober, Mindra, & Moreau, 2016). Similar to TCM, physicians are often concerned about the lack of clinical evidence and their knowledge of using medical cannabis in pain control (Crowell, 2016; Ko et al., 2016). However, patients have reported that their physicians' reluctance to prescribe medical cannabis or encourage them to seek alternative pain treatment undermined their relationship and faith in the physician, leaving them feeling unsupported in the decision-making process (Crowell, 2016).

As traditional Chinese therapies are becoming increasingly available through comprehensive cancer centres, health professionals need to increase their awareness and refer patients to these services with confidence. Since 2012, the registration of TCM practitioners has been regulated under the Australian Health Practitioners Registration Agency via the Chinese Medication Registration Board (Australia Traditional-Medicine Society, 2019). There is good control governing acupuncture, prescribing, and dispensing Chinese herbal medicine and other alternative therapies, such as tai chi, Qigong, Tuina, and dietary therapy (Australia Traditional-Medicine Society, 2019). Health professionals are encouraged to initiate conversations with their Chinese migrant cancer patients about their desire to use, or to trial TCM for their pain.

Integrating TCM into the decision-making processes may increase Chinese migrant cancer patients’ compliance with the recommended cancer pain management plan.

The nurses in this survey perceived that Chinese migrant cancer patients largely distrusted western medicine. However, there appears to be a mismatch between the nurses’ perceptions in this study and the perceptions of Chinese migrant cancer patients as reported in other studies. An earlier qualitative study conducted in Australia suggests that Chinese migrant cancer patients trusted western medicine, but they also wanted to use cultural-specific methods such as TCM, tai chi and food therapy to help them restore their health, minimise the side-effect of chemotherapy, and prevent cancer recurrence (Huang et al., 1999).

It is recommended when health professionals are aware that their Chinese migrant cancer patients are using TCM or other alternative therapies for their pain or cancer treatment, they should respect their patients’ choice and ask if the patients have any concerns about western medical treatment. Effective communication is vital in resolving any misunderstandings associated with cultural differences.

### *8.5.2 Cultural decision and action modes*

The culturally congruent pain management strategies suggested by the nurses in this study are linked to three ‘cultural decision and action modes’ of Leininger’s ‘Sunrise Enabler’: ‘Cultural care preservation and/or maintenance’; ‘Cultural care accommodation and/or negotiation’; and ‘Cultural care repatterning and/or restructuring’.

#### Leininger’s mode: ‘Cultural care preservation/and maintenance’

The nurses’ suggested strategies to strengthen their understanding of Chinese cultural beliefs and medicine in relation to pain management’ is related to Leininger’s mode of ‘cultural care preservation/and maintenance’. According to Leininger (Leininger, 2002; Webbe-Alamab & McFarland, 2015), ‘cultural care preservation/and maintenance’ occurs when health interventions and decisions are delivered in a culturally specific way with respect to an individual’s beliefs about care and death. Health professionals need to obtain knowledge about Chinese cultural beliefs on cancer, pain, and pain management, to increase their cultural awareness and to accept that individuals vary in their beliefs. Culturally specific knowledge and awareness are essential to enable nurses and other health professionals to provide culturally congruent pain care to Chinese migrant cancer patients.

Providing culturally congruent cancer pain care to Chinese migrant cancer patients is also consistent with the Code of Conduct of the Nursing and Midwifery Board of Australia (2018). The Board requires nurses to maintain culturally safe and respectful practice at all times. Since the patients and their family are the key persons to determine whether or not the care they received is culturally safe and respectful, nurses must deliver the care with understanding of the person's cultural attributes and beliefs related to their health, death and dying (Nursing and Midwifery Board of Australia, 2018).

Health organisations have a responsibility to provide cross-cultural competence training and resources to support individual nurses' personal development (Ian, Nakamura-Florez, & Lee, 2016). Improving knowledge about culture and awareness of non-English speaking patients' culturally specific needs may promote interaction between the nurses and the patients, and help nurses overcome the difficulties and frustrations they encounter while caring for this population (Ian et al., 2016).

Despite this recommendation, not all nurses in this survey had received training on providing culturally congruent or competent care. Several recent systematic reviews suggest that cultural competency training has been broadly implemented in the health workforce in Australia and other immigrant countries, to enhance health professionals' competences in providing cultural care for diverse population (Jongen, McCalman, & Bainbridge, 2018; McCalman, Jongen, & Bainbridge, 2017) . However, there is a lack of Chinese culturally specific competency training programs in the literature (Jongen et al., 2018; McCalman et al., 2017) or in current practice in Australia (National Centre for Cultural Competence, 2019). As the Chinese migrant population is rapidly increasing in Australia (ABS, 2017), providing regular education to health professionals to improve their understanding about Chinese migrant cancer patients' cultural beliefs and help-seeking behaviours in relation to cancer pain is essential to improve care outcomes for this population.

### Leininger's mode: 'Cultural care accommodation and/or negotiation'

The strategy of integrating culturally congruent care to cancer pain management is associated with the mode of cultural care accommodation and/or negotiation. This cultural care mode means that health professionals should recognise people's culturally specific care needs associated with their cultural beliefs, and encourage people to be actively involved in their care decisions via negotiation (Leininger, 2002; Webbe-Alamab & McFarland, 2015).

Involving multidisciplinary teams, Chinese-speaking health professionals, Chinese communities, and Chinese migrant cancer patients in their own pain care may provide opportunities for nursing and other health professionals to identify culture-related concerns and develop culturally appropriate interventions to meet their needs. The process of shared decision-making may promote mutual interaction and understanding between Chinese cancer patients, doctors and nurses in relation to the patients' cancer symptom (e.g. pain) management needs and enhance their capability for self-care (Lin, Cohen, Livingston, & Botti, 2019).

Effective communication between Chinese cancer patients and their doctors and nurses was key to patients obtaining advice and speaking about their concerns and needs throughout the decision-making process towards better symptom management (Lin, et al., 2019). Utilisation of interpreting services and English−Chinese language tools are suggested as useful means to promote culturally appropriate communication for mutual understanding between Chinese migrant cancer patients and health professionals.

**Leininger's mode: 'Cultural care repatterning and/or restructuring'**

The strategy of culturally appropriate education delivered in Chinese languages to the patients suggested by the nurses in this study is associated with the mode of 'cultural care repatterning and/or restructuring'. This mode recommends that health action should be delivered in a supportive way to assist individuals rearrange and adjust their lifeways and customs to achieve better care outcomes (Leininger, 2002; Webbe-Alamab & McFarland, 2015).

Consistent with reports by cancer patients living in China (Zeng et al., 2019) and other populations (Bender et al., 2008; Luckett et al., 2013), the nurses in this survey observed that Chinese migrant cancer patients perceived that cancer pain was an uncontrollable symptom. Inadequate knowledge about cancer pain and its management can negatively affect the ability to describe and report pain, and to discuss preferences about pharmacological and non-pharmacological pain treatment (Bender et al., 2008). Cultural factors amplify this knowledge gap.

Systematic reviews suggest that patient-based educational interventions (e.g. educational programs or coaching sessions about pain and pain management) can significantly improve cancer patients' knowledge and attitudes to pain and analgesia (Marie, Luckett, Davidson, Lovell, & Lal, 2013; Oldenmenger et al., 2018). Patient-based educational interventions are essential to eliminating cancer pain management knowledge barriers and improving adherence to pain medications across cultural groups (Oldenmenger et al., 2018), which can significantly improve pain management outcomes (Adam, Bond, & Murchie, 2015; Bennett, Bagnall, & José Closs, 2009; Ling, Lui, & So, 2012) and effectively reduce cancer patients' pain intensity (Bennett et al., 2009; Ling et al., 2012; Lovell et al., 2010; Marie et al., 2013).

In addition, another systematic review of Chinese and English literature suggests that nurse-led educational interventions (e.g. pain educational programs via home visits and follow-ups) can also achieve positive changes to cancer outpatients' perspectives on analgesics and pain management, and improve pain outcomes (Zhou et al., 2015). Effective education interventions are the starting point for Chinese cancer patients to be actively involved in their symptom management (Lin et al., 2019).

As nurses are at the frontline of cancer pain management, education, and research (Vallerand, Musto, Polomano, & Reports, 2011), they are ideally positioned to advocate and empower cancer patients to self-manage their pain. They also have a role in engaging patients and their families in patient-centred care, by providing education and support that assesses their educational needs and addresses the barriers preventing optimal pain treatment (Vallerand et al., 2011). Culturally specific and language appropriate educational interventions addressing Chinese migrant cancer patients' pain information needs and barriers would assist them to better cope with their pain and its management.

### *8.5.3 Implementation*

The nurses in this study suggested numerous strategies that they perceived would help promote more culturally congruent pain management for Chinese migrant cancer patients, including:

- adoption of a collaborative approach involving Chinese migrant cancer patients and their families, Chinese-speaking health professionals and Chinese committees (e.g. cancer support groups) for care, informed, and shared health decisions about pain treatment
- promotion of culturally appropriate communication using simple and translated communication tools, and better access to interpreter services
- greater access to Chinese educational resources and pain assessment tools
- delivery of culturally appropriate Chinese-language education in various formats, to eradicate misconceptions around cancer pain, opioids, and other analgesics
- provision of information on interactions between Chinese and western medicine

- involvement of family and interpreters into education
- provision of continual and culturally specific education to strengthen nurses' understanding of Chinese cultural beliefs and medicine, and how this influences Chinese migrant cancer patients' pain management.

## 8.6 Summary

The findings in this chapter suggest that from a nurse perspective, culturally specific patient and nurse education in a variety of formats is essential to promote mutual understanding and resolve cultural battles, thus assisting Chinese migrant cancer patients achieve optimal pain management.

The next chapter summarises the influences of 'cultural and social structural factors' on Chinese migrants' cancer pain management from both patient and nurse perspectives. Strategies are made to promote culturally congruent pain management for this population.

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# Chapter 9 Conclusion

## 9.1 Introduction

The findings reported in Chapters 5−8 suggest that a range of ‘cultural and social structural factors’ influenced Chinese migrants’ experiences, beliefs and use of pharmacological, TCM and non-pharmacological strategies to manage their cancer pain. These chapters provided deep insights into the pain management challenges this population experiencing.

The integration of these mixed methods findings is guided by Leininger’s ‘Sunrise Enabler’ and ‘Semi-Structured Inquiry Guide' and other key concepts of Leininger’s ‘Culture Care Theory’, and presented in the Joint Display Tables.

Emerging from the meta-inferences of the data integration are key considerations for providing culturally congruent cancer pain management. A series of evidence-based strategies to help health professionals better understand Chinese migrants’ cancer pain management needs are provided. The strength and limitations of this doctoral project are also discussed in this final chapter.

## 9.2 What are the cancer pain management experiences and needs of Chinese migrants living in Australia?

This doctoral project found that Chinese migrant cancer patients living in Australia experience moderate to severe levels of chronic cancer pain, which are very similar to the experiences of other cancer patients living in China (Xu, Luckett, Wang, Lovell, & Phillips, 2018), and in other parts of the world (van den Beuken-van Everdingen et al., 2007; van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). Chinese migrants, like their global counterparts, experience poorly controlled chronic cancer pain that adversely affects their physical, psychological and social wellbeing (Brant, 2014; Liang et al., 2015a; Ruseel & Tandon, 2011; Yates et al., 2002).

Under-treated cancer pain is a global problem and contributes to poor psychological and physical function, and impacts on the person’s mobility, daily activities, and sleep hygiene (Jensen et al., 2010; Lin et al., 2018). The phenomena of unrelieved cancer pain is experienced by Chinese (Lin et al., 2018) and non-Chinese cancer survivors (Jensen et al., 2010). The Chinese migrants in this doctoral project reported how persistent cancer pain impacted on their ability to work, contributed to loss of income and increased their dependence on their family, all of which contributed to their loss of self-esteem. For Chinese migrants, their level of social and psychological distress escalated, because they perceived that their family members and treating team barely understood their cancer pain or their pain-related fears, and felt that no one was able to assist them to stop their pain.

Chinese migrants' feeling of helplessness was aggravated when they: 1) received limited cancer pain management education and information; 2) experienced financial hardship because of their cancer and treatment and were unable to afford TCM and other pharmacological pain treatment; and 3) were unable to access physiotherapy and psycho-oncological care, cancer pain services and community-based cancer pain self-management support.

As previously discussed in Chapters 1 and 3, according to Leininger's (Leininger, 2002), 'Worldview' (i.e. how people see the things around them) and 'Ethnohistory' (i.e. where people originated from and grew up, and the primary language spoken at home) has an impact on people' care experiences and needs, particularly when the environmental context changes significantly following a move to a new country and learning to deal with a new health care system. Similar to previous qualitative studies conducted in Australia (Butow et al., 2010; Lim et al., 2019), Chinese migrants in this doctoral project perceived that there was very limited culturally specific support to help Chinese cancer patients better understand the Australian health care system.

This sense of vulnerability was exacerbated when Chinese migrant cancer patients had poorly controlled pain and unmet pain management needs, which they attributed to cultural misunderstandings and marginalisation. They struggled to integrate themselves in Australian society and navigate with the Australian health care system. A lack of social interaction may amplify the negative consequence of pain on people's quality of life (Mackey, Karayannis, Baumann, Melloh, & Sturgeon, 2018).

Chinese migrants' strong social identity as 'Chinese' and speaking a non-English language and lack of continual support after discharge drove them to seek help from Chinese cancer support groups, where they found a sense of belonging and cultural identity. Unfortunately, most of these peer support groups are based in Sydney and therefore, not easily accessible for migrants living in regional communities.

Chinese migrants living with cancer pain described feelings of rejection, especially when their concerns about pain were not responded to by health professionals or their cancer pain was not well managed. These situations resulted in dissatisfaction with their cancer pain management. This dissatisfactory eventually can lead to a loss of trust in health professionals, and poor engagement with their cancer care (Huang, Butow, Meiser, & Goldstein, 1999). Feeling unsupported by health professionals added to Chinese migrants' feelings of helpfulness and the frustration of having cancer pain.

When assessing Chinese migrants' cancer pain, health professionals need to understand both their pain experiences, and the negative consequences that unrelieved pain has on their holistic wellbeing, as well as how cultural beliefs shape their pain experience.

Providing an opportunity for cancer patients to express their concerns and needs regarding cancer pain and appreciating an individual's pain experiences may help health professionals identify pain and pain-related problems for better pain management and end-of-life care (Dunham, Allmark, & Collins, 2017).

## 9.3 What are the experiences and perceptions of Australian nurses in managing Chinese migrant patients' cancer pain?

The finding of this doctoral project suggests that Australian cancer and palliative care nurses felt inadequately prepared to manage Chinese migrant cancer patients' pain because of their lack of knowledge about Chinese culture and how this culture shapes Chinese migrants' pain experience and self-management practices. While many of the needs of Chinese migrants with cancer pain were almost identical to the needs of people from other cultures, the nurses noted that differences were largely due to Chinese migrant cancer patients' strong cultural beliefs and practices in relation to their cancer pain. Consequently, nurses with limited culturally congruent competencies found it challenge to manage Chinese migrants' cancer pain.

These nurses reported that Chinese migrants with cancer pain tended to under-report or endure the pain, delay seeking help for their cancer pain or reject opioids or other analgesics. The nurses also found that compared to non-Chinese cancer patients, these patients were often very stoic and did not want to bother others with their pain.

Along with the evidence from Chinese and other cancer patients (Jacobsen, Møldrup, Christrup, & Sjøgren, 2009; Xu et al., 2018), this doctoral project suggests that the 'cultural and social structural factors' underpinning Chinese migrants' cancer pain management may differ and require culturally appropriate interventions, such as a cultural campaign to raise nurses and other health professionals' awareness of Chinese migrants' cultural beliefs in relation to their cancer pain and treatment. Understanding the 'cultural and social structural factors' that hinder or enable Chinese migrants living with cancer pain to achieve optimal cancer pain management will assist nurses to provide culturally congruent pain care to Chinese migrants who present with unrelieved cancer pain.

## 9.4 What are the ‘cultural and social structural factors’ influencing Chinese migrants’ cancer pain management experience and needs?

Five domains of ‘Leininger’s Semi-Structured Inquiry Guide Enabler’ − ‘Cultural Values, Beliefs, and Lifeways’, ‘Religious/Spiritual/Philosophical Factors’, ‘Kinship and Social Factors’, ‘Language and Communication Factors’ and ‘Professional and Generic (folk lay) Care Beliefs and Practices’ − influence Chinese migrants’ ‘care expressions, patterns and practices’ and nurses confidence to manage this population’s pain management needs (refer Appendix K − Joint Display Table One). While many of the nurse’s perceptions of Chinese migrants’ cancer pain experiences and needs were congruent with those described by these patients, there were some distinct differences, as summarised in the following sections.

### *9.4.1 ‘Religious/Spiritual/ Philosophical Factors’ – philosophical health beliefs dominate Chinese migrants’ pain expression, patterns and practice*

The Chinese migrants living with cancer pain in this study held strong philosophical health beliefs that ‘the body can self-heal’ and ‘cancer pain is self-provoked’. Due to the influences of their philosophical health beliefs, they preferred to use a healthy regimen that was congruent with their culture to manage their pain.

Chinese migrants in the previous study attributed their cancer to their poor lifestyle choices (e.g. poor diet and smoking) or an imbalance of Yin and Yang (Huang et al., 1999). In this doctoral project, it was evident that Chinese migrants living with cancer pain were very committed to promoting their body’s self-healing and controlling their pain themselves. This behaviours reflects Chinese people’s cultural commitment to using natural and less harmful ways of managing their pain as a way of maintaining the Yin and Yang balance and strengthening their body (Chen & Yan, 2010).

Chinese migrants’ acceptance of their cancer pain is also most likely associated with their beliefs that being optimistic, accepting and having a strong desire to survive helps people to overcome the tough cancer journey that lies ahead and to achieve better outcomes (Huang et al., 1999). This doctoral project found that Chinese migrants’ eagerness to self-manage their pain often lead them to accepting, enduring, and normalising their pain during a pain assessment.

The lower ‘religious fatalism’ S-BQT scores of Chinese migrants living with cancer pain suggest that religious beliefs are not informing this population’s cancer pain management practices or preferences. This finding is in stark contrast to nurses’ perspectives that Chinese migrant cancer patients’ religious practice about removing all medications from their body prior to death was the main driver for this population not using analgesics and other pain treatments at the end of life. Whereas this doctoral project found that Chinese migrants with cancer pain were very willing to take opioids at the end of their life to avoid severe pain and extend their life. This disparity in views has important implications for clinical practice, and reinforces the importance of having an individualised pain management plan that is continually reassessed and amended, especially as the person deteriorates and requires end-of-life care. This finding also speaks to the importance of not assuming that just because a Chinese migrant with cancer pain has declined analgesia earlier in their disease trajectory, they will maintain this approach as they near the end of their life.

### *9.4.2 ‘Cultural Value, Beliefs and Lifeways’ – the main barrier for Chinese migrants to express their pain and receive pharmacological pain management*

The project findings confirmed that from both patient and nurse perspectives, Chinese cultural beliefs about cancer, pain and death influenced the persons’ pain expression, care patterns and practice related to pharmacological pain management. This finding is consistent with the findings from other study that Chinese migrants’ cultural values about cancer care are not changed or diluted by their move to Australia (Huang et al., 1999).

#### Cultural beliefs underlying Chinese migrants’ strong resistance to opioids and other analgesics

Understanding Chinese migrants’ extreme resistance to opioids and other analgesics is complex and quite nuanced. While much of this reluctance is derived by their perceptions about cancer pain being an inevitable part of cancer and its treatment, it is also shaped by ‘culture-related negative medication beliefs’ and ‘western biomedical model-related opioid fears’. The cultural beliefs and the opioid fears contribute to people’s delays to the commencement of opioids and/or poor adherence to a recommended pain management regimen, which it can be problematic if their cancer treatment continues for an extended period of time.

Chinese migrants' belief that cancer pain being an inevitable part of cancer and its treatment is probably the one that cancer and palliative care nurses involved in this doctoral project best understood, and was the one to which the nurses most frequently attributed to their Chinese patient's reluctance to use analgesics and/or opioids. Addressing Chinese migrants' unrelieved cancer pain in this scenario will be best achieved through the use of non-pharmacological pain management approaches, as they prefer to use a healthy way (e.g. exercise) to manage their pain.

Similar to cancer patients living in China (Xu et al., 2018) and in other high income counties (Flemming, 2010), people with cancer also often reject the use of opioids because of their  fears about addiction, side-effects and dependency. Opioid fears are known to be a major obstacle to achieving optimal cancer pain management (Flemming, 2010; Mackey et al., 2018; Xu et al., 2018). Chinese people's 'negative effect beliefs' about opioids doing harm to a person's body has been widely reported in both the Chinese and English peer-reviewed literature (Lai et al., 2004; Lai et al., 2002; Liang et al., 2013a; Liang et al., 2013b; Liang et al., 2015b; Liang, Yates, Edwards, & Tsay, 2008a, 2008b, 2012),

In this doctoral project, Chinese migrants' resistance to using opioids and other analgesics is also linked to their 'culture-related negative medication beliefs'. They framed all medications, including anti-cancer medications, opioids and other analgesics as 'poisons' that have the potential to damage their vital organs and worsen their health conditions, especially during cancer treatment. As a result of these strong cultural beliefs, Chinese migrants' will often reject opioids and other weak analgesics, especially when they are receiving cancer treatment.

The opioid-related fears exist in many populations and have been well documented (Flemming, 2010; OPEN Minds, 2005; Teoh et al., 2007), as have the safety concerns associated with adverse opioid events and side-effects of using opioids for pain treatment (Jacobsen et al., 2009; Kalso, Edwards, Moore, & McQuay, 2004; Manchikanti, Manchikanti, Kaye, Kaye, & Hirsch, 2018). While these fears are well justified, the rationale underpinning Chinese migrant's reluctance to use analgesics is driven by complex and deeply held cultural beliefs. This is different from cancer patients from non-Chinese cultures in which side-effects of opioids (e.g. addiction and tolerance) and inefficient pain treatment are their main concerns (Flemming, 2010). For western cancer patients, the side-effects of opioids impacting the enjoyment of their life and their sense of helplessness associated with ineffective pain treatment lead to their rejection to opioids  (Hackett, Godfrey, & Bennett, 2016).

### Conflicting cultural views underpinning the complex patterns and practices about the use of opioids at the end of life

This doctoral project also found that nurses and Chinese migrants had conflicting perceptions about Chinese migrant cancer patients' pain management practice towards the end of their life.

The nurses perceived that Chinese migrant cancer patients often rejected opioids at the end of life because of their fear that opioids may cause immediate death and their persistence with active treatment instead of palliation. They suggested that family members were the key decision-makers, who filter or withhold information from the Chinese migrant cancer patient. This behaviour reflects a strong Chinese cultural belief that psychological factors affect the patients' ability to fight cancer. Non-disclosure of a poor prognosis to the patient is therefore preferred to enable the patients' hope to be maintained (Mak, 2001; Xing et al., 2017). This approach is adopted even though the patient is often eager to know their cancer diagnosis and treatment (Huang et al., 1999), and their disease progress and end-of-life care plan (Ho et al., 2013; Mak, 2001). Therefore, as with the concerns raised by the nurses in this doctoral project, it is difficult to determine if their decision to reject opioids or other analgesics is truly the Chinese migrant cancer patients' preference or that of the families.

On the other hand, as previously discussed, the Chinese migrants in this doctoral project expressed strong willingness to take opioids to extend their life at the end stage of cancer, because they deeply feared having severe cancer pain as they heard from others.

Given the rapid growth in the number of Chinese migrants living in Australia (ABS, 2017), nurses need to better understand these nuanced cultural beliefs ,so they can reframe the actions of the family from one of being 'interfering' and 'controlling' to respecting that these actions are often grounded in an adherence to traditional cultural practices (Gregory, Christina, & David, 2014). Failure to understand and accommodate these cultural beliefs has the potential to contribute to patients and families' dissatisfaction with the pain care provided and nurses' feeling frustrated and/or disengaging from the situation. Nurses and other health professionals need to be aware of this diversity and promote shared decision-making between Chinese migrant cancer patients, their families and health professionals, to ensure that all cancer pain care meets the individual's cultural needs at the end of life.

### ‘Cultural Values, Beliefs and Lifeways’ underpinning Chinese migrants’ complexity of pain reporting and help-seeking behaviours

This doctoral project found that there is strong cultural expectation that Chinese people should endure their pain and that the ‘expression of pain is unacceptable’, as it is unacceptable to bother others with their pain or other personal difficulties. This cultural belief reflects Chinese migrants’ cultural values about the importance of maintaining harmonious relationships with others (Dayer-Berenson, 2014; Tjuin et al., 2007). Chinese cancer patients’ ‘desire to be good’ and ‘pain endurance beliefs’ are a major barriers to reporting and seeking help for their cancer pain (Xu et al., 2018).

However, as identified by this doctoral project, even though Chinese migrant cancer patients rarely complain about their pain and sometimes even deny its existence, this does not mean that they are unwilling to report their pain if asked in a culturally competent way. This finding contradicts the perceptions of the nurses who perceived that Chinese migrant cancer patients are unwilling to report their pain.

Similar to other cancer patients from western cultures (Hackett et al., 2016) or living in China (Xu et al., 2018), Chinese migrants’ beliefs about new or increasing cancer pain are thought to be linked with metastatic spread or cancer recurrence. This belief may worse Chinese migrant cancer patients’ emotional and psychological distress and affect their psychological wellbeing. Importantly, it is also an additional cultural driver for Chinese migrant cancer patients not taking opioids, because they believe taking analgesia may conceal signs of any future cancer reoccurrence and cause a delay in them receiving cancer treatment to save their life. While for Chinese people this belief may be cultural (Xu et al., 2018), the fear of pain being a signal of disease progression prevents many other cancer patients from discussing their ‘new’ pain with health professionals (Hackett et al., 2016), and can lead to patients denying the existence of their cancer pain (Dunham et al., 2017).

Notably, although Chinese migrants may put up with cancer pain without reporting it during a pain assessment, their eagerness to survive the cancer may drive them to report their pain to oncologists or other physicians during a clinic visit, when they would like to find out about the cause of cancer pain. Understanding these cultural contradictions will help health professionals to comprehend the complexity and challenges of managing Chinese migrants’ cancer pain symptoms within the framework of a much-nuanced cultural belief system.

### *9.4.3 'Professional and Generic (folk or lay) Care Beliefs and Practices' – barrier and enablers for Chinese migrants to use non-pharmacological approaches for their cancer pain*

The findings of this doctoral project suggest that 'Professional and Generic (folk or lay) Care Beliefs and Practices' shape Chinese migrants' care patterns and practices in relation to the use of non-pharmacological management, TCM and other complementary approaches to manage their pain. Chinese migrant cancer patients want to integrate TCM and other complementary approaches into their cancer pain management plan, as they believe it will assist their body to recuperate from the side-effects of cancer treatment and restore their physical functions. Despite these positive beliefs, the Chinese migrants were often hesitant to see local TCM practitioners or use Chinese herbal medicines because of their concerns about the qualification of local TCM practitioners, the safety and quality of Chinese herbal medicines, and how western medicine and TCM would interact. While most Chinese migrants prefer to use TCM for cancer pain, many would discontinue seeing TCM practitioners or using TCM for cancer pain once their anti-cancer treatment commenced.

Chinese migrants also highly valued regular exercise and movement. These were the most valued non-pharmacological methods that were perceived to relieve their cancer pain and improve overall wellbeing. They were also eager to access physiotherapy services, and receive exercise training and guidance about other complementary therapies to help restore their physical functioning and reduce their pain. They also perceived that psychosocial support was an important element of cancer pain treatment. They wanted access to psycho-oncological services to help them relieve their psychological distress associated with their cancer diagnosis and cancer pain.

Despite Chinese migrants wanting to use more TCM and non-pharmacological approaches to manage their pain, nurses in this doctoral project largely misunderstood the reasons for using these traditional approaches. They perceived that this population often only trust TCM and would hide their use of TCM and other alternative treatment approaches from their health care providers. However, as outlined above, these nurse perceptions are not necessarily aligned with Chinese migrants' cultural desire to integrate TCM in their overall pain management, but not at the expense of adversely impacting their cancer treatment.

Nurses and other health professionals also need to have greater awareness of Chinese migrants' concerns and needs in relation to their use of TCM, access to physiotherapy and psycho-oncology services. Given Chinese migrant cancer patients' preference to use culturally specific treatment to assist with their recovery from cancer treatment, they would benefit from an open conversation with their treating oncologists about how to effectively and safely integrate western medicine and TCM (Huang et al., 1999). While Chinese migrants' want to be referred by their treating oncologists to a qualified TCM practitioner for consultation about their concerns about Chinese herbal medicines, this is more challenging in the Australian health care system, given its emphasis on evidence-based practice and agreed referral pathways. However, cancer care professionals are ideally placed to refer this patient population to physiotherapists, psycho-oncologists and social workers, as required.

### *9.4.4 'Economic Factors' and 'Political and Legal Factors' impede Chinese migrants' access to traditional Chinese medicine and pharmacological pain treatment*

Most Chinese migrants in this doctoral project spoke of their financial difficulties as a result of living with cancer and having unrelieved pain. Many could not afford TCM or the prescribed pharmacological pain treatment even though they had access to universal health insurance (Medicare) or private health insurance. Managing their pain was costly because many of the pain treatments were ineffective and prolonged, and seeing a TCM practitioners and using TCM methods (e.g. acupuncture and massage) was not covered by Medicare. Many were not eligible for Centrelink financial assistance for a range of reasons. Prohibitive costs lead many Chinese migrants to discontinue using TCM and/or their prescribed pain medication.

### *9.4.5 'Kinship and Social Factors' – essential enablers for Chinese migrants to cope and manage their pain at home*

As previously mentioned, the perspectives of Chinese migrants living with cancer pain and the nurse perspectives reported in this doctoral project about family members' roles in relation to Chinese migrants' cancer pain treatment were quite contradictory. In Chinese culture, family is very important and they help Chinese migrants to cope with and manage their pain at home. Families are at the forefront of providing daily care, financial and emotional support, and assisting with communication between health professionals. The important role of family members being the liaison between health professionals and the cancer patient has been reported in other studies. These studies describe how in in Chinese culture, family members are the core decision-makers about the cancer patients' care and their pain treatment (Huang et al., 1999; Xu et al., 2018), The nurses in this doctoral project perceived that sometimes this kind of family involvement in decision-making interferes with Chinese migrant cancer patients' pain management regimen. Primarily, families are concerned about the side-effects and safety of opioids and other analgesics, which also shapes their negative attitudes towards these medications. Family attitudes can potentially lead to Chinese migrant cancer patients rejecting the use of opioids and reluctance to participate in pain management decisions. This behaviour is consistent with the pain management practices of cancer patients living in China (Xu et al., 2018). While the nurses perceived that the family members often withheld information about cancer diagnosis and prognosis, in contrast this doctoral project found that Chinese migrants were aware of their cancer diagnosis and wanted to receive information to enable them to better self-manage their cancer pain. This mismatch in perceptions and needs highlights the importance of providing culturally congruent pain care to people from a CALD background.

For Chinese migrants, sharing experiences, feelings and problems with peers living with cancer is not only valuable, but it also provides an opportunity for social interaction and helps restore social functioning. Chinese cancer support groups played a crucial role for the Chinese migrants to cope and deal with their pain at home. These types of groups, in addition to providing peer support, can improve the patient experience and address unmet needs by providing educational resources, and organising group activities and peer support programs.

### *9.4.6 'Language and Communication Factors' influence Chinese migrants' pain reporting and decision-making*

Both the Chinese migrants with cancer pain and the nurses in this doctoral project perceived that language, especially medical jargon, was a big barrier for Chinese migrant cancer patients to clearly express and understand their pain experience. As a result, many Chinese migrants did not feel confident in discussing their cancer pain experiences with their oncologists and other health professionals, and stopped expressing their pain concerns during medical consultations.

The nurses correctly perceived this 'silence' as Chinese migrant cancer patients' struggling to understand what was being said, and requiring an interpreter in order to understand what doctors and/or nurse were explaining. However, concerns about the quality of interpreter services was reported by both Chinese migrants with cancer pain and the nurses. Involving both Chinese−English-speaking family members and interpreters in medical consultations may promote mutual understanding between Chinese migrant cancer patients and health professionals, and enable the patients to make informed decisions for their cancer pain treatment.

As language posed a big barrier for informed decision-making, from the Chinese migrants' view, involving Chinese-speaking health professionals when it is possible would be helpful to promote effective communication for better cancer pain management. Bilingual education resources are required to enable Chinese migrants to clearly express their concerns and effectively communicate with health professionals for their cancer pain.

### *9.4.7 'General and Specific Care Factors' – the main barriers for Chinese migrants to seek help and take actions to effectively manage their pain at home*

While 'General and Specific Care Factors' were not identified in the nurse survey, the findings from the patient focus groups suggested that 'negative attitudes of physicians and nurses towards cancer pain and its management', 'difficulties in navigating with health care services for cancer pain', and 'lack of continuing support after discharge from hospital were the main barriers preventing Chinese migrants from seeking help and effectively managing their pain at home.

Chinese migrants are keen to consult with their oncologists and other physicians about how best to manage their cancer pain. However, they are discouraged from raising these concerns when their cancer treating physicians express any negativity about finding a solution for their cancer pain or suggest that pain is a normal part of cancer treatment.

The negative attitudes to cancer pain and its treatment by physicians and other health professionals are often associated with their inadequate knowledge about cancer pain and skills in pain assessment and pain treatment (Ger, Ho, & Wang, 2000; Kasasbeh, McCabe, & Payne, 2017; Liu, Luo, & Liu, 2007). They may therefore be over concerned about the safety of opioids (Ger et al., 2000; Liao, Hao, Guo, Reyes-Gibby, & Guo; Manchikanti et al., 2018; OPEN Minds, 2005) and exhibit a lack of confidence to assess and manage pain (Kasasbeh et al., 2017; Liao et al., 2013; Luckett et al., 2013). Some health professionals expected that the patients would have pain during the cancer treatment and hence did not think that they needed to treat the patients' pain (Kasasbeh, et al., 2017).

Chinese migrants were disappointed that physicians and nurses in hospitals and GPs failed to assess their cancer pain and treat their pain effectively. Ineffective cancer pain treatment leads to rejection or poor adherence to opioids and other analgesics, and discontinued pain treatment after discharge.

The Chinese migrants' unfamiliarity with the Australian health care system made it difficult for them to access the supports they needed to manage their pain at home. This finding is contradictory to the results of the 2018 National Survey in Australia with 5,790 adults, which suggest that overall 86% of Australians find it easy to navigate the health care system. Compared to younger people, older people were more likely to strongly agree that they had social support for health (ABS, 2019). And surprisingly, the survey shows that the older generation finds it easier to navigate the health care system than the younger generation (Australian Bureau of Statistics, 2019). However, this survey did not explicitly seek the views of people from CALD backgrounds.

The findings of this doctoral project suggest that very few Chinese migrants received the necessary follow-up after discharge, which made it difficult for them to effectively manage their cancer pain at home. Many ceased using their analgesics on discharge, or returned to the emergency department for management of their unrelieved pain. There is a need to ensure that all patients receive appropriate follow-up on discharge to ensure they are adequately supported to manage their cancer pain at home.

### *9.4.8 'Educational Factors' and 'Technological Factors' – inadequate knowledge and skills of cancer pain management impede Chinese migrants' capability to self-manage their pain at home*

Chinese migrants perceived that they lacked the necessary skills to self-manage their cancer pain at home and were unable to make informed decisions, because of the lack of cancer pain management education and information prior to discharge. This lack of adequate education contributed to them rejecting opioids or having poor adherence to their recommended pain management regimen on discharge from hospital. They were eager to be provided with pain management education and information, to effectively self-manage their cancer pain at home. Cancer and primary care health professionals need to be aware of, and promote the use of, various bilingual educational resources available for Chinese migrants so that they can achieve optimal care outcomes.

Despite the proliferation of web-based resources, health professionals need to be cognisant that safety concerns and difficulty in searching, reading and making judgements about the quality of electronic information online or via apps on smart phones limits older Chinese people’s access to relevant bilingual educational resources. While this need may be amplified in people whose first language is not English, it is also a problem for other older patients living with chronic pain who lack of access to computer or skills to makes an informed decision about the quality and reliability of the online content (Corcoran, Haigh, Seabrook, & Schug, 2010). Being referred to a reliable government website would do much to relieve a cancer patient’s anxiety of having to identify the best source of information to enable them to manage their cancer pain. In addition to being guided to the best source of online resources, Chinese migrants living with cancer pain would also benefit from access to face-to-face and online real-time consultation provided by their cancer treatment centre, and face-to-face bilingual cancer pain self-management educational workshops.

## 9.5 What strategies are optimal to promote culturally congruent cancer pain management for Chinese migrants?

The meta-inferences via collectively integrating the main findings of this doctoral project identified a number of strategies that will help to facilitate the provision of culturally congruent pain management to Chinese migrants living with cancer pain (Refer to Appendix L – Joint Display Table Two).

These strategies have been framed in accordance with Leininger’s ‘Culture Care Theory’, particular the three ‘Cultural Decisions and Action Modes’ of Leininger’s ‘Sunrise Enabler’, namely: ‘Cultural Care Preservation and/or Maintenance’; ‘Cultural Care Accommodation and/or Negotiation’; and ‘Cultural Care Repatterning and/or Restructuring’, as described in the following sections.

A culturally congruent pain management conceptual framework grounded in Leininger’s ‘Culture Care Theory’ is developed that demonstrates the interrelationship between ‘cultural and social structural factors’ and the three action codes that reflect and/or address the cultural care needs of Chinese migrants in relation to their cancer pain (refer to Figure 9.1).

### *9.5.1 ‘Cultural Care Preservation and/or Maintenance’*

The ‘cultural care preservation and/or maintenance’ strategies that will contribute to improving pain management for Chinese migrants living with cancer pain include:

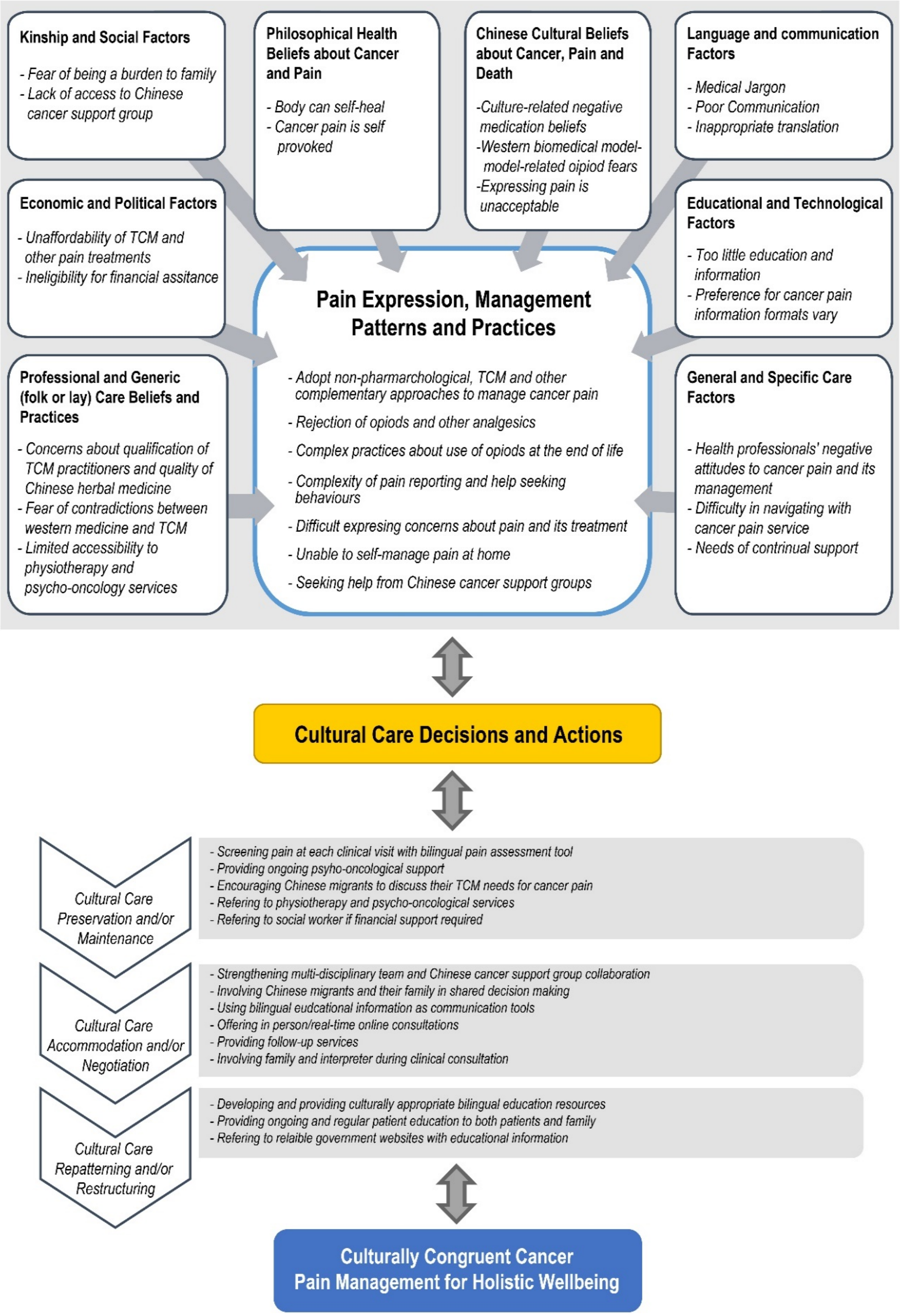

*Figure 9.1 Conceptual framework of factors and strategies to provide culturally congruent pain care for Chinese migrants living with cancer pain, adapted from McFarland and Wehbe-Alamah (2015).*

- Providing culturally congruent cancer pain management to Chinese migrants that acknowledges and respects their philosophical health beliefs about the importance of adopting a regimen that both effectively manages their pain and promotes the body's self-healing.
- Offering non-pharmacological interventions tailored to Chinese migrants' preferences and needs, including individualised exercise plans, physiotherapy, psycho-oncological care, TCM, and other complementary approaches, to help them effectively self-manage their cancer pain, especially while they are receiving active cancer treatments.
- Developing bilingual pain screening and assessment tools to ensure that all Chinese migrants' cancer pain is screened and assessed, if required, at each clinic visit, and providing opportunities for them to express any pain concerns and pain management preferences.
- Offering access to a social worker to assess Chinese migrants' financial concerns and direct them to relevant financial support services if they are struggling to pay for recommended cancer pain treatment or TCM.
- Encouraging Chinese migrants to discuss their needs for TCM with their cancer treatment team.
- Acknowledging the need to constantly reassess Chinese migrants' preferences about using opioids, as this preference is likely to change as their cancer progresses and enters into the end of life process.
- Ensuring that nurses and other health professionals are provided with culturally appropriate continuing professional development educational opportunities that strengthen their understanding and confidence in providing culturally congruent pain care to Chinese migrants and their family members.
- Providing ongoing education to all cancer and palliative care health professionals that enhances their knowledge and skills in pain assessment and managing Chinese migrants' cancer pain in accordance with their cultural beliefs.

### *9.5.2 'Cultural Care Accommodation and/or Negotiation'*

The 'cultural care accommodation and/or negotiation' strategies that will contribute to improving pain management for Chinese migrants living with cancer pain include:

- Adopting a collaborative approach involving Chinese migrants and their families, including, if available, Chinese-speaking cancer care coordinators, oncologists and/or other physicians, and Chinese cancer care support groups, for shared decision -making.

- Encouraging Chinese migrants living with cancer pain to take an active role in developing a cancer pain management plan with the goal of restoring their physical, psychological and social functions.
- Arranging discharge follow-up service to support Chinese migrants living with cancer pain, to increase their confidence and capability of navigating with the health care system and managing their own pain at home after discharge.
- Providing in-person or real-time online clinical consultation services via cancer care centres to help Chinese migrants resolve the problems associated with cancer treatment and pain at home.
- Providing Chinese−English educational tools, using plain language, to promote better communication between Chinese migrants and clinicians.
- Increasing access to trained cancer care interpreters and involving both the interpreter and the family member in the clinic consultation to increase mutual understanding between Chinese migrants and clinicians concerning agreed pain management plans.

### *9.5.3 ‘Cultural Care Repatterning and/or Restructuring’*

The ‘cultural care repatterning and/or restructuring’ strategies that will contribute to improving pain management for Chinese migrants living with cancer pain include:

- Developing and increasing accessibility to bilingual educational resources to enable Chinese migrants to take more active roles and effectively assess and manage their pain at home.
- Providing regular and ongoing patient education addressing Chinese migrants’ education and information needs about cancer pain and its management and addressing their pain and analgesic-related issues, to enhance their capacity of self-managing their own cancer pain and adherence to their prescribed pain treatment regimen.
- Referring to a reliable government website for educational information about cancer pain and pain management needs.
- Addressing the importance of pain reporting and the benefit of pain relief during patient education.

- Involving Chinese−English speaking family members and interpreters in Chinese migrants’ pain management education to promote better pain management education outcomes.

## 9.6 Project strengths and limitations

This doctoral project has many strengths, and a number of limitations, as outlined below.

### *9.6.1 Strengths*

This doctoral project is underpinned by a well-established cultural care framework of Leininger’s ‘Culture Care Theory’, and the Australian Cancer Pain Management Guidelines for Adults. It was overseen by a multidisciplinary clinical academic supervision team with extensive cancer pain management expertise who provided comprehensive viewpoints in developing and interpreting the data from nursing, sociology and medical perspectives. The doctoral student is a Chinese cancer nurse who has worked extensively in Chinese and Australian health care systems.

The doctoral project included the involvement of Chinese migrants with cancer pain who had lived in Australia for varying lengths of time. They had been treated in a number of different health care services across Sydney, NSW. The Chinese migrant focus groups were moderated by two bilingual Chinese−English speaking research assistants, one fluent in Mandarin and Cantonese, and the other in Mandarin. This doctoral project also included cancer and palliative care nurses from across Australia working in a variety of health care settings, and accessed the existing evidence published in Chinese and English literature. Together, these cultural considerations are considerable strengths of this doctoral project.

### *9.6.2 Limitations*

There were some methodological limitations in this doctoral project. Convenience sampling was used in the nurse survey, and these nurses may not have been able to distinguish the difference between the Chinese migrant cancer patients born in China or those born in Australia or other countries. It was likely that the nurses’ views about cultural influences on these patients were built on their perspectives about Chinese migrants from other countries as well.

Purposive sampling was used in the focus group, which from an ethical perspective meant that those patients with poor health conditions were not able to participate in the studies. Most of the participants in the focus groups were recruited via three Chinese cancer support groups. It is therefore likely that the participants have been proactive and tended to take an active role in their own cancer pain management. The participants in this doctoral project may not reflect the situations of the patients who did not attend the support groups.

All participants in the focus groups were recruited from Sydney, NSW. The findings may not represent the needs of Chinese migrants living in regional or remote areas.

## 9.7 Conclusion

Guided by Leininger's 'Culture Care Theory' and the Australian Guidelines for Cancer Pain Management in Adults and employed a convergent mixed-methods research design, this doctoral project identified a series of barriers and enablers that influenced Chinese migrants' use of pharmacological, non-pharmacological, TCM and other complementary approaches to manage their cancer pain. Uncontrolled cancer pain remains a serious issue for Chinese migrants living with cancer, as seen in other populations, negatively affecting their physical, psychological, and social wellbeing.

This doctoral project has highlighted the challenges Australian cancer and palliative nurses face when caring for Chinese migrants living with cancer pain. Culturally appropriate strategies emerging from this doctoral project will help to inform nurses and other health professionals, and to increase their cultural competence in providing culturally congruent pain care to this population.

### *9.7.1 Implications for clinical practice*

Chinese migrants living with cancer pain require multidisciplinary approaches, involvement of Chinese-speaking clinicians, patients and the family members, and assistance from Chinese cancer support groups. Multiple-dimensional and culturally appropriate interventions addressing Chinese migrants' cancer pain management needs and experiences are essential to promote culturally-congruent cancer pain management for holistic wellbeing.

The meta-interferences revealed that misunderstandings about Chinese migrants' pain expression and pain management practice exists. The misunderstandings may lead to frustration in patients, family members, and health professionals, which adversely impacts Chinese migrants' ability to access culturally competent pain care, particularly at the end stage of cancer.

Ongoing cultural-specific cancer pain education addressing Chinese migrants' educational and information needs and health professionals' learning needs are central to promoting and optimising cancer pain management for this population.

### *9.7.2 Implications for future research*

Strategies developed in this doctoral project need to be evaluated in the Chinese migrant population with a large sample size. Educational resources may be translated in a bilingual format and evaluated in this population to see if there is a need to add any culturally specific content. Exploring the needs of family members who are looking after Chinese migrants living with cancer pain is also required.

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## Appendix A: Publication

Study 1 reported in Chapter 2 is published in *Palliative and Supportive Care*:

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*Palliative and Supportive Care*

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**Review Article**

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# Cancer pain management needs and perspectives of patients from Chinese backgrounds: a systematic review of the Chinese and English literature

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## Abstract

**Objective.** More than half of all cancer patients experience unrelieved pain. Culture can significantly affect patients' cancer pain-related beliefs and behaviors. Little is known about cultural impact on Chinese cancer patients' pain management. The objective of this review was to describe pain management experiences of cancer patients from Chinese backgrounds and to identify barriers affecting their pain management.

**Method.** A systematic review was conducted adhering to Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. Studies were included if they reported pain management experiences of adult cancer patients from Chinese backgrounds. Five databases were searched for peer-reviewed articles published in English or Chinese journals between1990 and 2015. The quality of included studies was assessed using Joanna Briggs Institution's appraisal tools.

**Results.** Of 3,904 identified records, 23 articles met criteria and provided primary data from 6,110 patients. Suboptimal analgesic use, delays in receiving treatment, reluctance to report pain, and/or poor adherence to prescribed analgesics contributed to the patients' inadequate pain control. Patient-related barriers included fatalism, desire to be good, low pain control belief, pain endurance beliefs, and negative effect beliefs. Patients and family shared barriers about fear of addiction and concerns on analgesic side effects and disease progression. Health professional–related barriers were poor communication, ineffective management of pain, and analgesic side effects. Healthcare system–related barriers included limited access to analgesics and/or after hour pain services and lack of health insurance.

**Significance of results.** Chinese cancer patients' misconceptions regarding pain and analgesics may present as the main barriers to optimal pain relief. Findings of this review may inform health interventions to improve cancer pain management outcomes for patients from Chinese backgrounds. Future studies on patients' nonpharmacology intervention-related experiences are required to inform multidisciplinary and biopsychosocial approaches for culturally appropriate pain management.

## Introduction

Pain is one of the most feared symptoms across cultures for people diagnosed with cancer (Brant, 2014; Paice et al., 2010; Ruzicka, 2001) and it affects half of all cancer patients (Van Den Beuken-Van Everdingen et al., 2007). Inadequate cancer pain management may contribute to physical, psychological, social, and spiritual distress (Brant, 2014; Ruseel & Tandon, 2011) and have a negative impact on cancer patients' emotional wellbeing (Ruseel & Tandon, 2011; Yates et al., 2002).

Culture is a factor that can significantly influence cancer patients' pain experience, coping behaviors, and adherence to a recommended pain management plan (Al-Atiyyat, 2009; Lasch, 2000). Providing culturally appropriate care is an essential element of effective cancer pain management for patients from culturally and linguistically diverse backgrounds (Lasch et al., 2000).

People from Chinese backgrounds are dispersed around the globe and form one of the largest cultural and linguistically diverse communities in their host country (Australian Bureau of Statistics, 2012).The incidence of oversea-born Chinese cancer patients has sharply increased in the past two decades (Federation of Ethnic Communities' Councils of Australia, 2010). Prevalence of severe pain and/or undertreated pain were identified in Chinese cancer patients living in China and Western countries, which substantially affected their quality of life (Deng et al., 2012; Dhingra et al., 2011; Edrington et al., 2007; Liang et al., 2015; Liu et al., 2013).

Chinese culture may significantly affect cancer patients' communication, ability to cope with the cancer diagnosis and symptoms, and adherence to recommended care plans (Dayer-Berenson, 2014a; Yin et al., 2007). The pain perceptions and experiences of cancer patients from a Chinese background may be shaped by their cultural beliefs (Chen et al., 2008). The Chinese cultural beliefs can potentially influence people's interpretation and interaction to their pain treatment (Chung et al., 2000) and become contributing barriers for them to report their pain and use prescribed analgesics to achieve adequate pain control (Chen et al., 2008).

Immigrant Chinese cancer patients may experience additional barriers to their pain management. Research with different groups of immigrants suggests that Chinese immigrant cancer patients had special needs for their healthcare compared with other groups (Butow et al., 2010). Because of difficulties in communicating with non-Chinese-speaking health professionals and navigating new healthcare systems, Chinese immigrant cancer patients often felt culturally isolated when they were approaching health professionals for their cancer care needs (Butow et al., 2010). They also perceived that Western medications differed from their traditional health practices and failed to meet their needs (Butow et al., 2010).

Improving health professionals' understanding about health perspectives and needs of Chinese cancer patients is required to ensure the development of culturally appropriate pain management interventions. However, no literature review to date has provided information on how Chinese cancer patients perceive their pain management and what barriers might affect their decision making and adherence to the pain management plan.

### *Cancer pain management*

Cancer pain is a multidimensional experience (Edrington et al., 2007; Oldenmenger et al., 2009; Peng et al., 2006). Cancer pain management is a complex and ongoing care process that demands constant efforts by health professionals across hospitals and home care throughout the process of routine cancer pain screening, assessment of pain intensity and functional impairment, treatment, and follow-up (Dy et al., 2008).

Effective cancer pain management requires a coordinated multidisciplinary (Brant, 2014; Oldenmenger et al., 2009) and biopsychosocial approach (Van Den Beuken-Van Everdingen et al., 2016). This approach encompasses comprehensive pain assessment and appropriate pharmacological and nonpharmacological interventions to meet individual's physical, psychological, social, and spiritual needs (Brant, 2014; Paice et al., 2010).

Patients' self-report of pain is the most important step in cancer pain assessment; and health professionals, especially nurses, play primary roles in ongoing pain assessment (Brant, 2014). Inadequate knowledge and skills of cancer pain assessment were often found in both the patients and the health professionals and led to poor pain management outcomes (Oldenmenger et al., 2009).

Oral analgesics are one of the most effective pharmacological interventions for cancer pain (World Health Organization, 2015). About 30 years ago, the World Health Organization (WHO) launched a three-step cancer pain ladder to promote and guide usage of oral nonopioids and opioids in managing weak, mild, and severe cancer pain. It is recommended that cancer pain can be effectively controlled if the right does of oral analgesics are administrated around-the-clock based on pain assessment and are used in conjunction with adjuvants to control the fear and anxiety of patients (World Health Organization, 2015) .

Nonpharmacological interventions are an essential, but often overlooked component of pain management for cancer patients (Brant, 2014). Nonpharmacological interventions, such as cognitive-behavior therapy, musical therapy, herbal medicines, or superficial heating or cooling, have been reported as effective methods in cancer pain reduction (Brant, 2014; Yarbro et al., 2011). Nonpharmacological interventions might not be able to change the underlying pathology or alter the perception or sensations of pain, but rather help in variety of ways to decrease patient responses to pain, enabling them to deal with the pain positively and proactively (Yarbro et al., 2011).

Despite the multitude of pain management guidelines and strategies, unrelieved cancer pain persists because of patient, family, health professional, and/or healthcare system related barriers (Brant, 2014; Oldenmenger et al., 2009; Van Den Beuken-Van Everdingen et al., 2007). The poor outcomes of cancer pain management remain unchanged for decades though constantly efforts and attentions have addressed to this issue (Smith & Saiki, 2015; Van Den Beuken-Van Everdingen et al., 2016).

The barriers affecting appropriate cancer pain management reported in the literature have been different (Jacobsen et al., 2009; Van Den Beuken-Van Everdingen et al., 2016). Identifying and developing adequate interventions to overcome the barriers was the corner stone of effective cancer pain management (Van Den Beuken-Van Everdingen et al., 2016).

### *Objectives*

The purpose of this review is to explore current evidences describing the pain management experiences, beliefs, and needs of cancer patients from Chinese backgrounds. Integration of findings from international and Chinese literature has the potential to understand cultural influences and the barriers affecting cancer pain management in patients from a Chinese background and to inform the development of effective interventions for optimal pain management.

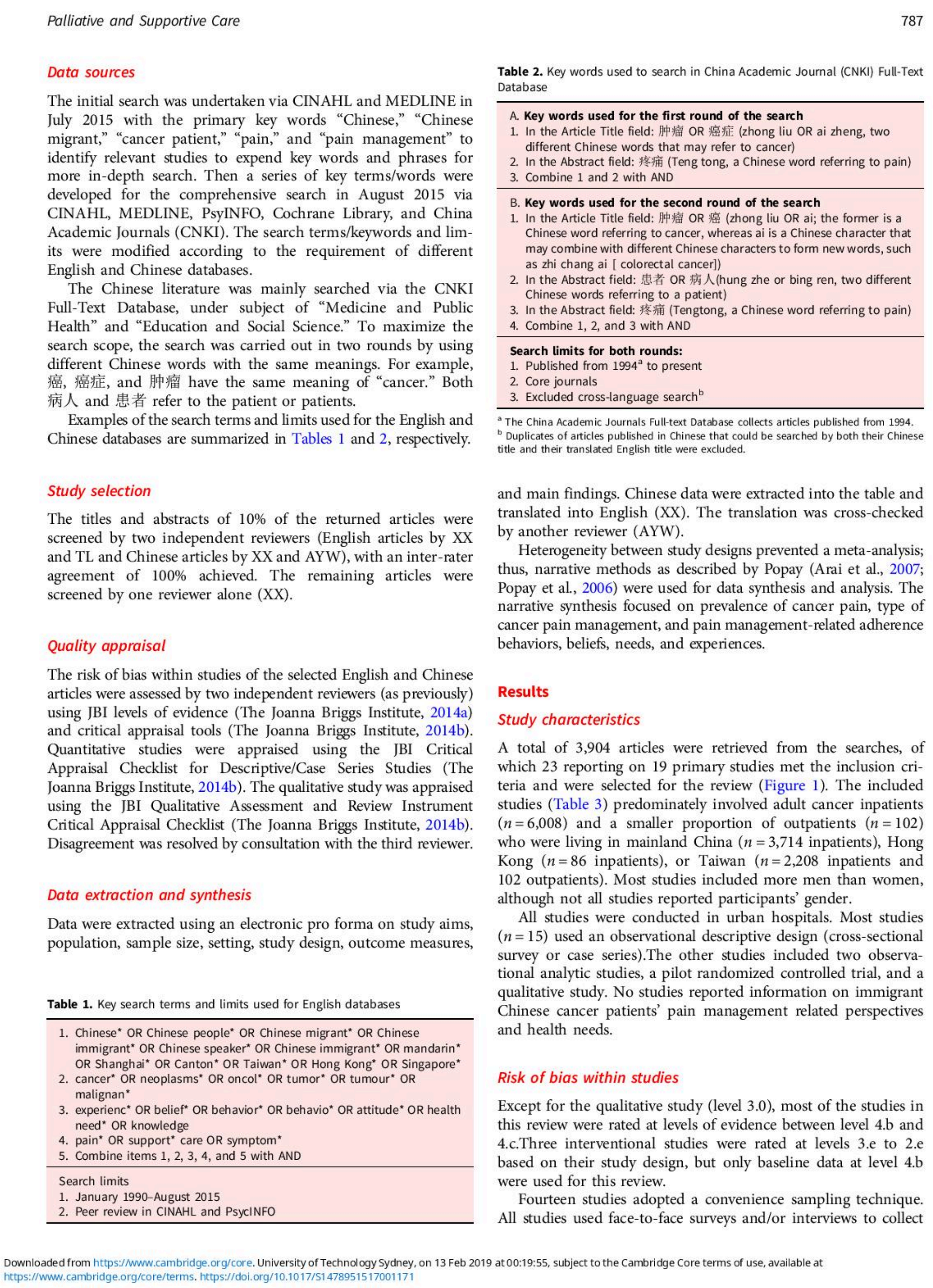
## Design

A protocol was developed according to the Joanna Briggs Institute's (JBI) Systematic Review method (The Joanna Briggs Institute, 2015) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Liberati et al., 2009) to guide the systematic review.

### *Inclusion criteria and exclusion criteria*

Articles were eligible if they (1) were published in peer-reviewed English journals or the Chinese core journals between January 1990 and August 2015 and (2) provided empirical data describing pain management experiences reported by adult cancer patients from Chinese cultures, including Chinese immigrant cancer patients living in Western countries or Chinese cancer patients living in Hong Kong, Taiwan, and mainland China. For studies evaluating a novel intervention, baseline rather than follow-up data were included to describe experiences during usual care.

Articles were excluded if they did not provide any patient-reported data about pain management, such as studies that reported patients' pain experiences only or studies solely used audit data.



### *Data sources*

The initial search was undertaken via CINAHL and MEDLINE in July 2015 with the primary key words "Chinese," "Chinese migrant," "cancer patient," "pain," and "pain management" to identify relevant studies to expend key words and phrases for more in-depth search. Then a series of key terms/words were developed for the comprehensive search in August 2015 via CINAHL, MEDLINE, PsyINFO, Cochrane Library, and China Academic Journals (CNKI). The search terms/keywords and limits were modified according to the requirement of different English and Chinese databases.

The Chinese literature was mainly searched via the CNKI Full-Text Database, under subject of "Medicine and Public Health" and "Education and Social Science." To maximize the search scope, the search was carried out in two rounds by using different Chinese words with the same meanings. For example, 癌, 癌症, and 肿瘤 have the same meaning of "cancer." Both 病人 and 患者 refer to the patient or patients.

Examples of the search terms and limits used for the English and Chinese databases are summarized in Tables 1 and 2, respectively.

**Table 2.** Key words used to search in China Academic Journal (CNKI) Full-Text Database

A. **Key words used for the first round of the search**
1. In the Article Title field: 肿瘤 OR 癌症 (zhong liu OR ai zheng, two different Chinese words that may refer to cancer)
2. In the Abstract field: 疼痛 (Teng tong, a Chinese word referring to pain)
3. Combine 1 and 2 with AND

B. **Key words used for the second round of the search**
1. In the Article Title field: 肿瘤 OR 癌 (zhong liu OR ai; the former is a Chinese word referring to cancer, whereas ai is a Chinese character that may combine with different Chinese characters to form new words, such as zhi chang ai [ colorectal cancer])
2. In the Abstract field: 患者 OR 病人(hung zhe or bing ren, two different Chinese words referring to a patient)
3. In the Abstract field: 疼痛 (Tengtong, a Chinese word referring to pain)
4. Combine 1, 2, and 3 with AND

**Search limits for both rounds:**
1. Published from 1994[a] to present
2. Core journals
3. Excluded cross-language search[b]

[a] The China Academic Journals Full-text Database collects articles published from 1994.
[b] Duplicates of articles published in Chinese that could be searched by both their Chinese title and their translated English title were excluded.

### *Study selection*

The titles and abstracts of 10% of the returned articles were screened by two independent reviewers (English articles by XX and TL and Chinese articles by XX and AYW), with an inter-rater agreement of 100% achieved. The remaining articles were screened by one reviewer alone (XX).

### *Quality appraisal*

The risk of bias within studies of the selected English and Chinese articles were assessed by two independent reviewers (as previously) using JBI levels of evidence (The Joanna Briggs Institute, 2014a) and critical appraisal tools (The Joanna Briggs Institute, 2014b). Quantitative studies were appraised using the JBI Critical Appraisal Checklist for Descriptive/Case Series Studies (The Joanna Briggs Institute, 2014b). The qualitative study was appraised using the JBI Qualitative Assessment and Review Instrument Critical Appraisal Checklist (The Joanna Briggs Institute, 2014b). Disagreement was resolved by consultation with the third reviewer.

### *Data extraction and synthesis*

Data were extracted using an electronic pro forma on study aims, population, sample size, setting, study design, outcome measures, and main findings. Chinese data were extracted into the table and translated into English (XX). The translation was cross-checked by another reviewer (AYW).

Heterogeneity between study designs prevented a meta-analysis; thus, narrative methods as described by Popay (Arai et al., 2007; Popay et al., 2006) were used for data synthesis and analysis. The narrative synthesis focused on prevalence of cancer pain, type of cancer pain management, and pain management-related adherence behaviors, beliefs, needs, and experiences.

**Table 1.** Key search terms and limits used for English databases

1. Chinese* OR Chinese people* OR Chinese migrant* OR Chinese immigrant* OR Chinese speaker* OR Chinese immigrant* OR mandarin* OR Shanghai* OR Canton* OR Taiwan* OR Hong Kong* OR Singapore*
2. cancer* OR neoplasms* OR oncol* OR tumor* OR tumour* OR malignan*
3. experienc* OR belief* OR behavior* OR behavio* OR attitude* OR health need* OR knowledge
4. pain* OR support* care OR symptom*
5. Combine items 1, 2, 3, 4, and 5 with AND

Search limits
1. January 1990–August 2015
2. Peer review in CINAHL and PsycINFO

## Results

### *Study characteristics*

A total of 3,904 articles were retrieved from the searches, of which 23 reporting on 19 primary studies met the inclusion criteria and were selected for the review (Figure 1). The included studies (Table 3) predominately involved adult cancer inpatients ($n = 6{,}008$) and a smaller proportion of outpatients ($n = 102$) who were living in mainland China ($n = 3{,}714$ inpatients), Hong Kong ($n = 86$ inpatients), or Taiwan ($n = 2{,}208$ inpatients and 102 outpatients). Most studies included more men than women, although not all studies reported participants' gender.

All studies were conducted in urban hospitals. Most studies ($n = 15$) used an observational descriptive design (cross-sectional survey or case series).The other studies included two observational analytic studies, a pilot randomized controlled trial, and a qualitative study. No studies reported information on immigrant Chinese cancer patients' pain management related perspectives and health needs.

### *Risk of bias within studies*

Except for the qualitative study (level 3.0), most of the studies in this review were rated at levels of evidence between level 4.b and 4.c.Three interventional studies were rated at levels 3.e to 2.e based on their study design, but only baseline data at level 4.b were used for this review.

Fourteen studies adopted a convenience sampling technique. All studies used face-to-face surveys and/or interviews to collect

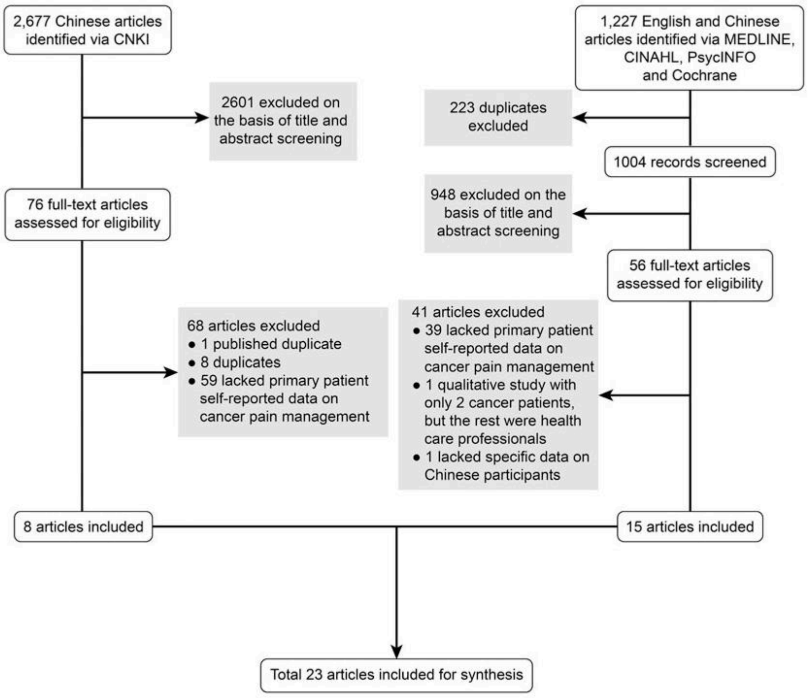


**Fig. 1.** Process and results of searching, screening, and selecting articles

their data. Of the 18 quantitative studies, 12 used validated tools and six used self-developed surveys to examine pain management–related beliefs and/or barriers. Most of the validated measures were originally established in Western populations and translated into Chinese; only one was psychometrically developed in the Chinese population (Chen et al., 2007). The levels of evidence and methodical appraisal results are summarized in supplementary tables (ST1, ST2, and ST3).

### *Prevalence of pain, type of pain management, and adherence behaviors*

Suboptimal analgesics use, delays in receiving pain treatment, and/or poor adherence to prescribed analgesics contributed the burden of participants' unrelieved pain. The majority of participants across the studies (83.5% inpatients and 100% outpatients) reported experiencing pain with a duration ranging from a few days to several months.

Across studies, pharmacological rather than nonpharmacological strategies were the main cancer pain management strategy used. Three studies reported using the WHO three-step ladder to guide the prescription of analgesics (Chen et al., 2007; Hu et al., 2010; Lu et al., 2006). Six studies specifically investigated the barriers of using opioids (Lai et al., 2002, 2004; Liang et al., 2008a, 2008b, 2012, 2013a, 2013b, 2015; Pang et al., 2013), whereas the remaining 13 studies explored participants' perspectives on using analgesics.

Only two studies noted that participants used a combination of analgesics (codeine or morphine) and nonsteroidal anti-inflammatory drugs (Lin, 2000; Song et al., 2014). Another two studies described participants using traditional Chinese medicine (e.g., acupuncture) or physiotherapy alone and/or in combination with analgesics for pain control (Chen et al., 2007; Huang, 2009).

The following poor analgesic-adhering behaviors were reported by the participants: (1) failing to take regular analgesics as prescribed (Lai et al., 2002, 2004; Song et al., 2014; Tse et al., 2012; Wills & Wootton, 1999; Xia, 2015); (2) only taking analgesics when pain occurred rather than around-the-clock analgesic regimen (Huang, 2009; Lin, 2000, 2001; Song et al., 2014; Tse et al., 2012) or when the pain became unbearable (Lin et al., 2013; Tse et al., 2012); and/or (3) titrating their analgesic doses without medical guidance (Tse et al., 2012; Xia, 2015).

### *Identified barriers*

The barriers prevented the participants to report their cancer pain, receive pain treatment, adhere to the prescribed analgesics, and achieve optimal pain control were identified as following:

#### *Patient-related barriers*

The patient-related barriers mostly arose from the participants' beliefs regarding cancer pain and/or analgesics, including pain related beliefs and analgesic-related misconceptions.

**Table 3.** Overview of study characteristics

| No.[a] | Authors/ year/ location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 1 | Liang *et al.* (2015)<br>Taiwan | To explore the relationship between oncology patients' pain experience and quality of life. | Inpatient ($n = 109$)<br>A teaching hospital | Cross-sectional | Medical characteristics (i.e., opioid used and side effects).<br>Methods of pain management.<br>European Organization for research and treatment of Cancer Quality of Life Group Questionnaire (version 3.0) (EORTC QLQ-C30).<br>Brief Pain Inventory-Chinese Version (BPI-Chinese). | Participants reported moderate levels of pain and duration being in pain from 1 to 49 months; and among them:<br>3/5 used analgesics together with other approach to control their pain;<br>2/5 used analgesics only to treat their pain; and<br>96.3% of them experienced side effect of opioids. |
| 2 | Xia (2015)<br>Mainland China | To evaluate adherence of elderly cancer patients to take oral analgesics and associated factors. | Inpatient with pain ($n = 115$)<br>An oncology teaching hospital | Cross-sectional | Self-designed questionnaire for analgesic adherence assessment:<br>taking by following prescription;<br>time of taking and dosage; and<br>adhering to long-term continual using analgesics. | Only about 1/2 of participants adhered to oral analgesics; 2/5 failed to take analgesics as per times of prescriptions; and 1/4 increased the dosage of analgesics without consulting with doctor.<br>Main concerns of the participants: adverse reaction (91.53%) and addiction (84.76%).<br>Significant associated factors of adherence: age, monthly income, status of medical insurance and intensity of pain ($p < 0.05$). |
| 3 | Song *et al.* (2014)<br>Mainland China | To determine pain prevalence and analgesic usage of inpatients; and to explore the factors associated with under-treatment cancer pain. | Inpatients ($n = 617$)<br>A teaching hospital | Cross-sectional | Information using analgesics: category, administration, time, and adverse effects of analgesics and economic burden. | 286 participants had moderate or severe cancer pain; among them:<br>92% of participants' medical cost was ≤1% of their total hospital expenses; and only 49.7% of participants used analgesic but 1/2 of them only took analgesics when pain occurred. |
| 4[b] | Liang *et al.* (2013a)<br>Taiwan | To explore the relationship among analgesic beliefs, analgesic adherence, and pain experience among Taiwanese cancer outpatients. | Outpatients ($n = 92$)<br>Two teaching hospitals | Cross-sectional | Pain Opioid Analgesic Beliefs Scale-Cancer (POABS- CA).<br>Opioid adherence.<br>BPI-Chinese. | Participants had a mean pain intensity score ≥3 for last 24 hours; 33.7%–68.5% of them had negative beliefs to pain and opioids.<br>Participants with negative effect beliefs about opioids and pain were less likely to adherence to around-clock analgesic regimen ($r = -0.30$, $p < 0.01$). |
|  | Liang *et al.* (2013b) | To describe oncology outpatients' responses to their beliefs regarding pain and prescribed opioids. | Same as above | Same as above | POABS-CA | Participants' beliefs to opioids and pain:<br>Opioids are not good for a person's body (about 2/3);<br>Worried opioid dependence (2/3);<br>If taking opioids at too early a stage, it would have less effect later (2/3);<br>Adults should not take opioids frequently (3/5) and should endure the pain (2/5). |
|  | Liang *et al.* (2012) | To explore levels of self-efficacy of outpatients in opioid taking for their cancer pain. | Same as above | Same as above | Opioid-taking Self-Efficacy Scale Cancer (OTSES-CA) | Majority participants reported low confidence in the tasks of tailoring medication regimens.<br>Participants with low education were significantly relate to lower score of self-taking opioids ($r = 0.28$, $p < 0.01$).<br>Participants without side effects significantly had higher total self-efficacy score ($p < 0.01$) and subtotal scores ($p < 0.05$–$<0.01$), compared with those with side effects. |
|  | Liang *et al.* (2008a) | To explore relationship among self-efficacy, beliefs, adherence behaviors, and pain experience of outpatients in related to opioid-taking for their cancer pain. | Same as above | Same as above | OTSES-CA; POABS-CA; opioid adherence. | Opioid beliefs and opioid-taking self-efficacy were significant predictors for participants' adherence to around-clock analgesic regimen (F = 4.71, $p < 0.01$).<br>Participants with negative opioid beliefs ($r = -30$, $p < 0.01$) and low level of self-efficacy ($r = 0.22$, $p < 0.35$) were likely to poorly adhere to around-the-clock analgesic regimen. |
| 5 | Pang *et al.* (2013)<br>Mainland China | To investigate and explore existing problems related to pain control and barriers for optimal pain management among cancer participants and their family members; and to explore their attitudes to cancer pain and pain management | Inpatients ($n = 30$); patients' family ($n = 29$)<br>Oncology teaching hospital. | Case series | Self-designed questionnaire:<br>Patients: effect of pain control; impact of pain on patients' sleep; mood and general activity; and factors that affect patient's satisfaction on pain control.<br>Numeric Rating Scale.<br>Patients and their family members: perceptions to pain; right way using analgesics; perceptions to safety of opioids; and other 5 domains in related to analgesic treatment. | Participants suffered mild to severe pain at the time of survey; of them:<br>5/6 had moderate or severe pain within 24 hours before survey; and 1/2 only taking analgesics when pain occurred.<br>Participants' and their families' perceptions to pain and analgesics: pain meant end-stage of cancer;<br>Analgesics should only be taken on time when pain occurred; opioids were not safe; worried about addiction to opioids; and<br>Better to suffer the pain and did not use any analgesics. |
| 6 | Lin *et al.* (2013)<br>Mainland China | To explore factors associated with cancer patients' adherence to pain treatment | Inpatients ($n = 228$)<br>A teaching hospital | Cross-sectional | Self-designed questionnaire:<br>Type of cancer, location and level of pain; patient's goal in relation to pain treatment, and knowledge or pain treatment and analgesics.<br>Numeric Rating Scale. | 189 participants suffered from mild to severe pain but only 1/3 of them taking analgesics on time.<br>Perceptions of pain treatment:<br>Only needed to reduce pain to the tolerant level;<br>Using opioids may result in permanent dependence;<br>Analgesics should be taken when pain became unbearable;<br>Long-term use of opioids might result in addiction;<br>Request to increase dosage of analgesics meant addiction; Should stop using opioids if adverse action occurred; and<br>Dosage of morphine was associated with level of severity of the cancer. |

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| 7 | Tse *et al.* (2012) Hong Kong | To investigate effectiveness of pain management program on pain intensity, use of as-needed drugs and nonpharmacological strategies for pain relief; and to explore barriers of cancer pain management. | Inpatients ($n=38$)<br>A public hospital | Case-controlled | Numeric Rating Scale.<br>Barriers questionnaire-Taiwan (BQT): fatalism, addiction, desire to be good, fear distort physician, decreased progress, tolerance, and side effects. | Baseline assessment:<br>All participants took analgesics to relief their pain and at least 2/3 of them used nonpharmacological methods for pain relief. However, they believed analgesics should be only be taken should when nurse gave to them; and had relatively high scores of BQT (>2) in addiction, fear disturbing physician, decreased process, tolerance and side effects. |
| 8 | Hu *et al.* (2010) Mainland China | To explore cancer patients' perceptions and attitudes toward pain treatment in hospitals; and to explore their attitudes to community medical staff in relation to the treatment | Inpatients ($n=120$)<br>A tumor hospital | Case series | Self-designed questionnaire:<br>Incident rate and type of treatment for pain;<br>Perceptions and attitudes to analgesics and pain treatment;<br>Perceptions to pain treatment at community hospital (i.e., accessibility to the service, availability of analgesics). | 2/5 of participants had cancer pain and among them 2/3 worried about adverse effects;<br>92.3% wished to receive more information on pain treatment and analgesics;<br>Only 1/3 regularly took analgesics;<br>1/3 took analgesics when pain occurred;<br>1/4 refused analgesics due to worrying adverse effects;<br>3/4 perceived possible inconvenience to get analgesics at community hospitals; and<br>4/5 thought community hospitals cannot provide satisfactory pain treatment.<br>Type of pain treatment: analgesic (59.6%), physical therapy plus rest (26.9%); chemotherapy and radiotherapy (13.5%) |
| 9[c] | Tang *et al.* (2010a) Taiwan | To characterize cancer patients' status and satisfaction with pain management. | Terminally ill cancer inpatients ($n=1,370$)<br>24 hospitals | Cross-sectional | Pain intensify score (0–5).<br>Toolkit of Instruments to Measure End-of-life Care.<br>Self-developed questionnaire: Patients' perceptions of clinicians' pain management practice with 4 questions regarding amount of pain medication received, duration of waiting for pain medication, understanding about pain treatment and pain relief experiences. | All participants experienced pain and about 1/2 of them were not satisfied with pain relief within 1 week of admission because they received an inadequate amount of pain medication and/or took too long to receive pain medication.<br>Significant correlation factors of participants' satisfaction: age ($r=0.05$, $p=0.05$); pain intensity ($r=-0.18$, $p<0.0001$). |
| | Tang (2010b) | To investigate the diffusion effects of a hospice unit on improvement of terminally ill inpatients perceived quality of cancer pain management. | Same as above | Same as above | Pain relief experiences; duration of waiting for pain medication. and amount of pain medication received. | Participants from hospice groups ($n=672$) were 2.40 times likely to report of unrelieved pain before admission.<br>Participants from non-hospice groups ($n=698$) was significantly more likely to waiting for too long for pain medication ($p<0.05$).<br>The participants in both groups ($n=1,370$): 1/2 had unrelieved pain prior to admission; 2/5 received inadequate analgesics and 2/5 still had unrelieved pain 7 days after hospital admission. |

(*Continued*)

**Table 3.** (*Continued.*)

| No.[a] | Authors/ year/ location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 10 | Huang *et al.* (2009) Mainland China | To investigate the characteristics and treatment of cancer pain of cancer patients in Shanghai | Inpatient (n = 1n131)<br>Level 2–3 hospitals or level 1 palliative cancer care hospitals with ≥300 beds | Cross-sectional | Intensity visual analogue scale<br>Self-designed questionnaire: pain treatment; patients' perceptions to analgesics and satisfaction to pain treatment as well as associated factors. | Among the participants:<br>Average interval from feeling pain to get treatment: 4.1 months.<br>2/5 only taking analgesics when pain occurred; 2/5 feared addiction; 2/3 could not get treatment when cancer pain occurred; 1/5 had difficulty to get pain treatment;<br>about 1/2 used 2 or more than 2 methods for pain treatment; 2/3 accessed the cancer pain clinic for pain control; and<br>0nly 5.5 % might get full reimbursement for their pain treatment.<br>The most highly rated effective treatments: analgesics (79.1%), physical therapy (8.1%), and traditional Chinese medicine (4.7%).<br>1/6 dissatisfied pain control because of adverse reaction, inefficient of pain control, inadequate dosage of analgesics and limited usage of analgesics because of financial burden. |
| 11 | Liang *et al.* (2008b) Taiwan | To explore outpatients' tasks and behaviors related to opioid-taking for cancer pain and factors affecting their self-efficacy of opioid-taking at home | Outpatients ($n=10$) with pain<br>Two teaching hospitals | Semistructured interview | Self-developed interview guide based on theoretical framework of self-efficacy. | Factors associated with participants' opioid-taking self-efficacy: Communication between health professions and the patients in related to pain;<br>Knowledge about effects of opioids, side effects of opioids and self-monitoring;<br>Capability of adjusting or swabbing their pain medications according to their conditions;<br>Difficulties in adhering to scheduled opioids due to limited access to opioids and after-hours pain service;<br>Support from family and doctors;<br>Concerns on accessibility and financial situation, side-effects of opioids and disease progression or worsening. |

**Table 3.** *(Continued.)*

| No.[a] | Authors/ year/ location | Aims | Population/ settings | Study design | Outcome measures | Main findings |
|---|---|---|---|---|---|---|
| 12 | Chen *et al.* (2007)<br>Mainland China | To explore pain behaviors of cancer patients in Zhanjiang area; and influence of psychosocial factors to their pain behaviors. | Inpatients ($n = 1,197$)<br>A tertiary hospital | Cross-sectional | Modified Questionnaire of National Cancer pain prevalence and associated factors for pain treatment.<br>Pain assessment scale. | 4/5 of participants experienced mild to severe levels of pain; among them:<br>Only 1/5 used strong opioids; and<br>About 1/5 used acupuncture, physical therapy, or Traditional Chinese medications.<br>Among 303 participants who had pain but never received pain treatment: 4/5 refused analgesics but requested acupuncture, scraping, moxa moxibustion, massage, or physical therapy.<br>1/5 refused any pain treatment because of:<br>fear of addiction (1/2); side effects (1/3); pain endurance belief (1/5); or economic or other reasons (1.65%). |
| 13 | Lu *et al.* (2006)<br>Mainland China | To evaluate effects of educational program on cancer patients' pain control. | Inpatients ($n = 112$)<br>A cancer hospital | Observational study without a control group | Patients' compliance to pain treatment.<br>Level of pain reliefs.<br>Satisfaction with their pain control.<br>Modified BQT. | All participants had pain and received oral analgesic or patch for pain treatment by following WHO 3-step ladder; and among them:<br>Only 2/5 adhered to the around-clock pain treatment;<br>Only 1/5 satisfied to level of pain control.<br>Total scores of the participants' barriers to pain and pain treatment were high at 2.81 ± 0.54; and all subscores $\geq 2$.<br>Barriers perceived: addiction; dependence; tolerance and side effect of using opioids; difficulty to get drug as pain getting worsen; feared pain relief interfering cancer treatment; feared disturbing nurse and family; tolerating pain meant strong; economy burden; and uncontrollable pain. |
| 14 | Lai *et al.* (2004)<br>Taiwan | To evaluate effects of a brief structured pain education program on inpatients' cancer pain experience. | Inpatient ($n = 30$)<br>A medical center. | A pilot randomized controlled trial | BPI-Chinese.<br>POABS-CA.<br>Coping Strategies Questionnaire-Catastrophizing and CSQ sense control over pain measures (CSQ-Cat) | Baseline assessment:<br>All participants were in pain for around 4 months;<br>Had high scores ($\geq 2.9$) in negative effect beliefs using opioids, pain endurance beliefs and catastrophizing; and Had Low sense of control pain score (1.90 ± 1.58). |
| 15 | Lai *et al.* (2002)<br>Taiwan | To explore oncology inpatients' pain beliefs and adherence to prescribed analgesics<br>To identify predictors of adherence to analgesics | Inpatients ($n = 194$)<br>4 teaching hospitals | Cross-sectional | Analgesic adherence: patient self-reported prescribed analgesic-taking options.<br>POABS-CA.<br>Survey of Pain Attitude.<br>Pain Numerical Rating Scale. | Duration of experienced pain: 3–7 months with mean intensity of pain at 3.49 ± 1.77 and peak intensity of pain up to 7.26 ± 2.39 for last 7 days.<br>1/3 of participants failed to adhere to prescribed analgesics.<br>Lower control belief (odds ratio = 0.393, $p = 0.0001$) and higher medication belief (odds ratio = 2.153, $p = 0.02$) were 2 significant predictors of participants' analgesic adherence. |
| 16 | Lin (2001)<br>Taiwan | To examine congruity between cancer patients' and their families' perceptions to cancer pain; and to determine if the congruity associated with patients' concerns on reporting their pain and using analgesics. | 89 dyads of inpatients and family caregivers<br>Two teaching hospitals | Cross-sectional | Patients:<br>BQT.<br>BPI-Chinese.<br>Eastern Cooperative Oncology<br>Group (ECOG) performance status scale.<br>Family caregivers: BPI – Chinese | 2/3 dyads participants and family care givers did not have congruent in cancer pain intensity.<br>Noncongruent group participants had significantly higher scores than those in congruent group at following aspects: disease progression and religious fatalism ($p < 0.01$); tolerance and total BQT scores ($p < 0.05$).<br>The participants in both groups had high scores (>2) in fatalism, addiction, distract physicians, disease progression, tolerance, side effects and as needed (taking analgesics as per need but not on an around-the-clock scheduled basis). |
| 17 | Lin (2000)<br>Taiwan | To compare attitudes between cancer patients and their family toward cancer pain management | 159 dyads of inpatients and family care givers (total $n = 318$)<br>A teaching hospitals | Cross- sectional | Patients:<br>BQT.<br>BPI-Chinese.<br>ECOG performance status scale.<br>Pain management Index (PMI).<br>Family caregivers: BQT | The patients had high sub-scores of BQT ($\geq 3$) in tolerance, disease progression, as needed, addiction, and side effects.<br>Only 2/3 of them accurately used of prescribed analgesics which significantly had lower BQT total scores than those who were under- medicated ($p < 0.05$).<br>More than 1/2 hesitated taking analgesics at last months and had significantly higher scores in addiction ($p < 0.01$), as needed, tolerance and the total BQT ($p < 0.001$); and the hesitance was significantly associated with their family caregivers' BQT scores ($p < 0.01$).<br>Family caregiver's total BQT scores were significantly predictors of patients' accuracy in using analgesics ($p < 0.05$). |
| 18 | Wills & Wootton (1999)<br>Hong Kong | To identify misconceptions and concerns related to cancer pain management among Hong Kong Chinese patients | Inpatients ($n = 48$)<br>A teaching hospitals | Cross sectional | 9 common concerns and misconception about analgesia divided into five subscales: good patients, fatalism, character building, addiction and side effects by Gordon & Ward (1995);<br>Visual Analog Scale. | 35 participants had pain;<br>1/4 avoided taking analgesics when admitted to a hospital;<br>4/5 did not want to distract physicians with their pain;<br>2/5 were not willing to disturb nurses with their pain as they thought nurse were very busy and needed to take care of other participants as well;<br>4/5 agreed that pain was unavoidable and a part of their admission to the hospital;<br>2/3 believed pain was uncontrollable based on their previous hospitalizing experience;<br>1/2 believed that analgesics could early cause addiction and should be the last option for pain management; and<br>2/3 were unwilling to tolerant the side-effects. |

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| 19 | Lin & Ward, 1995<br>Taiwan | To investigate cancer patients' concerns about reporting and using analgesics; and<br>To explore relationship between patients' concerns and their adequacy of analgesic usages | Inpatients ($n = 63$)<br>Five teaching hospitals | Cross sectional | BQT;<br>BPI-Chinese;<br>Pain management index (PMI);<br>Medication sheet. | The concerns most strongly held by the participants were tolerance, disease progression, time interval, and addiction.<br>4/5 wanted to save analgesics for the worst pain;<br>More than 1/2 hesitated reporting pain at last month and those participants were found having significant higher scores on fatalism, fear of addiction, distracting physicians, concerns about time interval and total BQT;<br>Among the participants ($n = 36$) reported pain at last 24 hours prior to data collection, 2/3 had negative PMI scores which indicated inadequate amount of using analgesics. |

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[a] The studies are listed in a chronological order.
[b] Four articles were written based on one study.
[c] Two articles were written based on one study.

### Pain-related beliefs

Participants' conceptualization of their pain experiences significantly influenced their pain management behaviors (Lai et al., 2002) and decision-making (Lai et al., 2004; Liang et al., 2013b; Lin et al., 2013; Wills & Wootton, 1999). "Fatalism" was identified as a major obstacle to preventing participants from using analgesics to relieve their cancer pain (Lin, 2000, 2001; Wills & Wootton, 1999). Inpatients with higher fatalism scores considered pain as an inevitable experience of hospitalization, hesitated to use analgesics, and often endured pain for months (Lin, 2000; Wills & Wootton, 1999).

Participants with a higher "desire to be good" score, as measured by the "Barriers Questionnaire," were more reluctant to talk about their pain because they did not want to disturb their nurses and/or doctors (Lin, 2000, 2001; Wills & Wootton, 1999). In addition, many participants believed that pain was an indication of "disease progression" (Liang et al., 2008a; Lin, 2000, 2001; Lin & Ward, 1995; Tse et al., 2012). This belief discouraged them from accepting pain treatment (Liang et al., 2008b; Lin et al., 2013), made them reluctant to report their pain to health professionals (Lin, 2000, 2001; Lin & Ward, 1995; Tse et al., 2012), and/or failed to adhere an around-the-clock analgesic regimen (Liang et al., 2008a 2013a).

"Pain endurance belief" refers to "the belief that one should endure as much pain as possible" (Lai et al., 2002, p 416). "Pain control belief" is a belief "that one can control his/her pain" (Lai et al., 2002, p 416). The high scores of "pain endurance belief" and the lower scores of "pain control belief" were significant negative predictors of analgesic adherence (Lai et al., 2004; Liang et al., 2013b).

In several studies, participants described the need to "be brave" (Chen et al., 2007; Pang et al., 2013) and/or to "bear the pain" (Lin et al., 2013). In fact, some participants did not realize that their pain could be relieved (Lin et al., 2013; Lu et al., 2006; Pang et al., 2013).

### Analgesic-related misconceptions

Cancer patients with lower education levels (Chen et al., 2007; Xia, 2015) and older ages (Xia, 2015) or misconceptions to analgesics had greater difficulty adhering to analgesics.

In the studies investigating participants' perspectives on opioid use, participants commonly held "negative effect beliefs" (Lai et al., 2002, 2004; Liang et al., 2008a, 2008b, 2012, 2013a. 2013b, 2015). The "negative effect belief" is "a belief that opioids have negative effects on the body" (Lai et al., 2002, p 416). Participants with a high opioid "negative effect belief" ($r = -30$, $p < 0.01$) were less likely to adhere to an around-the-clock analgesic regimen (Liang et al., 2008a, 2013b). Concerns about side effects and addictions were also reported as barriers of using opioids (Pang et al., 2013). In contrast, the patients' belief that medications could be effective in treating pain (Lai et al., 2002) and high self-efficacy for administering opioids (Liang et al., 2008a, 2008b, 2012) were indicators of high adherence to opioids for cancer pain treatment.

In the studies exploring participants' perspective on analgesics in general, findings suggested that poor analgesic adherence was mainly linked to a disproportionate "fear of addiction" or "analgesic dependence" (Chen et al., 2007; Huang, 2009 ; Lin, 2000, 2001; Lin & Ward, 1995; Lin et al., 2013; Tse et al., 2012; Wills & Wootton, 1999; Xia, 2015) and "concerns about side effects" (Chen et al., 2007; Huang, 2009; Lin, 2001; Lin et al., 2013; Tang, 2010; Tse et al., 2012; Wills & Wootton, 1999; Xia, 2015).

### Family-related barriers

The participants in the qualitative study regarding cancer patients' opioid-taking task and behaviors perceived their family as the "bridge" between themselves and their healthcare providers and considered family support the central to helping them cope with their pain and pain treatment (Liang et al., 2008b). The family members' perspectives to cancer pain and its management may have an impact on participants' adherence to analgesics.

In a few studies that involved both patients and their families, some family members perceived pain as an indicator of "disease progression" and worried that taking analgesics to control the pain would mask warning signs of cancer progression (Lin, 2000; Pang et al., 2013). Analgesic side effects and safety (Lin, 2000, 2001; Pang et al., 2013), addictions, and tolerance (Lin, 2000) were also major concerns of family members.

Congruency between patients' and families' cancer pain management perceptions is essential for analgesic adherence (Lin, 2000, 2001).The perception of barriers among family caregivers was a significant negative predictor of patients' accuracy and attitudes in using analgesics ($p < 0.05$) (Lin, 2000) and a predictor of patients' hesitation to take analgesics ($p < 0.01$) (Lin, 2000).The noncongruent group of patients had significantly higher ($p < 0.01$ or $p < 0.05$) total barrier scores and subscores on "disease progression," "religious fatalism," and "tolerance" than those in the congruent group and were less likely to adhere to their pain treatment (Lin, 2000).

### Health professional-related barriers

The main health professional-related barriers reported by the participants were ineffective management of analgesic side effects (Huang, 2009; Lin et al., 2013) or delays in treating side effects (Chen et al., 2007; Hu et al., 2010; Pang et al., 2013). Inefficient pain control also led to participant dissatisfaction with their pain management (Huang, 2009; Lin et al., 2013). Poor communication and/or a lack of information on pain treatment were barriers to optimal pain control (Liang et al., 2008b).

### Healthcare system-related barriers

Participants had difficulty accessing opioids after hours (Liang et al., 2008b) and obtaining analgesics to manage unexpected pain (Pang et al., 2013). Participants were also dissatisfied with delays of their cancer pain treatment and/or the limited supply of analgesics that was not commensurate with the dosing regimen required to control their pain (Huang, 2009; Lin & Ward, 1995; Tang, 2010; Tang et al., 2010).

Participants with low incomes (Chen et al., 2007; Xia, 2015) and/or those without health insurance (Huang, 2009; Liang et al., 2008b; Lu et al., 2006; Xia, 2015) had even more limited access to analgesics because of concerns about affordability. Even participants with health insurance had limited access to analgesics and quality pain treatment because the amount of insurance funds contributed to pain treatment was extremely restricted (Song et al., 2014). Participants also worried that community hospitals might not be able to provide analgesics and appropriate treatment for their cancer pain (Hu et al., 2010).

## Discussion

This systematic review revealed a range of patient-, family-, health professional-, and healthcare system-related barriers that contributed to the experience of unrelieved pain, delay in receiving pain treatment, and poor adherence to prescribed analgesics in Chinese cancer patients.

The patients' pain beliefs such as "fatalism" and "desire to be good," "pain endurance belief", low "pain control beliefs" and "concerns about disease progression" are analogous with those reported in the Western literature (Oldenmenger et al., 2009). However, the culture influences that underpin these beliefs need to be addressed to help health professionals understand Chinese cancer patients' pain management-related behaviors and needs.

Buddhism teaches that "pain is a power, unwanted but existent…" (Chen et al., 2008, p 105).This perspective leads people to view pain as a "natural thing" that is an indicator of their body reacting to the cancer (Chen et al., 2008, p 105; Im et al., 2008). Fatalism can extend beyond pain to the cancer itself (Chung et al., 2000). Cancer pain is considered both a "fate" associated with misery and a reminder of life and that what patients can do when confronted with pain is to wait until death comes (Chung et al., 2000).

The desire to be "a good patient" may stem from the influence of Confucianism. Confucianism encourages people to strive for a harmonious relationship with nature and others (Dayer-Berenson, 2014b). Chinese patients' desire to maintain harmonious relationships with others may lead to a reluctance to "bother" health professionals with their health problems (Dayer-Berenson, 2014b; Tjuin et al., 2007).

The "pain endurance belief" is also likely associated with the influence of Confucianism. Chinese people generally are not comfortable expressing feelings in front of others when they experience hardships. This stoicism is seen as important to winning others' respect. Therefore, Chinese often perceive pain as a "trial" that tests their strength and that pain is part of the sensation of being human (Chen et al., 2008). Although cultural beliefs of this kind may help with coping in some instances, they have the potential to generate feelings of helplessness and misery in Chinese cancer patients (Chung et al., 2000). These patients tend to suffer in silence rather than seek help before their pain becomes severe (Chen et al., 2008).

In addition, Chinese cancer patients perceived pain as an indicator of disease progression (Liang et al., 2008a; Lin, 2000, 2001; Lin & Ward, 1995; Tse et al., 2012).They worried that if their pain was controlled, this could eventually prevent the warning signs of cancer from reoccurring or advancing (Chen et al., 2008). This may also explain why Chinese cancer patients tended to suffer in pain instead to obtaining help.

The "negative effect belief" to opioids and "fear of addiction" among Chinese cancer patients are very likely due to a lack of cancer pain and treatment information (Lai et al., 2004; Lu et al., 2006; Tse et al., 2012) and/or inefficient communication between patients and healthcare professionals (Liang et al., 2008b). Without adequate information, the patients may find that it is difficult to communicate with health professionals about their concerns and to know where to seek help (Butow et al., 2010; Liang et al., 2008b).

As with patient-related barriers, the strong influence of a family's beliefs on pain management reported by Chinese cancer patients reflects the cultural importance of family relationships, loyalty, obligation, obedience, cooperation, interdependence, and reciprocity in Chinese society (Dayer-Berenson, 2014b). In a traditional Chinese family, health decisions are based on a process of family consensus in which the oldest family members or the eldest son usually has the greatest influence. Being able to stay with family helps overcome hardships (Chung et al., 2000); however, this closeness can change patients' pain perceptions because they may fear that the cancer will spread to other family members or they may feel shamed in front of their friends (Chung et al., 2000).

The stigma and concern over social networks may prevent Chinese cancer patients from sharing their experiences of pain with their families. This dynamic has implications for how healthcare professionals engage family members in shared decision-making regarding pain management. Strategies aiming to empower patients and their families to self-manage pain are essential for optimal pain management (Luckett et al., 2013).

Patient education in relation to reporting pain and use of analgesics was an essential method to improve cancer patients' knowledge's and adherence to analgesics (Oldenmenger et al., 2009). Educational interventions for the families about managing side effects, disease progression, and around-the-clock analgesics were also important because Chinese cancer patients were heavily dependent on their families, especially during palliative care (Lin, 2000).

The health professional-related barriers reported by patients in this study are consistent with those reported by physicians and nurses (Oldenmenger et al., 2009), which may be associated with health professionals' analgesic beliefs (e.g., concerns about addiction and side effects) and inadequate knowledge and skills in cancer pain management (Li et al., 2013; Oldenmenger et al., 2009).

The limited reports of using the WHO three-step ladder to guide pain treatment and inadequate prescription of opioids for cancer patients reflect the importance of increasing healthcare professionals' awareness of analgesic use in cancer pain management. The outcome of pain treatment can only be improved when routine pain education and appropriate doses of opioids are provided and treatment are regularly adjusted (Dy et al., 2008). Health policies need to be reinforced to provide training programs for health professionals to enhance their knowledge and skills in pain control and to promote opioid usage in Chinese cancer patients (Lin et al., 2016).

The inadequate prescription of opioids and the limited access to opioids reported in the included studies was similar to the findings of Western researchers; opioid-related fears have been commonly observed in Western literature (Flemming, 2010) and were likely associated with government restrictions on opioid usage (Open Minds, 2005). Although understanding the effectiveness and safety of opioids in chronic pain management was gradually increasing and the importance of opioids in pain relief had been addressed, opioid use remained restricted because many national laws have focused on controlling misconduct, abuse, and addiction (Open Minds, 2005). The rules and regulations should be updated to eliminate the fear of opioids (Open Minds, 2005).

At the healthcare system level, limited access to analgesics, a lack of after-hours access to opioids, and concerns on the quality of pain management services at local community hospitals. This suggested that health service reforms should focus on increasing affordability and accessibility of analgesic and community-based pain services and supporting pain self-management for cancer patients and their families at home.

The similarities between the barriers reported in Chinese populations and in the Western literature may partly result from most of the validated measures used in the included studies were developed for non-Chinese-speaking populations and only focused on patients' perspectives to pain and analgesics. Evaluating influential cultural and social factors affecting unrelieved cancer pain is urged to inform effective interventions for cancer pain management (Jacobsen et al., 2009). A reliable and valid instrument should be developed to ensure better coverage of barriers that reflect specific Chinese cultural considerations.

## Limitations and strengths

The generalizability of findings in this review may be limited because of the small numbers of articles identified and multiple methodological factors. The majority of the studies used a cross-sectional design and a convenience sampling technique. More than half of them were conducted at a single study site. All studies were undertaken in hospital settings of metropolitan areas and participants' demographic data in some studies were unclear, so it was uncertain if the studies included participants from remote areas.

Only small numbers of participants were outpatients; therefore, the barriers and needs reported in this review may not reflect patient barriers and specific needs in cancer pain management when they were discharged home. That the majority of participants in the included studies were males may potentially have led to bias because of gender differences in pain and pain management.

Despite these limitations, the findings of this review have been strengthen by adhering to a review protocol with multiple reviewers involved throughout the process of search, quality appraisal, data extraction and analysis, and reporting to maintain the consistence and rigorousness. The Chinese data translations were cross-checked by a highly qualified bilingual academic to ensure completeness and accuracy.

Even though the sample size in some studies were small. the findings of this review were based on primary data reported by more than 6,000 Chinese cancer patients. It may provide valuable information to health professionals and researchers for future development in clinical practice and research and improve outcomes of cancer pain management for people from Chinese backgrounds.

## Conclusion

Adequate cancer pain management for cancer patients of Chinese backgrounds needs to start with an understanding of patient and family perspectives on pain and analgesics and the barriers preventing them from achieving optimal pain outcomes.

The findings of this review may inform development of health interventions to meet information needs of Chinese cancer patients and their families in relation to the pain and analgesics to (1) encourage patients to report their pain; (2) be actively involved in their pain treatment, adhere to the around-the-clock analgesic regimen, and increase their use of oral analgesics; and (3) increase their access to after-hour pain services.

Findings of this study may also be used to develop educational programs for health professionals to enhance their competence in managing cancer pain for patients from Chinese backgrounds, particularly to increase their awareness regarding importance of using adequate analgesics in cancer pain management and to strengthen their skills in effective communication and management of analgesic side effects.

Cancer patients from Chinese backgrounds are more likely to seek traditional Chinese medicines and/or to engage with the culture-related health practices such as Qigong, acupuncture, and transitional Chinese massage for their pain control. However, this review was not able to provide information about the needs and barriers of Chinese cancer patients in relation to nonpharmacological interventions because the existing literature has mainly focused on pharmacological analgesia. Future studies based on cancer pain management guidelines addressing this area are needed to inform development of multidisciplinary and biopsychosocial pain management approaches that are culturally appropriate.

Another notable gap in the literature concerns the absence of studies focusing on Chinese immigrants' cancer pain management-related experiences. Further research directed by cultural care theories or models is required to identify cancer pain management-related barriers and cultural influential factors in Chinese immigrants living in countries that have different cultures, especially those who have less support after they are discharged home and/or are receiving pain treatment at clinics or community services.

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# Appendix B information sheet and consent forms – Patient

## Appendix B-1: Participant information sheet and consent forms – Patient (English)

**[Insert name of local institution/s where research is being conducted]**

**Chinese Migrants Cancer Pain Project**

### Invitation

You are invited to participate in a research study into the cultural influence on pain management related experiences and needs of Chinese migrants with cancer.

The study is being conducted by the following researchers:

- Professor Jane L. Phillips, Director, Centre for Cardiovascular and Chronic Care, Faculty of Health, University of Technology Sydney (UTS)
- Dr Tim Luckett, Senior Lecturer, Centre for Cardiovascular and Chronic Care,

  Faculty of Health, UTS
- Associate Professor Melanie Lovell, Medical Director of Greenwich Palliative Care Services and Clinical Associate Professor of Sydney Medical School of University of Sydney
- Professor Meera Agar, Staff Specialist, Palliative Care, SWSLHD, NSW
- Ms Xiangfeng Xu, PhD candidate, Faculty of Health, UTS

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will be involved. Please take the time to read the following information carefully and discuss it with others if you wish.

### 1. What is the purpose of this study?

The purpose of this study to explore cultural influences on cancer pain management experiences and needs for Chinese migrants who live with cancer.

### 2. Why have I been invited to participate in this study?

You are eligible to participate in this study because you: 1) were born in Mainland China, Hong Kong or Taiwan; and 2) have received or currently are receiving cancer pain treatment at an ambulatory cancer or palliative care centre/clinic. Your participation will help inform the development of pain management strategies and/or interventions for Chinese migrants with cancer living in Australia.

### 3. What does participation in this study involve?

If you agree to participate in this study you will then be asked to contact the researcher or give the permission that the researcher may contact you, so that the researcher may assign you to a focus group together with other participants and arrange a convenient time and venue that suits you for the focus group interview. You need to read the Participant Information and Consent Form provided by your health care team or by the researcher; and sign the consent form.

The focus group interview will last for approximately for 90 minutes, which includes time to complete a questionnaire. The focus group interview will be facilitated by a researcher in Mandarin or in Cantonese; and will be assisted by a scribe who will take notes; and the interview will be audio recorded for analysis.

Any information obtained in connection with this doctoral project that can identify you will remain confidential.

### 4. What if I don’t want to take part in this study, or if I want to withdraw later?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. You can leave the focus group or withdraw your responses before we start or complete the data analysis. However, it may not be possible to remove your data from the study results if your identifying details have already been removed.

### 5. How is this study being paid for?

No funds have been paid for this study.

### 6. Are there risks to me in taking part in this study?

The foreseeable risks in taking part in this study are: During the focus group interview, you may feel some questions we ask are stressful or upsetting; or you may have new questions about your health care. If you do not wish to answer a question, you may skip it and go to the next question; or you may stop immediately. If you need psychological support or need help to deal with the new questions, you may consult with your doctor or nurses or you may call NSW Cancer Council’s Cancer Information and Support service via 131120. The call will link to a cancer specialist from whom you may seek information and emotional support. This service only costs a local call from anywhere of Australia and secure for all people who are affected by cancer. And you may contact the National Translating and Interpreter Service via 131450 and ask for immediate phone interpreting service should you require language support.

If you are likely to experience breakthrough pain (that is ‘severe pain” not controlled by your regular pain medication(s)’) please bring your breakthrough analgesics with you, so that you can take this medication if you experience pain during the 90 minutes focus group. If your pain becomes unbearable and you are no longer able to continue the focus group, please inform the researchers who are leading the discussion immediately, so they can stop the interview and assist you manage your breakthrough pain. Please be advised that you do not have to attend the focus group if you are experiencing any pain at the time you come to the focus group but instead seek advice from you medical team.

**7. Will I benefit from the study?**

This study will not directly benefit you but the information you provided may help development of health strategies or interventions to improve cancer pain management services for Chinese migrant cancer patients in future.

**8. Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything, nor will you be paid.

**9. How will my confidentiality be protected?**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above and the HREC will have access to your details and results that will be held securely in a locked cabinet at Faculty of Health of UTS and/or on a password secured computer and a hard drive.

**10. What happens with the results?**

If you give us your permission by signing the consent document, we plan to discuss/publish the results in following ways:

- Publishing in a peer reviewed academic journal;
- Reporting in a doctoral thesis as required by UTS;
- Presenting at conferences or forums or workshops;
- Reporting to the HREC for monitoring purposes and to the sponsors (while it is applicable), and
- The results will be used to inform and guide the development of future cancer pain management: studies; health strategies; interventions and/or instrument (e.g. culture related pain assessment tool).

In any publication/reports, information will be provided in such a way that you cannot be identified.

**11. What should I do if I want to discuss this study further before I decide?**

When you have read this information, the researcher, Ms Xiangfeng Xu (Renee), will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on her mobile [redacted] *or her email: Xiangfeng.Xu@student.uts.edu.au.*

Alternatively, you may contact Professor Jane Phillips by her email (Jane.Phillips@uts.edu.au) or by her contact number (+61 2 9514 4822), should you have any questions about the study; or you may contact *[insert site principal investigator's contact details*], should you have any questions about the study.

### 12. Who should I contact if I have concerns about the conduct of this study?

This study has been approved by the South Eastern Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email SESLHD-RSO@health.nsw.gov.au and quote *HREC ref no: 16/294*.

The conduct of this study at the [*name of site*] has been authorised by the [*name of health district*]. Any person with concerns or complaints about the conduct of this study may also contact [*details of the Research Governance Officer of the health district*]

**Thank you for taking the time to consider this study.**
**If you wish to take part in it, please sign the attached consent form.**
**This information sheet is for you to keep.**

***[Insert name of local institution/s where research is being conducted]***

**CONSENT FORM**

[To be used in conjunction with a Participant Information Sheet]

**Chinese Migrants Cancer Pain Project**

1. I,…………………………..of........................
………………………………………..

agree to participate in the study described in the participant information statement

set out above ***(or attached to this form).***

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to ***the ………………………………………………………………… ……… (Insert the name of local study site where the research is being conducted).***

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact *Ms Xiangfeng Xu* on telephone *0481294207*, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Complaints may be directed to the Research Support Office, South Eastern Sydney Local Health District, Prince of Wales Hospital, Randwick NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email SESLHD-RSO@health.nsw.gov.au.

**Signature of participant** **Please PRINT name** **Date**

**[Or person responsible] (Insert or delete as necessary)**

_________________________ _____________________

_______________

**Signature of witness** **Please PRINT name** **Date**

___________________________ _________________________ _________________ **Signature of investigator** **Please PRINT name** **Date**

_________________________ _______________________

________________

**[Insert name of local institution where research is being conducted]**

## Chinese Migrants Cancer Pain Project

### REVOCATION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with ____________ *Hospital or my medical attendants*.

**Signature of participant** **Please PRINT name** **Date**

**[Or person responsible] (Insert or delete as necessary)**

________________________ ________________________

____________

The section for Revocation of Consent should be forwarded to Principal investigator: Name: Professor Jane L. Phillips, Director

Address: Centre for Cardiovascular and Chronic Care,
Faculty of Health, University of Technology Sydney (UTS)
Building 10, Level 3, 235 Jones St,
Ultimo NSW 2007 (PO Box 123)
Fax: + 61 2 9514 4474
Email: Jane.Phillips@uts.edu.au

## Appendix B-2: Participant information sheet and consent form − Patient (simplified Chinese)

### [Insert name of local institution/s where research is being conducted]

### 参与者信息和同意书 - 患者（简体中文）

### 华人移民癌症疼痛项目

邀请

我们邀请您参加一项关于文化对华人移民癌症患者疼痛管理经历和需求影响的研究。

该项研究由以下研究人员开展：

- Jane Philip 教授　悉尼科技大学健康系心血管及慢性疾病研究中心主任
- Tim Luckett 博士　悉尼科技大学健康系心血管及慢性疾病研究中心高级讲师
- Melanie Lovell 副教授 Greenwich 姑息治疗中心主任和悉尼大学医学院临床副教授
- Meera Agar 教授　悉尼西南地区卫生局姑息治疗主任医师
- Xiangfeng Xu 女士　悉尼科技大学健康系博士研究生

在您决定是否希望参加这项研究之前，请您一定要了解该研究项目的目的以及它所涉及的范围，这很重要。请您花时间仔细阅读以下信息; 并且如果您愿意的话, 还可以和别人进行讨论。

### 1. 该项研究的目的是什么？

该项研究旨在探讨文化对华人移民癌症患者疼痛管理的经历和需求的影响。

### 2. 我为何被邀请参与该项研究？

因为您符合参加这项调查的条件:1) 您出生在中国大陆、香港或者台湾；2)曾经或者目前正在一个癌症或者姑息治疗中心或是门诊接受癌症疼痛治疗。您的参加将有助于为在澳大利亚居住的华人移民癌症患者发展疼痛管理的策略或是干预措施。

### 3. 参加这项研究将涉及什么方面？

如果您同意参加这项研究，您需要与研究人员联系；或是允许研究人员和您联系，以便研究人员能把您和其他几位参加者分到一个小组；为您们安排合适的时间和地点对您们进行焦点小组访谈。您需要阅读您的医疗团队或是该项目的研究人员为您提供的《参与者信息和同意书》；并签署同意书。

焦点小组访谈将持续约 90 分钟；其中包括完成一个问卷调查。焦点小组访谈将由一位研究者用普通话或是或是广东话主持，并由一位秘书协助和做记录；访

谈将被录音后用以分析研究。在这项研究中收集到的任何可以用来识别您的信息将被保密。

### 4. 如果我不想参加这项调查；或参与后想要退出，会怎样？

参加这项研究纯属自愿。是否参加完全由您决定。如果您决定不参加，它将不会影响您现在或今后的治疗。无论您如何决定，都不会影响您和照顾您的工作人员之间的关系。

在参加这项研究之后，如果您希望的话，您可以在任何时候退出， 而且不用提供任何理由。您可以从焦点小组中退出；或者在我们开始或完成资料分析之前撤销您的回答。但是，您的资料可能无法从研究结果中撤销，因为可以识别您的信息已经被删除了。

### 5. 这项研究有资金来源吗？

目前没有。

### 6. 参与研究对我是否有风险？

参与该项研究可能预见的风险是：在焦点小组访谈期间，您有可能会发现访谈中的我们问的一些问题可能会让您感到紧张或郁闷；或者您可能会有关于您医疗保健方面的新的疑问。如果您不想回答访谈中的某个问题，您可以跳过它然后回答下一个问题或者立即停止访谈。如果您觉得您需要心理支持或是需要寻求帮助去解答您在健康方面所产生的新的疑问，您可以向您的医生和护士咨询。或者您可以拨打新南威尔州癌症协会的癌症信息与支持服务电话 131120。拨通电话后，您将可以和一位癌症专家交谈，寻求信息与精神支持。无论您在澳大利亚的任何地方，您只需要支付本地通话费就可以享受这项服务。并且这项服务是保密的、面向所有受癌症影响的人。如果您需要语言支持，您可以拨打国家翻译及口译员服务的电话 131450，要求即时电话翻译服务。

如果您有可能经历突破性疼痛（就是那种您平时常规服用的止痛药无法控制的“剧烈疼痛”），请您携带您用来控制突破性疼痛的止痛药， 以便当疼痛在 90 分钟的焦点小组访谈过程中发生的时候，您可以服用。 如果疼痛变得难以忍受，您不能继续焦点小组访谈，请您立即通知负责主持焦点小组访谈的研究者；以便她们能够停止访谈并协助您管理您的剧烈疼痛。 同时建议您，如果在要来参加焦点小组访谈时发生疼痛，您不必来参加访谈，而是应该寻求您的医疗团队的建议。

### 7. 我将从研究中获益吗？

您将不会因为参加这项研究而直接受益，但您提供的信息可能在将来会有助于发展卫生策略或干预措施，改善对华人移民癌症病人的疼痛管理方面的医疗服务。

### 8. 参加此项研究会对让我产生任何费用吗; 我是否会获得报酬？

参加这项研究将不会对您产生任何费用； 同时您将不会得到任何报酬。

### 9. 我的隐私将如何得到保护？

所有收集到的关于您与此项研究有关的任何可识别的信息是保密的；只有在获得您的允许之后或是除了法律要求之外才会公开。只有上面提到名字的研究人员和

人类研究伦理委员会才能查阅您的详细资料和结果。这些资料和结果将被锁在悉尼科技大学健康系的柜子里并且、或是储存在密码保护的电脑和移动硬盘里。

### 10. 研究结果如何处理？

如果您签署同意书表示同意，我们计划通过以下方式讨论或是发表研究结果：

- 发表在同行评审的学术期刊上；
- 按照悉尼科技大学的要求通过博士论文进行报告；
- 在会议、论坛或者培训班进行交流报告；
- 按照人类研究伦理委员会的监管要求提交报告，以及如果适用的话向研究资助者的提交报告；
- 并且研究结果将在未来为发展癌症疼痛管理的研究项目、健康策略、干预措施以及量表（例如：文化相关的疼痛评估表）提供信息和指导。

无论在任何出版物或者报告中，都不会提及可以识别您的信息。

### 11. 在我做出决定之前如果我想对这项研究进行进一步讨论，应该怎么办？

当您阅读了这些信息后，Xiangfeng Xu (Renee) 女士可以和您进一步讨论这些信息并回答您的任何疑问。如果您在研究的任何阶段希望了解更多信息，请通过她电子邮件 Xiangfeng.Xu@student.uts.edu.au ; 或是拨打她的手机 [redacted] 与她联系。

或者您可以通过邮件或者电话和 Jane Phillips 教授联系；她的邮箱地址是：Jane.Phillips@uts.edu.au；电话：+61 2 9514 4822。或者您可以联系[在此插入项目研究点主要负责的研究者的联系方式]， 如果您对这项研究有任何问题。.

### 12. 如果我对研究的开展有任何疑虑，应该和谁联系？

该项研究已获得新南威尔士悉尼东南地区卫生局人类研究伦理委员会的批准。任何人如果对这项研究的开展有任何疑虑或者要进行投诉的话，请与指定的接受研究参与者投诉的研究支持办公室联系。您可以拨打电话：02 9382 3587； 或是发送邮件到: SESLHD-RSO@health.nsw.org.au. 联系时请引用该研究项目的人类研究伦理委员会的项目号: [*HREC ref no: 16/294*].

该研究项目是在〔*插入项目地点*〕开展的；已经获得了〔*插入卫生局的名字*〕的批准。 任何人对该研究的开展有任何疑虑或是要进行投诉的话，也可以和*〔插入XX卫生局的研究治理官员的具体联系方式〕*联系。

**感谢您花时间考虑该项研究。**

**如果您希望参加该研究项目，请在随后附上的同意书上签字。**

**本资料单由您保存。**

## [ 插入项目研究点的名称]

## 同意书

[ 此同意书要与参与者信息说明共同使用]

## 华人移民癌症疼痛项目

1. 我，................................................

   现住：......................................................................................................................
   同意参加以上（或本同意书随附的）参与者信息申明中所陈述的研究。

2. 我承认我已阅读了参与者信息声明。该申明说明了我为何被选中参与该研究、研究的目的和性质以及调查可能涉及的风险。而且关于声明的内容我已经得到满意的解释。

3. 在签署本同意书之前，我已得到机会询问关于参加调查可能遭受到的任何身体和精神伤害的问题；并得到了满意的答复。

4. 我知道我可以随时退出这项研究；而且这不会损害我与.................. [ 插入项目研究点的名称]的关系。

5. 我同意在无法识别我的身份的前提下，从研究结果中收集的研究数据可以被发表。

6. 我知道如果我对参与这项研究有任何疑问，可以致电 [redacted] 联系 Xiangfeng Xu 女士。她将很乐意回答我的这些问题。

7. 我承认已收到本《同意书》和《参与者信息声明》。

如果要进行投诉的话，我可以直接请与新南威尔士悉尼东南地区卫生局人类研究伦理委员会研究支持办公室联系。该办公室位于澳大利亚新南威尔士州 Randwick 区（邮编：2031），威尔士王子医院。电话：02 9382 3587；传真：02 9382 2813；电子邮件地址: SESLHD-RSO@health.nsw.org.au. 联系时请引用该研究项目的人类研究伦理委员会的项目号: *HREC ref no: 16/294*

**参与者签名** **请用正体填写姓名** **日期**

**[或负责人]**

______________________ ______________________ ________________

**见证人签名** **请用正体填写姓名** **日期**

**研究人员签名** **请用正体填写姓名** **日期**

## [插入项目研究点的名称]
## 华人移民癌症疼痛项目

### 撤销同意书

我特此希望撤回我同意参加上述研究的承诺；这样的退出不会影响任何治疗或者我和_____________医院或我的医疗人员的关系。

**参与者签名** **请用正体填写姓名** **日期**

**[或负责人]**

**请将此撤销同意书转发给该研究项目的负责人：**

姓名: Jane L. Phillips 教授、主任
地址：Centre for Cardiovascular and Chronic Care,
Faculty of Health, University of Technology Sydney (UTS)
Building 10, Level 3, 235 Jones St,
Ultimo NSW 2007 (PO Box 123)

新南威尔士州 Ultimo 市 Jones 街 235 号 10 号楼 3 楼
悉尼科技大学健康科学系心血管及慢性疾病中心
邮编: 2007
邮箱号: PO Box 123
传真: + 61 2 9514 4474
电子邮箱: Jane.Phillips@uts.edu.au

## Appendix B-3: Participant information sheet and consent form − Patient (traditional Chinese)

**[Insert name of local institution/s where research is being conducted]**

### 參與者信息和同意書 – 患者（繁體中文）

### 華人移民癌癥疼痛項目

邀請

我們邀請您參加壹項關於文化對華人移民癌癥患者疼痛管理經歷和需求影響的研究。

該項研究由以下研究人員開展：

- Jane Philip 教授 悉尼科技大學健康系心血管及慢性疾病研究中心主任
- Tim Luckett 博士 悉尼科技大學健康系心血管及慢性疾病研究中心高級講師
- Melanie Lovell 副教授 Greenwich 姑息治療中心主任和悉尼大學醫學院
  臨床副教授
- Meera Agar 教授 悉尼西南地區衛生局姑息治療主任醫師
- Xiangfeng Xu 女士 悉尼科技大學健康系博士研究生

在您決定是否希望參加這項研究之前，請您壹定要了解該研究項目的目的以及它所涉及的範圍，這很重要。請您花時間仔細閱讀以下信息；並且如果您願意的話，還可以和別人進行討論。

**1. 該項研究的目的是什麼？**

該項研究旨在探討文化對華人移民癌癥患者疼痛管理的經歷和需求的影響。

**2. 我為何被邀請參與該項研究？**

因為您符合參加這項調查的條件:1) 您出生在中國大陸、香港或者臺灣；2)曾經或者目前正在壹個癌癥或者姑息治療中心或是門診接受癌癥疼痛治療。您的參加將有助於為在澳大利亞居住的華人移民癌癥患者發展疼痛管理的策略或是幹預措施。

**3. 參加這項研究將涉及什麼方面？**

如果您同意參加這項研究，您需要與研究人員聯系；或是允許研究人員和您聯系，以便研究人員能把您和其他幾位參加者分到壹個小組；為您們安排合適的時間和地點對您們進行焦點小組訪談。您需要閱讀您的醫療團隊或是該項目的研究人員為您提供的《參與者信息和同意書》；並簽署同意書。

焦點小組訪談將持續約 90 分鐘；其中包括完成壹個問卷調查。焦點小組訪談將由壹位研究者用普通話或是廣東話主持，並由壹位秘書協助和做記錄；訪談將被錄音後用以分析研究。在這項研究中收集到的任何可以用來識別您的信息將被保密。

### 4. 如果我不想參加這項調查；或參與後想要退出，會怎樣？

參加這項研究純屬自願。是否參加完全由您決定。如果您決定不參加，它將不會影響您現在或今後的治療。無論您如何決定，都不會影響您和照顧您的工作人員之間的關系。

在參加這項研究之後，如果您希望的話，您可以在任何時候退出， 而且不用提供任何理由。您可以從焦點小組中退出；或者在我們開始或完成資料分析之前撤銷您的回答。但是，您的資料可能無法從研究結果中撤銷，因為可以識別您的信息已經被刪除了。

### 5. 這項研究有資金來源嗎？

目前沒有。

### 6. 參與研究對我是否有風險？

參與該項研究可能預見的風險是：在焦點小組訪談期間，您有可能會發現訪談中的我們問的壹些問題可能會讓您感到緊張或郁悶；或者您可能會有關於您醫療保健方面的新的疑問。如果您不想回答訪談中的某個問題，您可以跳過它然後回答下壹個問題或者立即停止訪談。如果您覺得您需要心理支持或是需要尋求幫助去解答您在健康方面所產生的新的疑問，您可以向您的醫生和護士咨詢。或者您可以撥打新南威爾州癌癥協會的癌癥信息與支持服務電話 131120。撥通電話後，您將可以和壹位癌癥專家交談，尋求信息與精神支持。無論您在澳大利亞的任何地方，您只需要支付本地通話費就可以享受這項服務。並且這項服務是保密的、面向所有受癌癥影響的人。如果您需要語言支持，您可以撥打國家翻譯及口譯員服務的電話 131450，要求即時電話翻譯服務。

如果您有可能經歷突破性疼痛（就是那種您平時常規服用的止痛藥無法控制的“劇烈疼痛”），請您攜帶您用來控制突破性疼痛的止痛藥， 以便當疼痛在 90 分鐘的焦點小組訪談過程中發生的時候，您可以服用。 如果疼痛變得難以忍受，您不能繼續焦點小組訪談，請您立即通知負責主持焦點小組訪談的研究者；以便她們能夠停止訪談並協助您管理您的劇烈疼痛。 同時建議您，如果在要來參加焦點小組訪談時發生疼痛，您不必來參加訪談，而是應該尋求您的醫療團隊的建議。

### 7. 我將從研究中獲益嗎？

您將不會因為參加這項研究而直接受益，但您提供的信息可能在將來會有助於發展衛生策略或幹預措施，改善對華人移民癌癥病人的疼痛管理方面的醫療服務。

### 8. 參加此項研究會對讓我產生任何費用嗎；我是否會獲得報酬？

參加這項研究將不會對您產生任何費用； 同時您將不會得到任何報酬。

### 9. 我的隱私將如何得到保護？

所有收集到的關於您與此項研究有關的任何可識別的信息是保密的；只有在獲得您的允許之後或是除了法律要求之外才會公開。只有上面提到名字的研究人員和

人類研究倫理委員會才能查閱您的詳細資料和結果。這些資料和結果將被鎖在悉尼科技大學健康系的櫃子裏並且、或是儲存在密碼保護的電腦和移動硬盤裏。

### 10. 研究結果如何處理？

如果您簽署同意書表示同意，我們計劃通過以下方式討論或是發表研究結果：

- 發表在同行評審的學術期刊上；
- 按照悉尼科技大學的要求通過博士論文進行報告；
- 在會議、論壇或者培訓班進行交流報告；
- 按照人類研究倫理委員會的監管要求提交報告，以及如果適用的話向研究資助者提交報告；
- 並且研究結果將在未來為發展癌癥疼痛管理的研究項目、健康策略、幹預措施以及量表（例如：文化相關的疼痛評估表）提供信息和指導。

無論在任何出版物或者報告中，都不會提及可以識別您的信息。

### 11. 在我做出決定之前如果我想對這項研究進行進壹步討論，應該怎麼辦？

當您閱讀了這些信息後，Xiangfeng Xu (Renee) 女士可以和您進壹步討論這些信息並回答您的任何疑問。如果您在研究的任何階段希望了解更多信息，請通過她電子郵件 Xiangfeng.Xu@student.uts.edu.au; 或是撥打她的手機 [redacted] 與她聯系。

或者您可以通過郵件或者電話和 Jane Phillips 教授聯系；她的郵箱地址是：Jane.Phillips@uts.edu.au；電話：+61 2 9514 4822。或者您可以聯系[在此插入項目研究點主要負責的研究者的聯系方式]， 如果您對這項研究有任何問題。

### 12. 如果我對研究的開展有任何疑慮，應該和誰聯系？

該項研究已獲得新南威爾士悉尼東南地區衛生局人類研究倫理委員會的批準。任何人如果對這項研究的開展有任何疑慮或者要進行投訴的話，請與指定的接受研究參與者投訴的研究支持辦公室聯系。您可以撥打電話：02 9382 3587； 或是發送郵件到: SESLHD-RSO@health.nsw.org.au. 聯系時請引用該研究項目的人類研究倫理委員會的項目號: [HREC ref no: 16/294].

該研究項目是在〔插入項目地點〕開展的；已經獲得了〔插入衛生局的名字〕的批準。 任何人對該研究的開展有任何疑慮或是要進行投訴的話，也可以和〔插入 XX 衛生局的研究治理官員的具體聯系方式〕聯系。

**感謝您花時間考慮該項研究。**

**如果您希望參加該研究項目，請在隨後附上的同意書上簽字。**

**本資料單由您保存。**

[ 插入項目研究點的名稱]

## 同意書

[ 此同意書要與參與者信息說明共同使用]

華人移民癌癥疼痛項目

1. 我，.............................................

現住：..........................................................

同意參加以上（或本同意書隨附的）參與者信息申明中所陳述的研究。

2. 我承認我已閱讀了參與者信息聲明。該申明說明了我為何被選中參與該研究、研究的目的和性質以及調查可能涉及的風險。而且關於聲明的內容我已經得到滿意的解釋。

3. 在簽署本同意書之前，我已得到機會詢問關於參加調查可能遭受到的任何身體和精神傷害的問題；並得到了滿意的答復。

4. 我知道我可以隨時退出這項研究；而且這不會損害我與................. [插入項目研究點的名稱] 的關系。

5. 我同意在無法識別我的身份的前提下，從研究結果中收集的研究數據可以被發表。

6. 我知道如果我對參與這項研究有任何疑問，可以致電 [redacted] 聯系 Xiangfeng Xu 女士。她將很樂意回答我的這些問題。

7. 我承認已收到本《同意書》和《參與者信息聲明》。

如果要進行投訴的話，我可以直接與新南威爾士悉尼東南地區衛生局人類研究倫理委員會研究支持辦公室聯系。該辦公室位於澳大利亞新南威爾士州 Randwick 區（郵編：2031），威爾士王子醫院。電話：02 9382 3587；傳真：02 9382 2813；電子郵件地址: SESLHD-RSO@health.nsw.org.au. 聯系時請引用該研究項目的人類研究倫理委員會的項目號: HREC ref no: 16/294

| | | |
|---|---|---|
| 參與者簽名<br>[或負責人] | 請用正體填寫姓名 | 日期 |
| 見證人簽名 | 請用正體填寫姓名 | 日期 |
| 研究人員簽名 | 請用正體填寫姓名 | 日期 |

______________________ ________________________________

___________________

[插入項目研究點的名稱]

華人移民癌癥疼痛項目

**撤銷同意書**

我特此希望撤回我同意參加上述研究的承諾；這樣的退出不會影響任何治療或者我和_____________醫院或我的醫療人員的關係。

| | | |
|---|---|---|
| **參與者簽名**<br>***[或負責人]*** | **請用正體填寫姓名** | **日期** |
| ______________________ | ______________________ | ________________ |

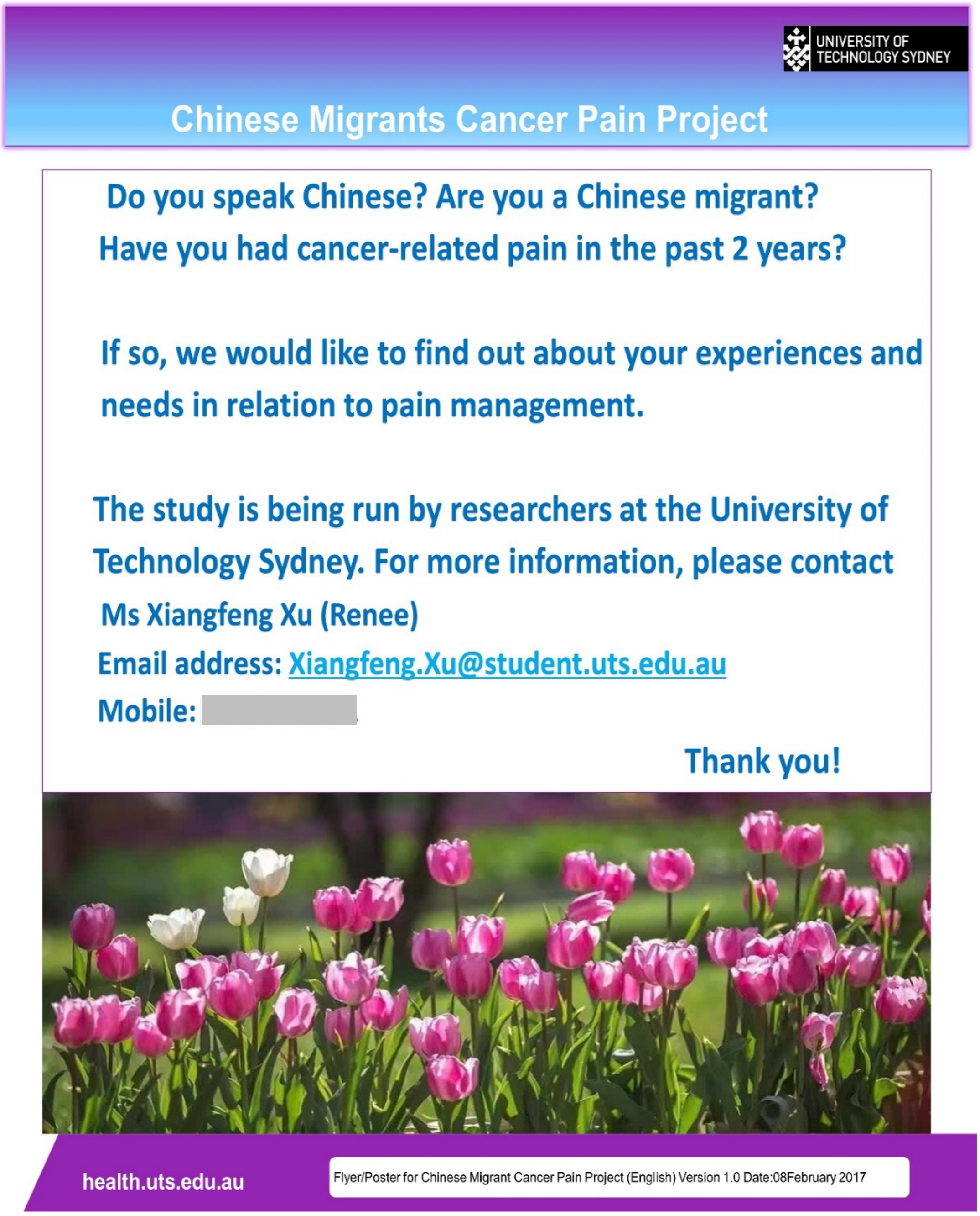
姓名: Jane L. Phillips 教授、主任

地址：Centre for Cardiovascular and Chronic Care,
Faculty of Health, University of Technology Sydney (UTS)
Building 10, Level 3, 235 Jones St,
Ultimo NSW 2007 (PO Box 123)

新南威爾士州 Ultimo 市 Jones 街 235 號 10 號樓 3 樓
悉尼科技大學健康科學系心血管及慢性疾病中心
郵編: 2007
郵箱號: PO Box 123
傳真: + 61 2 9514 4474
電子郵箱: Jane.Phillips@uts.edu.au

# Appendix C: Invitation letters/posters – Patient

## Appendix C-1: Invitation poster (English)



**Chinese Migrants Cancer Pain Project**

**Do you speak Chinese? Are you a Chinese migrant?**
**Have you had cancer-related pain in the past 2 years?**

**If so, we would like to find out about your experiences and needs in relation to pain management.**

**The study is being run by researchers at the University of Technology Sydney. For more information, please contact**
**Ms Xiangfeng Xu (Renee)**
**Email address: Xiangfeng.Xu@student.uts.edu.au**
**Mobile:** [redacted]

**Thank you!**

health.uts.edu.au

Flyer/Poster for Chinese Migrant Cancer Pain Project (English) Version 1.0 Date:08February 2017

## Appendix C-2: Invitation poster – Patient (simplified Chinese)

**Chinese Migrants Cancer Pain Project**

您会讲中文吗？您是华人移民吗？在过去的两年里您有过与癌症相关的疼痛吗？

我们想了解您在疼痛管理方面的经历和需求。悉尼科技大学的研究人员正在开展这项研究。

如果您想了解更多信息，请联系：
徐湘凤 (Renee) 女士
电子邮件：Xiangfeng.Xu@student.uts.edu.au
手机：[redacted]

谢谢！

health.uts.edu.au

Flyer/Poster for Chinese Migrants Cancer Pain Project (Simplified Chinese) Version 1 Date:08 February 2017

## Appendix C-3: Invitation poster – Patient (traditional Chinese)

UNIVERSITY OF TECHNOLOGY SYDNEY

**Chinese Migrants Cancer Pain Project**

**您會講中文嗎？您是華人移民嗎 ？在過去的兩年裏您有過與癌癥相關的疼痛嗎？**

**我們想了解您在疼痛管理方面的經歷和需求。悉尼科技大學的研究人員正在開展這項研究。**

**如果您想了解更多信息，請聯系：**
**徐湘鳳 (Renee) 女士**
**電子郵件：Xiangfeng.Xu@student.uts.edu.au**
**手機：**[redacted]

**謝謝！**

health.uts.edu.au

Flyer/Poster for Chinese Migrant Cancer Pain Project (Traditional Chinese) Version 1.0 Date:08 February 2017

## Appendix D: Focus group questionnaires − Patient

### Appendix C-1: Focus group questionnaire − Patient (English)

Section to be completed by the researcher: 该部分由研究人员填写

Participant code: _______________ Time & Date: ________________

Focus group number: __________ Venue: ____________________

**Dear participant:**

Thank you for taking part in the *Chinese Migrants Cancer Pain Project*. This questionnaire consists of two sections: participant's demographic data and the short Chinese vision of Barriers Questionnaire. Please follow the instruction for each section to complete the questionnaire.

**Part A: Participant demographic data**

Please read following information; and check ( √ ) the box in front of the item that is appropriate for you or write down the information over the underlines:

1. **Age: ___ years**
2. **Gender:** ☐ Male ☐ Female
3. **Years living in Australia: ________ years**
4. **Marital status:**
   - ☐ Single
   - ☐ Married or in a long term relationship
   - ☐ Divorced/separated
   - ☐ Widowed
5. **Australian residential postcode: ____________**
6. **Language spoken at home:**
   - ☐ English
   - ☐ Mandarin
   - ☐ Cantonese

☐ Other; please specify: ____________

7. **Level of the highest educational qualification you have completed:**

☐ Primary school ☐ Middle school ☐ Secondary School ☐ Diploma ☐ Advanced diploma ☐ Bachelor Degree

☐ Post graduate education (Graduate certificate/Master Degree/Doctoral degree)

8. **What are your current employment status?**

☐ Full-time ☐ Part-time ☐ Retired ☐ Unemployed

9. **What is your primary cancer diagnosis:**

☐ Liver ☐ Lung ☐ Stomach (Gastric)

☐ Colorectal ☐ Cervical ☐ Breast

☐ Other, please specific: ______________

10. **Please rate the worst pain you have ever had in last two years:**

from 0 (no pain) to 10 (worst pain imaginable) _______________

11. **Where did/do you get your pain treated? Tick as many as apply**

☐ Cancer care centre

☐ Palliative care centre

☐ GP (General Practitioner)

☐ Traditional Chinese medicine doctor

☐ Other, please specify: _________________

12. **What type of treatment have you received for the cancer pain: Tick as many as apply**

1) Simple pain medication：*Tick as many as apply*

☐ Aspirin

☐ Paracetamol

☐ Ibuprofen or Nurofen

☐ Others, please specify: _______________________

2) Stronger pain medication (Oral/patch)：Tick as many as apply

☐ Codeine

☐ Dihydrocodeine /Hydrocodone

☐ Oxycodone

☐ Methadone

☐ Fentanyl

☐ Others, please specify: ______________

3) Traditional Chinese Medicine: *Please tick as many as apply*

☐ Chinese herbs

☐ Acupuncture

☐ Cupping

☐ Others, please specify: ___________________________

4) Non- pharmacological therapies: *Please tick as many as apply*

☐ Massage

☐ Heat

☐ Ice

☐ Music

☐ Qigong

☐ Taijiquan

☐ Others, please specify: ____________

## Part B: Short Version of Barrier Questionnaire

Dear Participants,

Following are 9 statements about pain and pain medication. Please circle the number at the column after each statement based on your own opinions (please be aware that you may only select one number for each item). From 0 to 5, 0 refers to strongly disagree; and 5 refers strongly agree. Your opinions are important which may help medical and nursing staff to effectively improve patients' pain management. Thank you!

| | **Strongly Disagree** | | | | | **Strongly Agree** |
|---|---|---|---|---|---|---|
| 1. I am afraid to get addicted to pain medication. | 0 | 1 | 2 | 3 | 4 | 5 |
| 2. The experience of pain is a sign that illness has become worse. | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. Pain medication should be "saved" in case of the pain becoming worse. | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. Pain medication cannot really control the pain. | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. I am predestined to bear the pain. | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. Pain medications are better given on an as-needed instead of on an around-the-clock basis. | 0 | 1 | 2 | 3 | 4 | 5 |
| 7. Pain medicine will cause harm to kidney or liver or stomach. | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. The patients often complain to doctors about the pain, which might distract the doctors' attention from curing the diseases. | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. Doctors and nurses might find it annoying to be told about pain. | 0 | 1 | 2 | 3 | 4 | 5 |

## Appendix D-2: Focus group questionnaire − Patient (simplified Chinese)

### 患者焦点小组问卷调查（简体中文）

Section to be completed by the researcher: 该部分由研究人员填写

Participant code: _______________ Time & Date: ________________

Focus group number: __________ Venue: ____________________

**Dear participant，**
Thank you for taking part in the *Chinese Migrants Cancer Pain Project*. This questionnaire consists of two sections: participant's demographic data and the short Chinese vision of Barriers Questionnaire. Please follow the instruction for each section to complete the questionnaire.

亲爱的参与者：

感谢您对 ***"华人移民癌症疼痛项目"*** 的支持。这份问卷调查包含两个部分：《参与者人口学统计信息》和《中文简短版止痛药障碍因子问卷调查》。请根据要求填写。

**Part A: Participant Demographic Data**

Please read following information; and check ( √ ) the box in front of the item that is appropriate for you or write down the information over the underlines:

### 第一部分：参与者人口学信息统计

请阅读下列信息，请在您认为合适的选项前的格子里打勾；或者在下划线上面填写您的答复。

1. **Age: ___ years 年龄：__________岁**
2. **Gender:** □ Male □ Female **性别：** □ 男 □ 女
3. **Years living in Australia: _______ Years 在澳大利亚居住的时间 ___________年**
4. **Marital status: 婚姻状况**

   □ Single 单身

   □ Married or in a long term relationship 已婚或是处于长期的（伴侣）关系中

   □ Divorced/separated 离婚/分居

☐ Widowed 孀居

5. **Australian residential postcode: _____ 澳大利亚住址的邮政编码：______**

6. **Language spoken at home: 在家里所使用的语言**

☐ English 英文

☐ Mandarin 普通话

☐ Cantonese 广东话

☐ Other; please specify: ________ 其它， 请注明：__________

7. **Level of the highest educational qualification you have completed: 您的最高学历：**

☐ Primary school 小学

☐ Middle school 中学

☐ Secondary School 高中

☐ Diploma 中专

☐ Advanced diploma 大专

☐ Bachelor Degree 本科

☐ Post graduate education (Graduate certificate/Master Degree/Doctoral degree)
研究生教育 （研究生证书/硕士/博士）

8. **What are your current employment status? 您目前的工作状态是什么？**

☐ Full-time 全职

☐ Part-time 兼职

☐ Retired 退休

☐ Unemployed 失业

9. **What is your primary cancer diagnosis? 您最初的癌症诊断是什么？**

☐ Liver 肝 (癌)

☐ Lung 肺 (癌)

☐ Stomach (Gastric) 胃 (癌)

☐ Colorectal 结直肠 (癌)

☐ Cervical 宫颈 (癌)

☐ Breast 乳腺 (癌)

☐ Other, please specific: __________ 其它， 请注明_______________

10. **Please rate the worst pain you have ever had in last two years:** from 0 (no pain) to 10 (worst pain imaginable) ________________

    **请评估您在过去两年中经受过的最厉害的疼痛：**从 0 （没有疼痛）到 10 (可以想象到的最厉害的疼痛) __________________________

11. **Where did/do you get your pain treated?** ***Tick as many as apply***

    **您在什么地方得到疼痛治疗的？*请选择所有适用的选项***

☐ Cancer care center 癌症护理治疗中心

☐ Palliative care center 姑息治疗中心

☐ GP (General Practitioner) 全科医生

☐ Traditional Chinese medicine doctor 中医师

☐ Other, please specify: _______________ 其它， 请注明

_______________

12. **What type of treatment have you received for the cancer pain？?** ***Tick as many as apply***

    **您曾经接受过什么样的癌症疼痛治疗？*请选择所有适用的选项***

1) Simple pain medication：Tick as many as apply

   普通的止痛药：*请选择所有适用的选项*

☐ Aspirin 阿司匹林

☐ Paracetamol 扑热息痛

☐ Ibuprofen or Nurofen 布洛芬

☐ Others, please specify: _____________其它， 请注明

_______________

2) Stronger pain medication (Oral/patch)：*Tick as many as apply*

强止痛药（口服/贴片）：*请选择所有适用的选项*

☐ Codeine　可待因

☐ Dihydrocodeine /Hydrocodone 双氢可待因/氢可酮

☐ Oxycodone 羟考酮

☐ Methadone 美沙酮

☐ Fentanyl 芬太尼

☐ Others, please specify: ______________ 其它，请注明 ________________

3) Traditional Chinese Medicine: *Please tick as many as apply*

中医：*请选择所有适用的选项*

☐ Chinese herbs 中草药

☐ Acupuncture 针灸

☐ Cupping 拔火罐

☐ Others, please specify: _________ 其它，请注明_____________

4) Non- pharmacological therapies: Please tick as many as apply

非药物疗法：*请选择所有适用的选项*

☐ Massage 按摩

☐ Heat 热(敷）

☐ Ice 冰(袋）

☐ Music 音乐

☐ Qigong 气功

☐ Taijiquan 太极拳

☐ Others, please specify: ____________其它，请注明________________

## 第二部分：中文简短版止痛药障碍因子问卷 （简体中文）

尊敬的参与者：

下面有 9 个关于疼痛和止痛药的选项。 请根据您自己的意见，在相应栏目里的数字上画圈（请您注意每个栏目只能选一个数字）。从 0 到 5，0 分代表完全不同意；5 分代表完全同意。您的意见很重要，将可以帮助医护人员有效地改善病人疼痛的管理。 谢谢！

| | **完全不同意** | | | | | **完全同意** |
|---|---|---|---|---|---|---|
| 1. 我担心用了止痛药可能会上瘾。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 2. 我觉得痛代表病情加重了。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. 止痛药应该留在以后万一疼痛加剧时使用。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. 止痛药并不能真正的控制疼痛。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. 我命中注定要承受现在的疼痛之苦。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. 我觉得止痛药应该痛的时候才用，而不是按照时间用。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 7. 止痛药吃多了会伤肾、伤肝、伤胃。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. 时常向医师抱怨疼痛，可能会分散医师对治癒疾病的注意力。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. 如果常向医护人员抱怨疼痛，医护人员可能会觉得不耐烦。 | 0 | 1 | 2 | 3 | 4 | 5 |

## Appendix D-3: Focus group questionnaire − Patient (traditional Chinese)

### 焦點小組問卷調查（繁體中文）

This section to be completed by the researcher: 該部分由研究人員填寫

Participant code: ______________ Time & Date: _______________

Focus group number: _________ Venue: ___________________

Dear participant,

Thank you for taking part in the Chinese Migrants Cancer Pain Project. This questionnaire consists of two sections: participant’s demographic data and the short Chinese vision of Barriers Questionnaire. Please follow the instruction for each section to complete the questionnaire.

親愛的參與者：

感謝您對 “華人移民癌癥疼痛項目” 的支持。這份問卷調查包含兩个部分：《參與者人口學統計信息》和《中文簡短版止痛藥障礙因子問卷調查》。請根據要求填寫

## Part A: Participant Demographic Data Sheet

Please read following information; and check (√) the box in front of the item that is appropriate for you or write down the information over the underlines or the blank textbook:

**第一部分：參與者人口學信息統計**

請閱讀下列信息，請在您認為合適的選項前的格子裏打勾；或者在下劃線上面或者空白欄裏填寫您的答復。

1. Age: ___ years 年齡：__________歲

2. Gender: □Male □Female 性別：□男 □女

3. Years living in Australia: ________ Years

在澳大利亞居住的時間___________年

4. Marital status: 婚姻狀況

□Single 單身

□Married or in a long term relationship 已婚或是處於長期的（伴侶）關系中

□Divorced/separated 離婚/分居

□Widowed 孀居

**5. Australian residential postcode:** ____________

澳大利亞住址的郵政編碼：____________

**6. Language spoken at home:** 在家裏所使用的語言

□English 英文

□Mandarin 普通話

□Cantonese 廣東話

□Other; please specify: ________ 其它， 請註明：__________

**7. Level of the highest educational qualification you have completed:**

您的最高學歷：

□Primary school 小學

□Middle school 中學

□Secondary School 高中

□Diploma 中專

□Advanced diploma 大專

□Bachelor Degree 本科

□Post graduate education (Graduate certificate/Master Degree/Doctoral degree) 研究生教育 （研究生證書/碩士/博士）

**8. What are your current employment status?** 您目前的工作狀態是什麼？

□Full-time 全職

□Part-time 兼職

□Retired 退休

□Unemployed 失業

**9. What is your primary cancer diagnosis?** 您最初的癌癥診斷是什麼？

□Liver 肝（癌）

□Lung 肺（癌）

□Stomach (Gastric) 胃（癌）

□Colorectal 結直腸（癌）

□Cervical 宮頸（癌）

□Breast 乳腺（癌）

□Other, please specific: __________ 其它， 請註明_______________

**10. Please rate the worst pain you have ever had in last two years:** from 0 (no pain) to 10 (worst pain imaginable) ________________

請評估您在過去兩年中經受過的最厲害的疼痛：從0 （沒有疼痛）到 10（可以想象到的最厲害的疼痛） __________________________

**11. Where did/do you get your pain treated? Tick as many as apply**

您在什麼地方得到疼痛治療的？請選擇所有適用的選項

□Cancer care center 癌癥護理治療中心

□Palliative care center 姑息治療中心

□GP (General Practitioner) 全科醫生

□Traditional Chinese medicine doctor 中醫師

□Other, please specify: _______________ 其它， 請註明_______________

**12. What type of treatment have you received for the cancer pain? ? Tick as many as apply**

您曾經接受過什麼樣的癌癥疼痛治療？請選擇所有適用的選項

**1) Simple pain medication：Tick as many as apply**

普通的止痛藥：請選擇所有適用的選項

□ Aspirin 阿司匹林

□ Paracetamol 撲熱息痛

□ Nurofen 布洛芬

□ Others, please specify: _____________其它， 請註明_______________

**2) Stronger pain medication (Oral/patch) ：Tick as many as apply**

強止痛藥（口服/貼片）：請選擇所有適用的選項

□ Codeine 可待因

□ Dihydrocodeine /Hydrocodone 雙氫可待因/氫可酮

□ Oxycodone 羥考酮

□ Methadone 美沙酮

□ Fentanyl 芬太尼

□ Others, please specify: _____________ 其它， 請註明_______________

**3) Traditional Chinese Medicine: Please tick as many as apply**

中醫：請選擇所有適用的選項

□ Chinese herbs 中草藥

□ Acupuncture 針灸

□ Cupping 拔火罐

□ Others, please specify: ________ 其它， 請註明____________

4) Non- pharmacological therapies: Please tick as many as apply

非藥物療法：請選擇所有適用的選項

□ Massage 按摩

□ Heat 熱(敷）

□ Ice 冰(袋）

□ Music 音樂

□ Qigong 氣功

□ Taijiquan 太極拳

□ Others, please specify: ___________其它， 請註明_________________

## 第二部分：中文簡短版止痛藥障礙因子問卷 （繁体中文）

尊敬的參與者：

下面有 9 个關於疼痛和止痛藥的选项。 请根據您自己的意见，在相應欄目的數字上畫圈（請您注意每個欄目只能選一個數字）。從 0 到 5，0 分代表完全不同意；5 分代表完全同意。您的意見很重要，將可以幫助醫護人員有效地改善病人疼痛的管理。谢谢！

| | 完全不同意 | | | | | 完全同意 |
|---|---|---|---|---|---|---|
| 2. 我擔心用了止痛藥可能會上癮。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. 我覺得痛代表病情加重了。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. 止痛藥應該留在以後萬一疼痛加劇時使用。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. 止痛藥並不能真正的控制疼痛。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. 我命中注定要承受現在的疼痛之苦。 | 0 | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 7. 我覺得止痛藥應該痛的時候才用，而不是按照時間用。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. 止痛藥吃多了會傷腎、傷肝、傷胃。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. 時常向醫師抱怨疼痛，可能會分散醫師對治癒疾病的注意力。 | 0 | 1 | 2 | 3 | 4 | 5 |
| 10. 如果常向醫護人員抱怨疼痛，醫護人員可能會覺得不耐煩。 | 0 | 1 | 2 | 3 | 4 | 5 |

# Appendix E: Focus group question routes – Patient

## Appendix E-1: Focus group question route – Patient (English)

Researcher’s notes: The questions are developed based on the Leininger’s Inquiry Modes of 12 Domain of Inquiry (Wehbe-Alamah and McFarland, 2015). These domains are listed for the purpose of data analysis and should not be mentioned during the focus group.

**A. Domain 1 ‘Worldview’，Domain 2 ‘Ethnohistory’ & Domain 12 ‘General and specific nursing care factors’**

1. I am interested to find out a little about your cancer pain. How did the pain affect your life?
2. How do you decide to seek assistance for your cancer pain?
3. What is the meaning of pain management to you?
4. Have you found any barriers or facilitators for you managing your pain at home?

**B. Domain 4 ‘Cultural values, beliefs, and lifeways’& Domain 5 ‘Religious/spiritual/philosophical factors’：**

5. Do you think the Chinese cultural and social values may influence your cancer pain management experiences and needs? (Please Clarify).

**C. Domain 11 ‘Professional and generic (folk or lay) care beliefs and practices’：**

6. How can different health professionals best help you manage your cancer pain?

**D. Domain 3 ‘Kinship and social factors’:**

7. What are the things that your family members and/or friends do to support you manage your cancer pain management?

**E. Domain 7 ‘Economic factors & Domain 8 ‘Political and legal factors’：**

8. I am wondering if there are any economic or other factors that have ever limited your access to pain management at your cancer service.

**F. Domain 6 ‘Technological factors’, Domain 9 ‘Educational factors & Domain 10 ‘Language and communications factors’:**

9. How would you like to communicate your pain management related issues with others (e.g. your doctors/nurses/families)?
10. What information and technology support do you need to help you control your cancer pain?

## Appendix E-2: Focus group question route −Patient (simplified Chinese)

### 患者焦点小组问题提纲（简体中文）

Researcher’s notes: The questions are developed based on the Leininger’s Inquiry Modes of 12 Domain of Inquiry (Wehbe-Alamah and McFarland, 2015). These domains are listed for the purpose of data analysis and will be not be mentioned during the focus group.

**A. Domain 1 ‘Worldview’， Domain 2 ‘Ethnohistory’ & Domain 12 ‘General and specific nursing care factors’：**

1. I am interested to find out a little about your cancer pain. How did the pain affect your life?

我希望能够了解一点您的癌症疼痛。疼痛是如何影响您的生活的？

2. How do you decide to seek assistant for your cancer pain?

当您因为疼痛需要寻求帮助的时候， 您是如何决定的？

3. What is the meaning of pain management to you?

对您来说，疼痛管理意味着什么？

4. Have you found any barriers or facilitators for you managing your pain at home?

您有没有发现什么因素阻碍或是帮助您在家里管理您的疼痛？

**B. Domain 4 ‘Cultural values, beliefs, and lifeways & Domain 5 ‘Religious/spiritual/philosophical factors’：**

5. Do you think the Chinese cultural and social values may influences your cancer pain management experiences and needs? (Please clarify).

您认为中国的文化和社会价值观会影响您的癌症疼痛管理的经历和需求吗？（请说明）

**C. Domain 11 ‘Professional and generic (folk or lay) care beliefs and practices’：**

6. How can different health professionals best help you manage your cancer pain?

不同的健康工作者如何能够最好地帮助您管理您的疼痛？

**D. Domain 3 ‘Kinship and social factors’:**

7. What are the things that your family members and/or friends do to support you manage your cancer pain?

在您的癌症疼痛管理过程中您的家人和朋友是怎么支持您的？

**E. Domain 7 ‘Economic factors’ & Domain 8: ‘Political and legal factors’**

8. I am wondering if there are any economic or other factors that have ever limited your access to pain management at your cancer service.

我在想，有什么经济或是其它的因素限制了您去接受癌症疼痛管理的服务。

**F. Domain 6 'Technological factors', Domain 9 'Educational factors'& Domain 10 'Language and communications factors':**

9. How would you like to communicate your pain management related issues with others (e.g. your doctors/nurses/families)?

您希望用什么方式和其他人（比如您的医生、护士和家人）就您的疼痛管理的问题进行沟通？

10. What information and technology support do you need to help you control your cancer pain?

您需要什么样的信息和技术支持来帮助您的癌症的疼痛？

## Appendix E-3: Focus group question route – Patient (traditional Chinese)

### 患者焦點小組問題提綱（繁體中文）

Researcher’s notes: The questions are developed based on the Leininger’s Inquiry Modes of 12 Domain of Inquiry (Wehbe-Alamah and McFarland, 2015). These domains are listed for the purpose of data analysis and will be not be mentioned during the focus group.

**A. Domain 1 ‘Worldview’， Domain 2 ‘Ethnohistory’ & Domain 12 ‘General and specific nursing care factors’：**

1. I am interested to find out a little about your cancer pain. How did the pain affect your life?

   我希望能夠了解一點您的癌癥疼痛。疼痛是如何影響您的生活的？

2. How do you decide to seek assistance for your cancer pain?

   當您因為疼痛需要尋求幫助的時候， 您是如何決定的？

3. What is the meaning of pain management to you?

   對您來說，疼痛管理意味著什麼？

4. Have you found any barriers or facilitators for you managing your pain at home?

   您有沒有發現什麼因素阻礙或是幫助您在家裏管理您的疼痛？

**B. Domain 4: ‘Cultural values, beliefs, and lifeways’& Domain 5: ‘Religious/spiritual/philosophical factors’：**

5. Do you think the Chinese cultural and social values may influence your cancer pain management experiences and needs? (Clarify).

   您認為中國的文化和社會價值觀會影響您的癌癥疼痛管理的經歷和需求嗎？（請說明）

**C. Domain 11: ‘Professional and generic (folk or lay) care beliefs and practices’：**

6. How can different health professionals best help you manage your cancer pain?

   不同的健康工作者怎麼能夠最好地幫助您管理您的疼痛？

**D. Domain 3: ‘Kinship and social factors’:**

7. What are the things that your family members and/or friends do to support you manage your cancer pain management?

   在您的癌癥疼痛管理過程中您的家人和朋友是怎麼支持您的？

**E. Domain 7: 'Economic factors' & Domain 8: 'Political and legal factors'：**

8. I am wondering if there are any economic or political factors that have ever limited your access to pain management at your cancer service.

我在想，有什麼經濟或是其它的因素限制了您去接受癌癥疼痛管理的服務。

**F. Domain 6 'Technological factors', Domain 9 'Educational factors & Domain 10 'Language and communications factors':**

9. How would you like to communicate your pain management related issues with others (e.g. your doctors/nurses/families)?

您希望用什麼方式和其他人（比如您的醫生、護士和家人）就您的疼痛管理的問題進行溝通？

10. What information and technology support do you need to help you control your cancer pain?

您需要什麼樣的信息和技術支持來幫助您的癌癥的疼痛？

# Appendix F: Focus Group Enrolment Form

**Focus group ID (**i.e. FG1**): _______** **Audio file ID (**i.e. AF-FG1**): _________**

**Facilitator: ____________** **Scribe: ____________**

**Venue: ____________** **Date: __________** **Time: __________**

**Number of participants: ________** **Language: ______________**

| **Informant ID** | **First Name** | **Age** | **Gender** | **Type of Cancer** | **Participant Information Received?** | **Consent Form signed?** | **Demographic data completed?** | **Barrier Questionnaire completed?** | **Comments** |
|---|---|---|---|---|---|---|---|---|---|
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## Appendix G: Transcription and translation protocol for the focus group transcripts

**Version: 1.0**
**Date: 1 December 2016**

**Purpose**

This protocol is used to guide the process about how the focus group transcripts for Chinese migrant cancer patients will be transcribed and translated and checked.

**Procedures**

Chandler and Reynolds' (2013) guidance on developing qualitative research protocols and suggested Standard Operational Procedures for preparing and translating focus group transcripts has informed the process for translating the focus group transcripts, as described below:

Preparing the transcriptions

a. During the focus group, field notes will be taken by the facilitator who is a Chinese-English-speaking researcher (XX) and the scribe (a Chinese-English-speaking academic), in order to capture any additional observations which may not be captured through audio recording (Streubert and Carpenter, 2011).

b. The audio file will be transcribed verbatim into simplified Chinese by the researcher (XX) within 24 hours of the focus group completion. This transcription will include all non-verbal occurrences, utterances, cross-talking, incomplete sentences and information captured by the observation (Chandler and Reynolds, 2013).

c. Each speaker will be assigned a new line in the transcription which will be labelled with the participant code.

d. Non-verbal occurrences such as hesitations, pause, laugher, disagreement and agreement will be marked in square brackets, for example, [participants hesitated when answering question 2].

e. When a participant's speech is interrupted by another, the interruption will be indicated with '…'; and the interrupter's words will be started in a new line with '…' and a lower case letter. For example,

   - Participant 1: I think culture has influences on …
   - Participant 3: …no, I do not think so.

f. The overlapping parts of the speech will be enclosed with <<…>>, when several participants are speaking at the same time. For example,

   - Participant 2: <<My doctor does not understand>> what I am saying when I have questions about the pain medication.
   - Participant 5: eh, <<my doctor does not understand me either>>.

g. The observational information will be included into the appropriate place of the transcripts within square brackets.

h. If some sentences or words are unclear, a suggested sentence or word will be typed in italic followed by the question mark and surrounded by brackets. For example,

   - Participant 3: My family always support me when (*I am in pain?*)

i. The transcripts will be proof-read against audio file by the researcher (XX) to check accuracy and completeness. Then it will be checked by a Chinese-English speaker (an academic staff member) and revised accordingly when error occurs; and all identified details (e.g. participants' name or location of the focus group) will be removed.

j. All the original and refined transcripts will be filed and labelled with focus group number (e.g. FG1_original Chinese and FG1_refined Chinese); and the refined version will be translated into English.

Translating the transcripts

a. A meaning-based approach will be employed to translate Chinese into English by the Chinese-English speaking researcher (XX) who knows well about the theoretical perspective and objective of the research (Chandler and Reynolds, 2013).

b. The researcher will read the transcripts, exploring the meaning of the original narratives and utterances; and re-expressing the meaning by using English natural grammar (Chandler and Reynolds, 2013).

c. The translated English texts will be typed underneath each short section of 4-5 lines of the Chinese transcripts for easy cross-checking.

d. For words/phases with different meaning in the Chinese context, the researcher will write down the most appropriate meaning and put other possible meanings into the brackets.

e. When undertaking the translation and cross-checking, following criteria will be taken into account to increase the trustworthiness of the translation:

   - comprehensibility, focusing on the culture related specific concepts;
   - appropriateness in terms of the content and approach; and
   - accuracy, focusing on the faithfulness of the original source texts and the key facts (Downing & Bogoslaw as cited in Chandler and Reynolds, 2013).

Cross-checking the translations

a. The translated transcripts will be cross-checked by a Chinese-English-speaking academic via reading the sections of English translation and the Chinese transcripts to check clarity and accuracy (Chandler and Reynolds, 2013).

b. If there are many translation disagreements (e.g. more than one page) identified by the bilingual staff member, the entire file will be sent back to the researcher with suggestions and retranslated before the cross-checking is repeated.

c. If the translation disagreements are minor or if some part of the English translation is unclear, the bilingual staff member will work with the researcher until an agreement is reached.

d. The translation in the word document will be corrected using track changes to show the range of interpretations and saved as a new version. A clean copy of the corrected translation will be sent to a native English-speaking researcher for the proof reading.

e. All the original, the corrected and the final proof-read copies of the translated transcripts will be filed (e.g. FG1-origral English, FG1-corrected English and FG1-final English).

f. The final copy of the translations will be uploaded into the NVivo software for coding and analysis.

**References**

Chandler, C. I. R. & Reynolds, J. 2013. *The ACT Consortium guidance: qualitative research protocol template with examples tools and SOPs* [Online]. Available: http://www.actconsortium.org/data/files/resources/72/Qualitative-Research-Protocol-Template-with-example-Tools-and-SOPs_Dec2013.docx [Accessed 12 July 2016].

Streubert, H. J. & Carpenter, D. R. 2011. *Qualitative research in nursing: Advancing the humanistic imperative,* Philadelphia, PA, Lippincott Williams & Wilkins.

## Appendix H: Invitation letter − Nurses

**Invitation for Participating the Survey of**
**Cancer and Palliative Care Nurses**
**(Chinese Migrants Cancer Pain Project)**

Dear colleagues,

You are invited to take part in a survey to explore experiences and perceptions of nurses in managing Chinese migrant patients’ cancer pain. The survey is being undertaken by researchers at University of Technology Sydney (UTS).

Participation in this study is anonymous and voluntary. We would be very appreciated for your assistance. If you are interested in participating, you may complete the survey online by logging on the website as following:

https://www.surveymonkey.com/r/RBJ2NN2

Alternatively, you may complete the enclosed survey and return it to the researchers directly; or send it back to researchers by mail or email to following address:

Professor Jane Phillips
CC: Ms Xiangfeng Xu (Renee)
Faculty of Health, University of Technology Sydney
Level 3, 235 Jones St, Ultimo NSW 2007 (PO Box 123)
Email: Xiangfeng.Xu@student.uts.edu.au

Yours sincerely,

The Research Team

## Appendix I: Survey of cancer and palliative care nurses

Dear participant:

Thank you for taking part in the *"Chinese Migrants Cancer Pain Project"*. This is an anonymous survey. Completion of this survey will be taken as evidence of informed consent to participate.

Please read following information; and check ( √ ) the box in front of the item that is appropriate for you, or write down the information over the underlines or in the box. Thank you!

### Part A. Confirm eligibility

**1.** Are you an RN or an RN working in different roles (e.g. CNC, CNS, CNE, Nurse Managers, Practice Nurse, Research Nurse, or Research Coordinator)? (Please check "Yes" if you are working in any of these roles).

☐ Yes. Please continue.

☐ No. Please stop here and thank you for your participation.

**2. Have ever had experiences of caring for Chinese migrant patients with cancer related pain in the last five years?**

☐Yes. Please continue.

☐ No. Please stop here and thank you for your participation.

**3. Have you ever worked in an ambulatory care service of cancer care or palliative care centre?**

☐Yes. Please continue.

☐ No. Please stop here and thank you for your participation.

### Part B. Participant characteristics

**4. Age ________ Gender ___________**

**5. What is the main language you speak at home?**

☐ English

☐ Other, please specific_____________________

**6. Which area are you currently working in?**

☐ Cancer care

☐ Palliative care

**7. Work postcode _________________**

**8. How many years have you worked as a registered nurse? ________ Years**

**9. Have you received any specific training about cancer pain management?**

☐ None

☐ Compulsory training at my workplace

☐ Elective training

**10. Have you received any training about culturally congruent or competent care?**

☐ None

☐ Compulsory training at my workplace

☐ Elective training

## Part C: Experiences of providing cancer pain care to Chinese patients

**11. To what degree do you think that Chinese cultural background influences patients' cancer pain management needs (other than any obvious language differences)?**

☐ Very much

☐ Somewhat

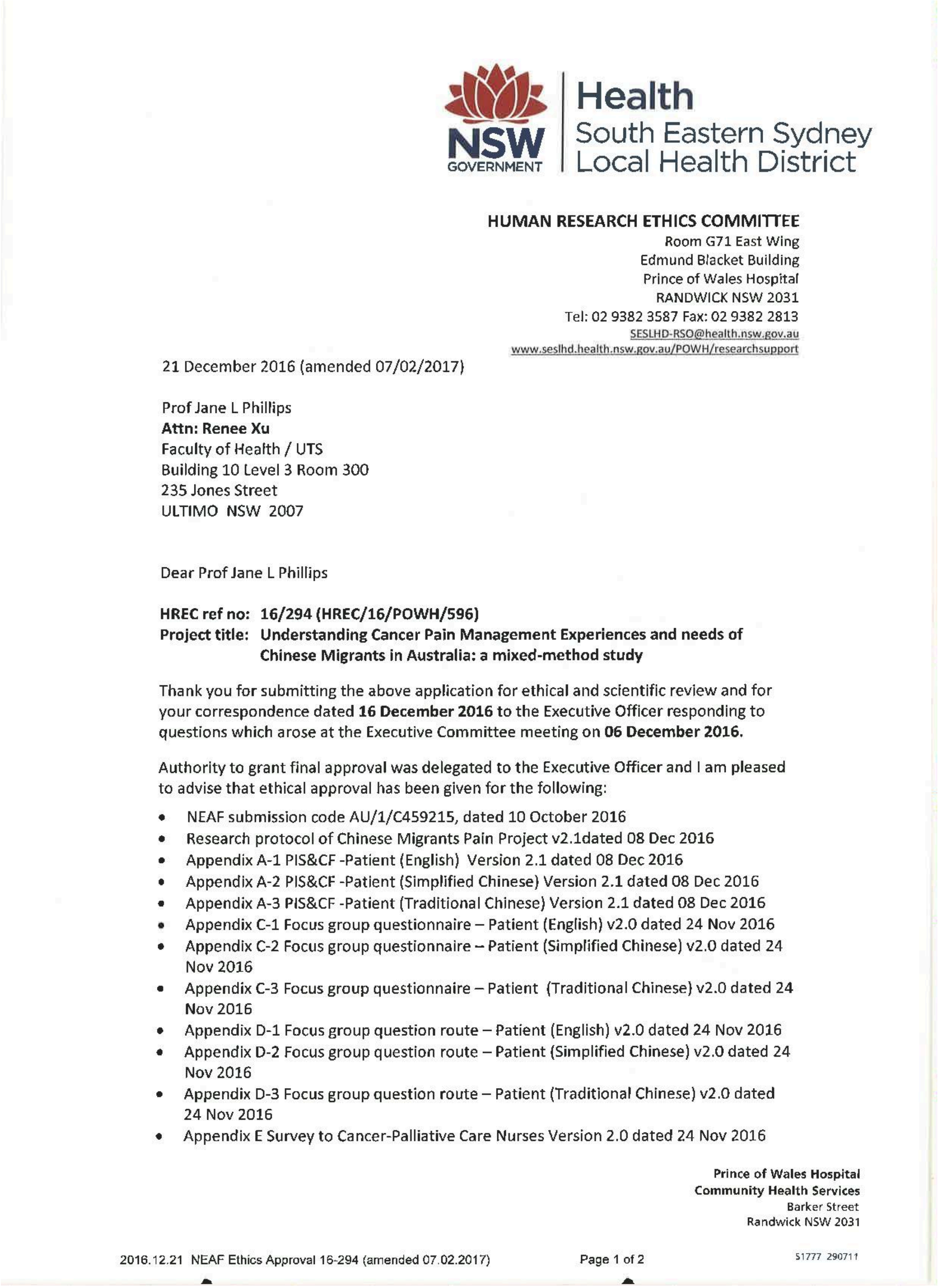
☐ Not at all or hardly at all (Please stop here and thank you for your participation.)

11 a. In what ways does culture influence Chinese patients' cancer pain management needs?

11 b. What (if any) education or resources do you think would be useful in helping to meet the pain management needs of Chinese patients?

| |
|---|
| Patient education resources: |
| Nurse education resources: |

# Appendix J: Ethics and governance approvals



NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

**HUMAN RESEARCH ETHICS COMMITTEE**
Room G71 East Wing
Edmund Blacket Building
Prince of Wales Hospital
RANDWICK NSW 2031
Tel: 02 9382 3587 Fax: 02 9382 2813
SESLHD-RSO@health.nsw.gov.au
www.seslhd.health.nsw.gov.au/POWH/researchsupport

21 December 2016 (amended 07/02/2017)

Prof Jane L Phillips
**Attn: Renee Xu**
Faculty of Health / UTS
Building 10 Level 3 Room 300
235 Jones Street
ULTIMO NSW 2007

Dear Prof Jane L Phillips

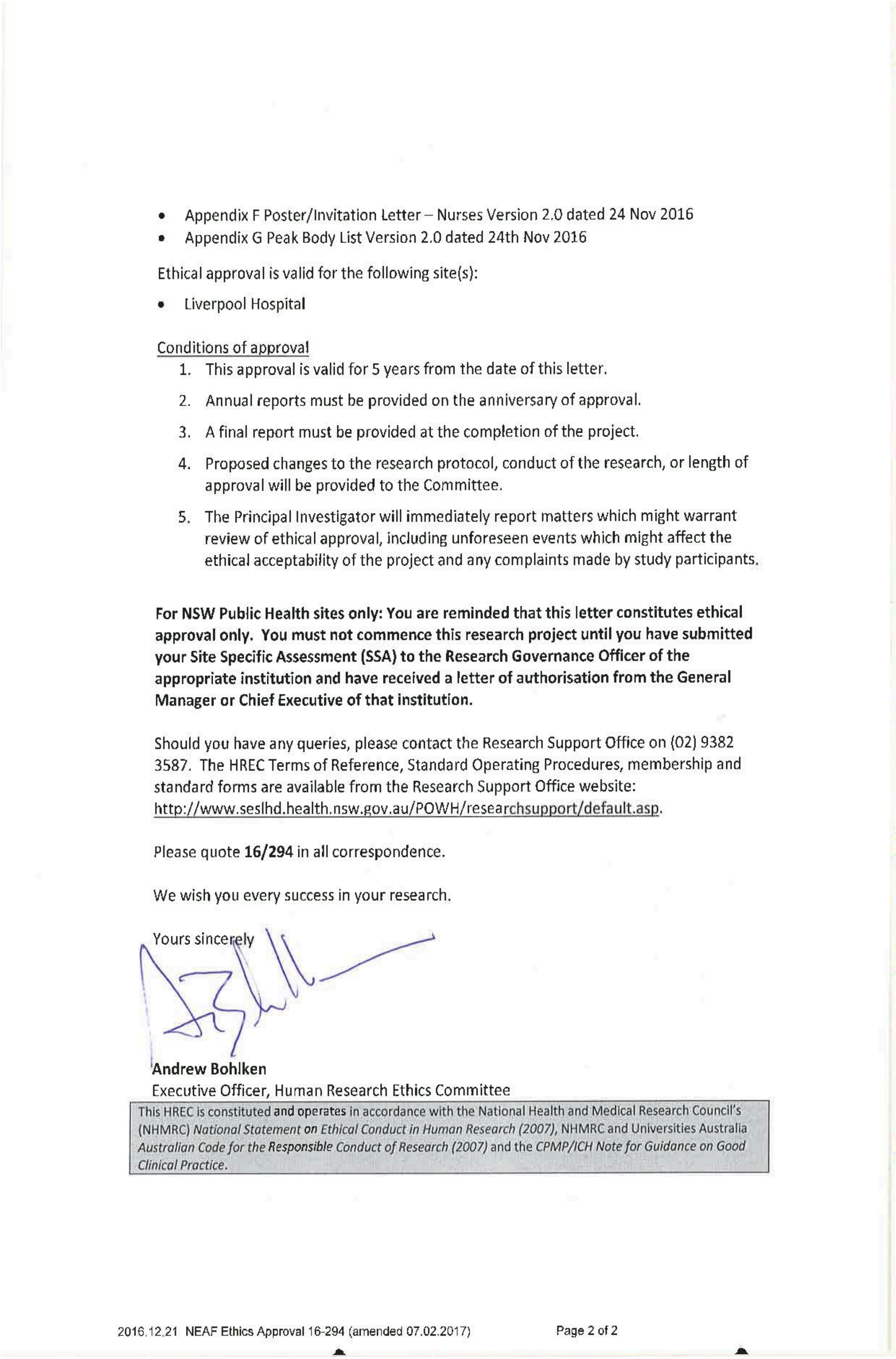
**HREC ref no: 16/294 (HREC/16/POWH/596)**
**Project title: Understanding Cancer Pain Management Experiences and needs of Chinese Migrants in Australia: a mixed-method study**

Thank you for submitting the above application for ethical and scientific review and for your correspondence dated **16 December 2016** to the Executive Officer responding to questions which arose at the Executive Committee meeting on **06 December 2016.**

Authority to grant final approval was delegated to the Executive Officer and I am pleased to advise that ethical approval has been given for the following:

- NEAF submission code AU/1/C459215, dated 10 October 2016
- Research protocol of Chinese Migrants Pain Project v2.1dated 08 Dec 2016
- Appendix A-1 PIS&CF -Patient (English) Version 2.1 dated 08 Dec 2016
- Appendix A-2 PIS&CF -Patient (Simplified Chinese) Version 2.1 dated 08 Dec 2016
- Appendix A-3 PIS&CF -Patient (Traditional Chinese) Version 2.1 dated 08 Dec 2016
- Appendix C-1 Focus group questionnaire – Patient (English) v2.0 dated 24 Nov 2016
- Appendix C-2 Focus group questionnaire – Patient (Simplified Chinese) v2.0 dated 24 Nov 2016
- Appendix C-3 Focus group questionnaire – Patient (Traditional Chinese) v2.0 dated 24 Nov 2016
- Appendix D-1 Focus group question route – Patient (English) v2.0 dated 24 Nov 2016
- Appendix D-2 Focus group question route – Patient (Simplified Chinese) v2.0 dated 24 Nov 2016
- Appendix D-3 Focus group question route – Patient (Traditional Chinese) v2.0 dated 24 Nov 2016
- Appendix E Survey to Cancer-Palliative Care Nurses Version 2.0 dated 24 Nov 2016

**Prince of Wales Hospital**
**Community Health Services**
Barker Street
Randwick NSW 2031



- Appendix F Poster/Invitation Letter – Nurses Version 2.0 dated 24 Nov 2016
- Appendix G Peak Body List Version 2.0 dated 24th Nov 2016

Ethical approval is valid for the following site(s):

- Liverpool Hospital

Conditions of approval

1. This approval is valid for 5 years from the date of this letter.
2. Annual reports must be provided on the anniversary of approval.
3. A final report must be provided at the completion of the project.
4. Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the Committee.
5. The Principal Investigator will immediately report matters which might warrant review of ethical approval, including unforeseen events which might affect the ethical acceptability of the project and any complaints made by study participants.

**For NSW Public Health sites only: You are reminded that this letter constitutes ethical approval only. You must not commence this research project until you have submitted your Site Specific Assessment (SSA) to the Research Governance Officer of the appropriate institution and have received a letter of authorisation from the General Manager or Chief Executive of that institution.**

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp.

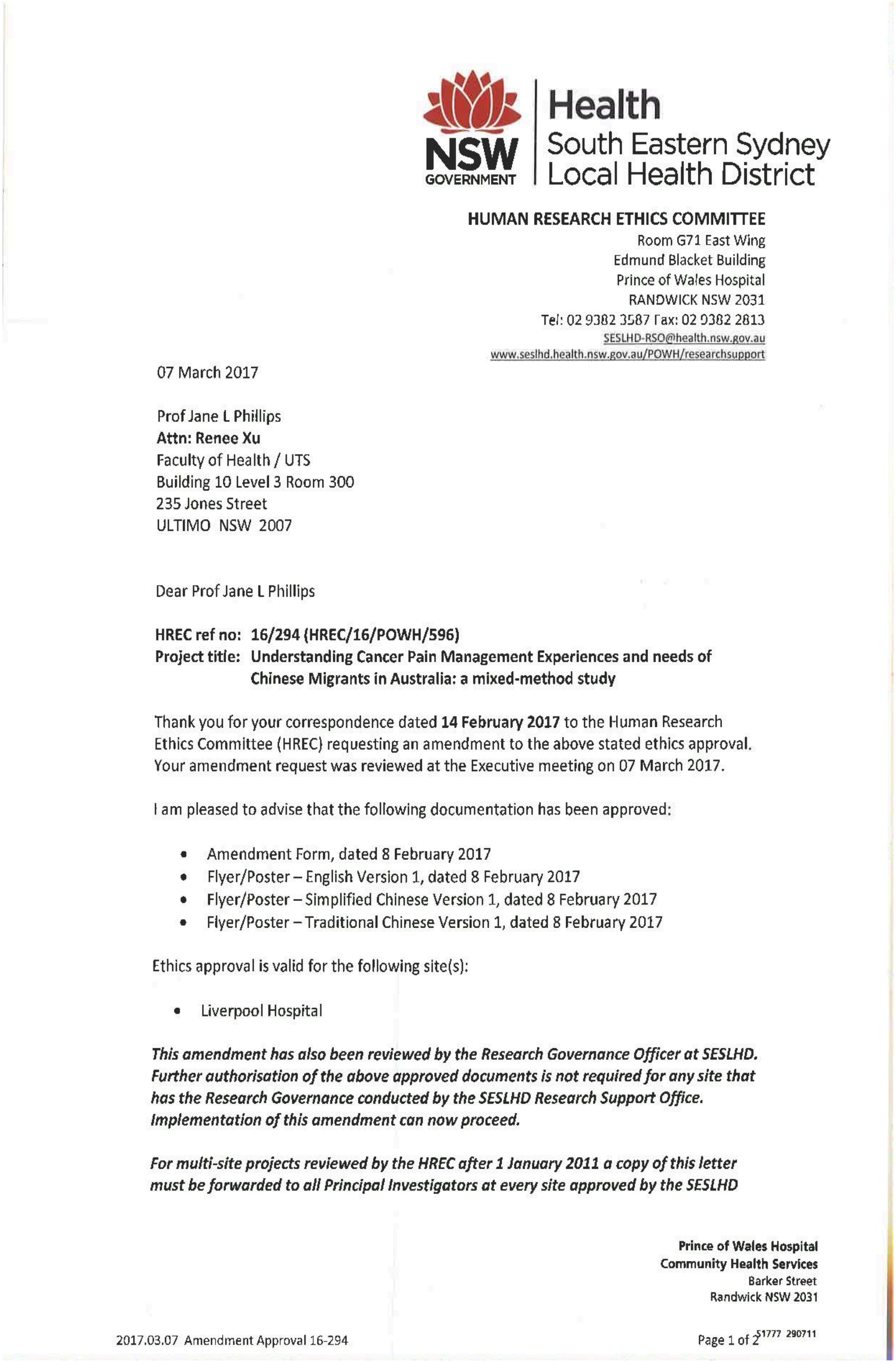
Please quote **16/294** in all correspondence.

We wish you every success in your research.

Yours sincerely

**Andrew Bohlken**
Executive Officer, Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, NHMRC and Universities Australia *Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.



NSW GOVERNMENT
**Health**
South Eastern Sydney
Local Health District

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07 March 2017

Prof Jane L Phillips
**Attn: Renee Xu**
Faculty of Health / UTS
Building 10 Level 3 Room 300
235 Jones Street
ULTIMO NSW 2007

Dear Prof Jane L Phillips

**HREC ref no: 16/294 (HREC/16/POWH/596)**
**Project title: Understanding Cancer Pain Management Experiences and needs of Chinese Migrants in Australia: a mixed-method study**

Thank you for your correspondence dated **14 February 2017** to the Human Research Ethics Committee (HREC) requesting an amendment to the above stated ethics approval. Your amendment request was reviewed at the Executive meeting on 07 March 2017.

I am pleased to advise that the following documentation has been approved:

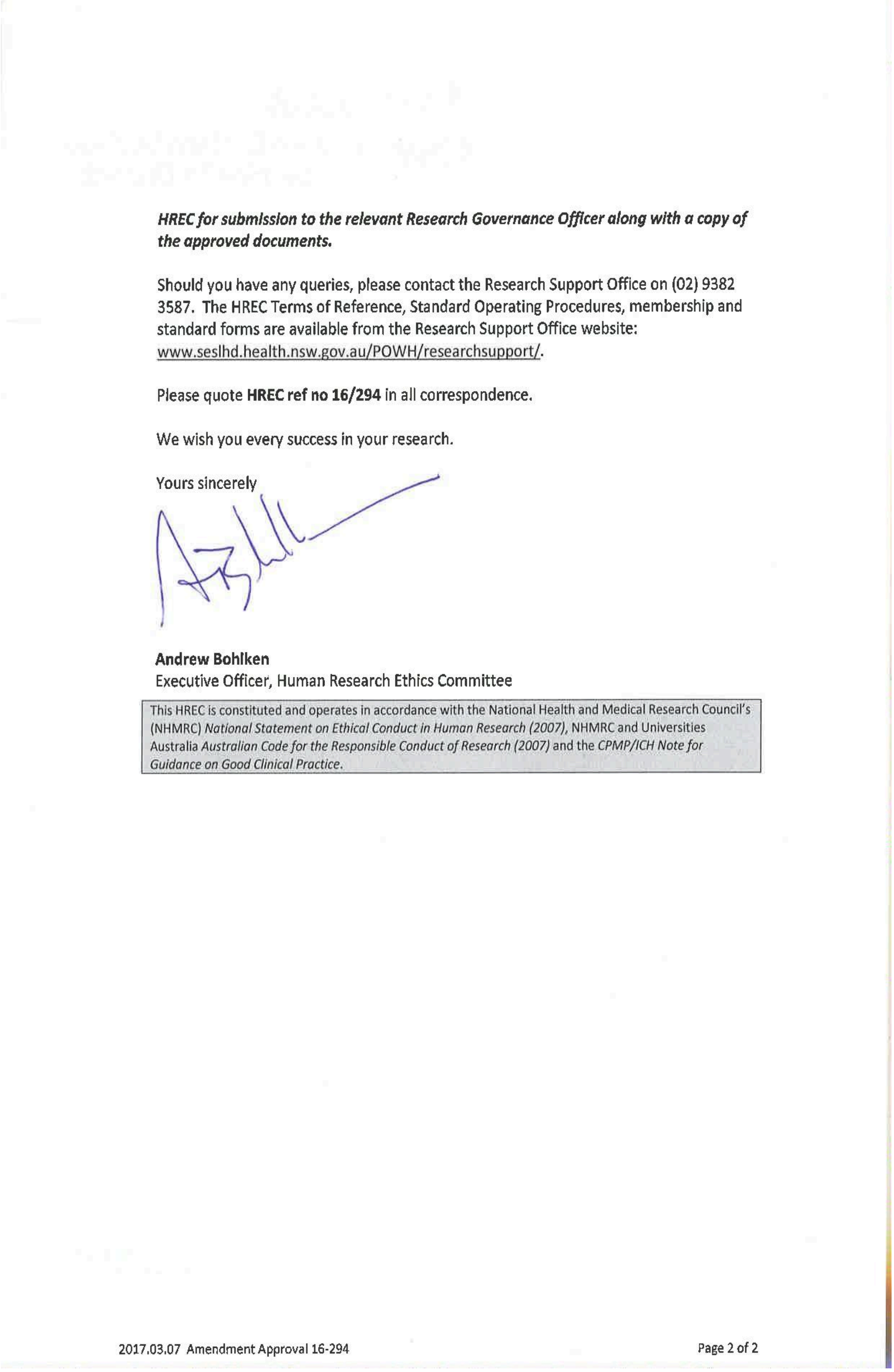
- Amendment Form, dated 8 February 2017
- Flyer/Poster – English Version 1, dated 8 February 2017
- Flyer/Poster – Simplified Chinese Version 1, dated 8 February 2017
- Flyer/Poster – Traditional Chinese Version 1, dated 8 February 2017

Ethics approval is valid for the following site(s):

- Liverpool Hospital

***This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.***

***For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD***



***HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.***

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: www.seslhd.health.nsw.gov.au/POWH/researchsupport/.

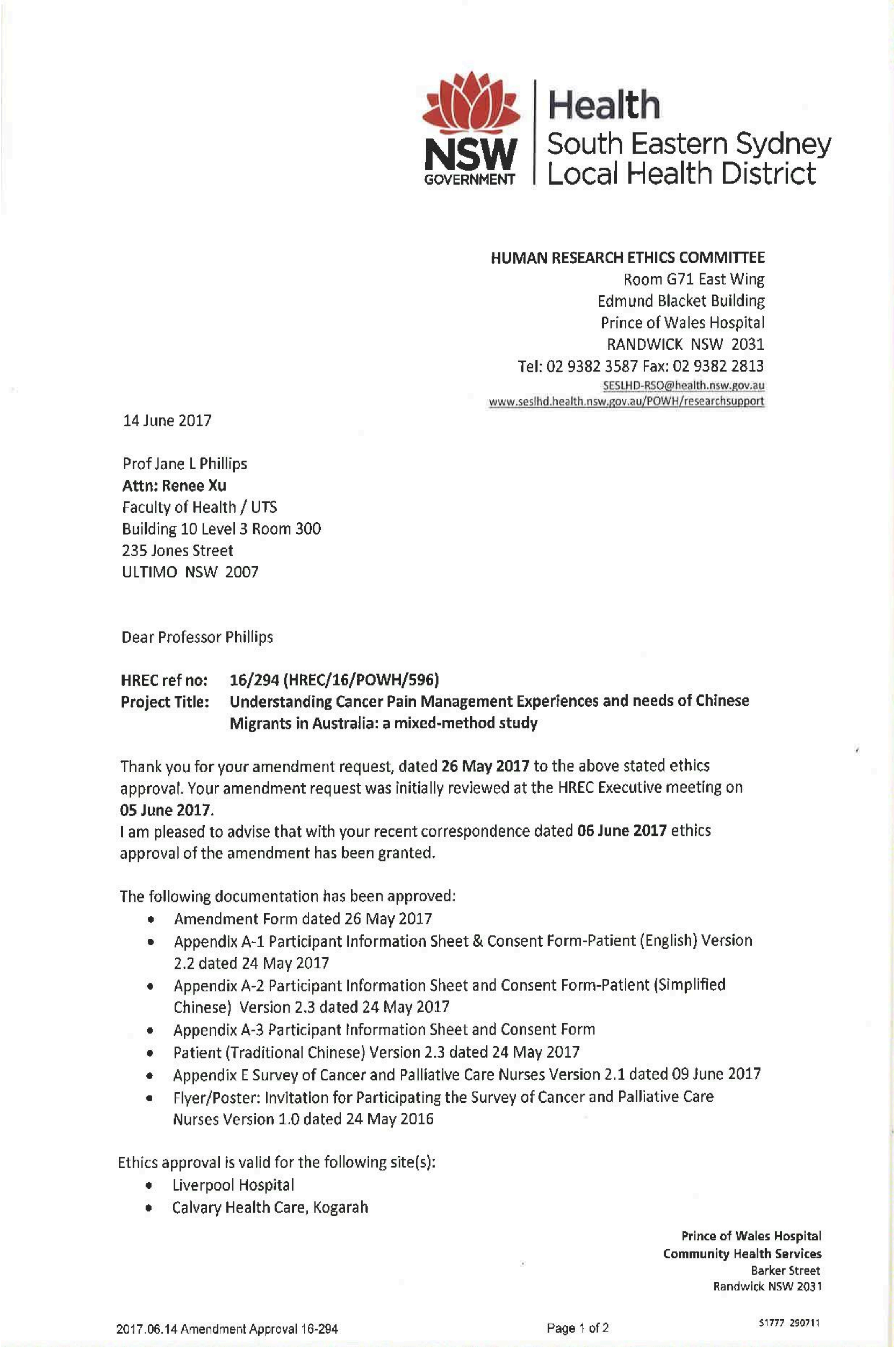
Please quote **HREC ref no 16/294** in all correspondence.

We wish you every success in your research.

Yours sincerely

**Andrew Bohlken**
Executive Officer, Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, NHMRC and Universities Australia *Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*



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14 June 2017

Prof Jane L Phillips
**Attn: Renee Xu**
Faculty of Health / UTS
Building 10 Level 3 Room 300
235 Jones Street
ULTIMO NSW 2007

Dear Professor Phillips

**HREC ref no:** **16/294 (HREC/16/POWH/596)**
**Project Title:** **Understanding Cancer Pain Management Experiences and needs of Chinese Migrants in Australia: a mixed-method study**

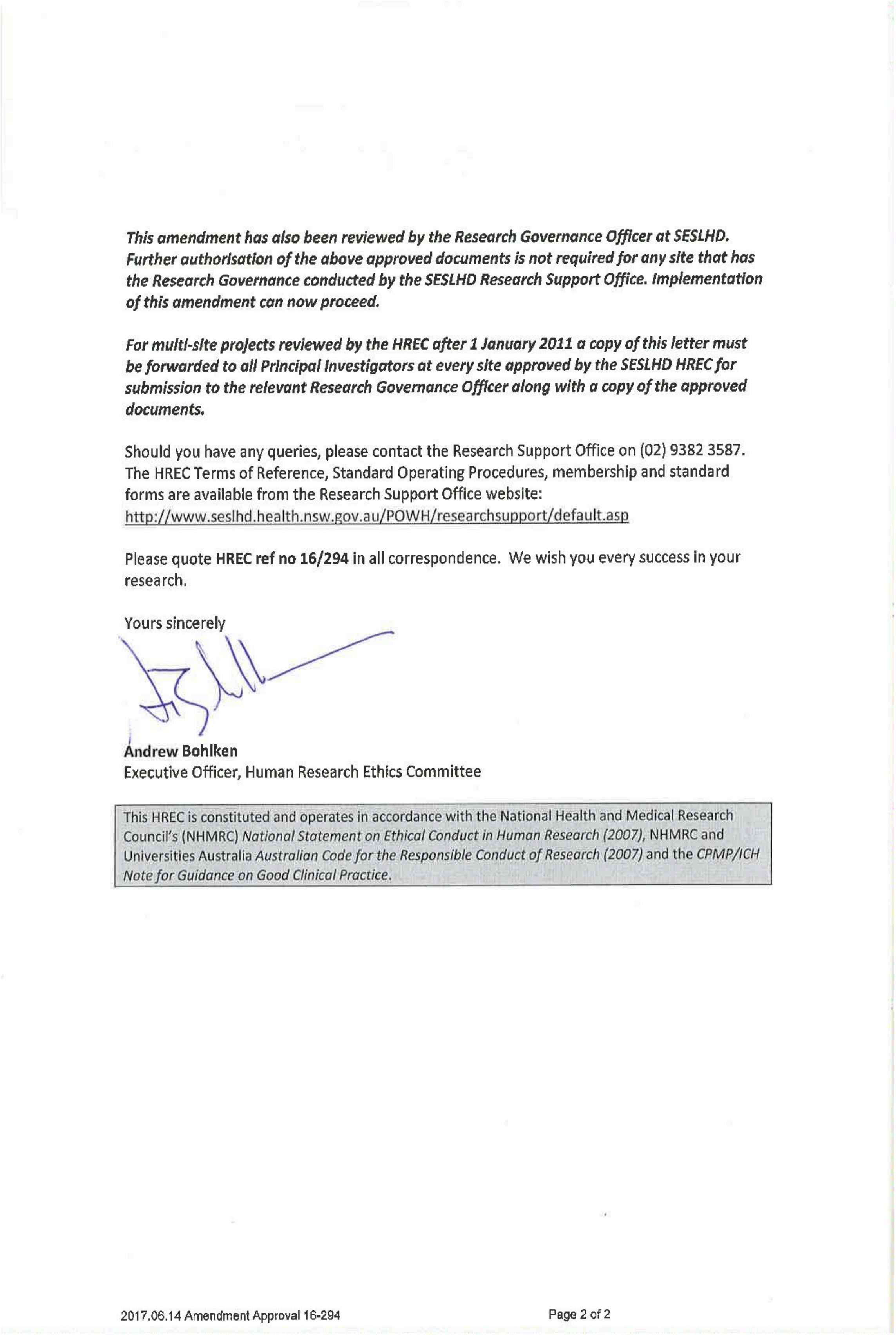
Thank you for your amendment request, dated **26 May 2017** to the above stated ethics approval. Your amendment request was initially reviewed at the HREC Executive meeting on **05 June 2017**.
I am pleased to advise that with your recent correspondence dated **06 June 2017** ethics approval of the amendment has been granted.

The following documentation has been approved:

- Amendment Form dated 26 May 2017
- Appendix A-1 Participant Information Sheet & Consent Form-Patient (English) Version 2.2 dated 24 May 2017
- Appendix A-2 Participant Information Sheet and Consent Form-Patient (Simplified Chinese) Version 2.3 dated 24 May 2017
- Appendix A-3 Participant Information Sheet and Consent Form
- Patient (Traditional Chinese) Version 2.3 dated 24 May 2017
- Appendix E Survey of Cancer and Palliative Care Nurses Version 2.1 dated 09 June 2017
- Flyer/Poster: Invitation for Participating the Survey of Cancer and Palliative Care Nurses Version 1.0 dated 24 May 2016

Ethics approval is valid for the following site(s):

- Liverpool Hospital
- Calvary Health Care, Kogarah



***This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.***

***For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.***

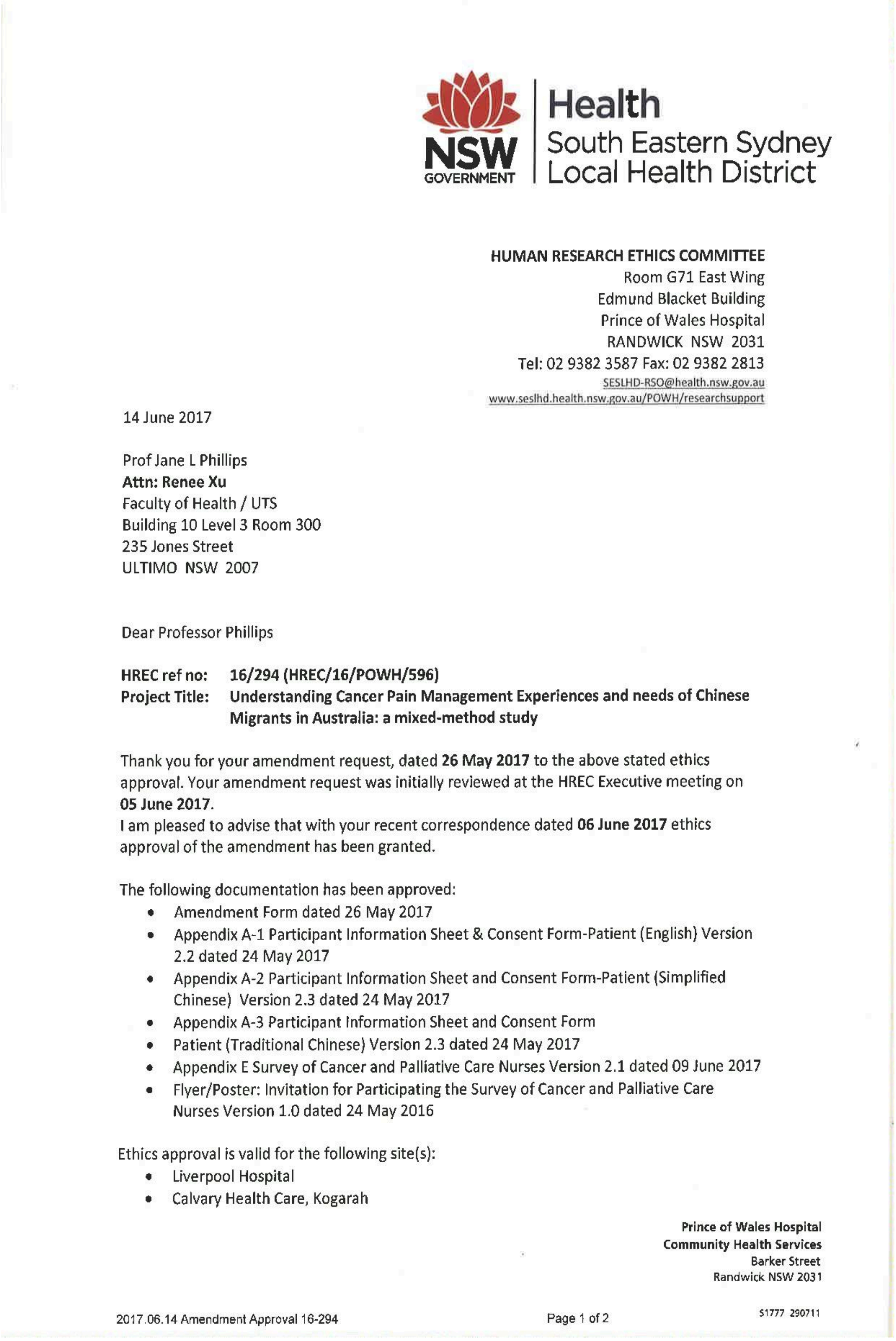
Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp

Please quote **HREC ref no 16/294** in all correspondence. We wish you every success in your research.

Yours sincerely

**Andrew Bohlken**
Executive Officer, Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, NHMRC and Universities Australia *Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.



NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

**HUMAN RESEARCH ETHICS COMMITTEE**
Room G71 East Wing
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14 June 2017

Prof Jane L Phillips
**Attn: Renee Xu**
Faculty of Health / UTS
Building 10 Level 3 Room 300
235 Jones Street
ULTIMO NSW 2007

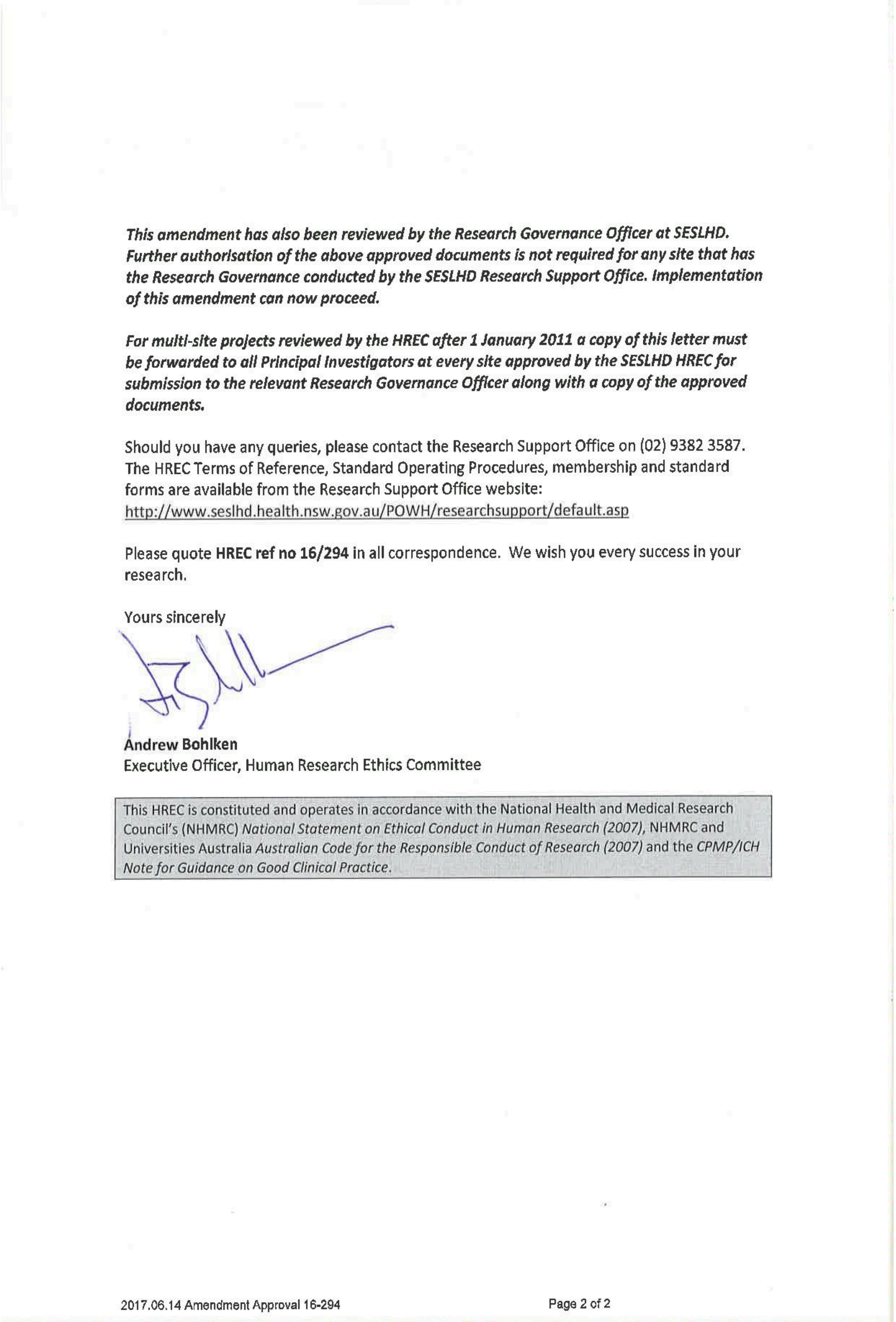
Dear Professor Phillips

**HREC ref no:** **16/294 (HREC/16/POWH/596)**
**Project Title:** **Understanding Cancer Pain Management Experiences and needs of Chinese Migrants in Australia: a mixed-method study**

Thank you for your amendment request, dated **26 May 2017** to the above stated ethics approval. Your amendment request was initially reviewed at the HREC Executive meeting on **05 June 2017**.
I am pleased to advise that with your recent correspondence dated **06 June 2017** ethics approval of the amendment has been granted.

The following documentation has been approved:
- Amendment Form dated 26 May 2017
- Appendix A-1 Participant Information Sheet & Consent Form-Patient (English) Version 2.2 dated 24 May 2017
- Appendix A-2 Participant Information Sheet and Consent Form-Patient (Simplified Chinese) Version 2.3 dated 24 May 2017
- Appendix A-3 Participant Information Sheet and Consent Form
- Patient (Traditional Chinese) Version 2.3 dated 24 May 2017
- Appendix E Survey of Cancer and Palliative Care Nurses Version 2.1 dated 09 June 2017
- Flyer/Poster: Invitation for Participating the Survey of Cancer and Palliative Care Nurses Version 1.0 dated 24 May 2016

Ethics approval is valid for the following site(s):
- Liverpool Hospital
- Calvary Health Care, Kogarah



***This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.***

***For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.***

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp

Please quote **HREC ref no 16/294** in all correspondence. We wish you every success in your research.

Yours sincerely

**Andrew Bohlken**
Executive Officer, Human Research Ethics Committee

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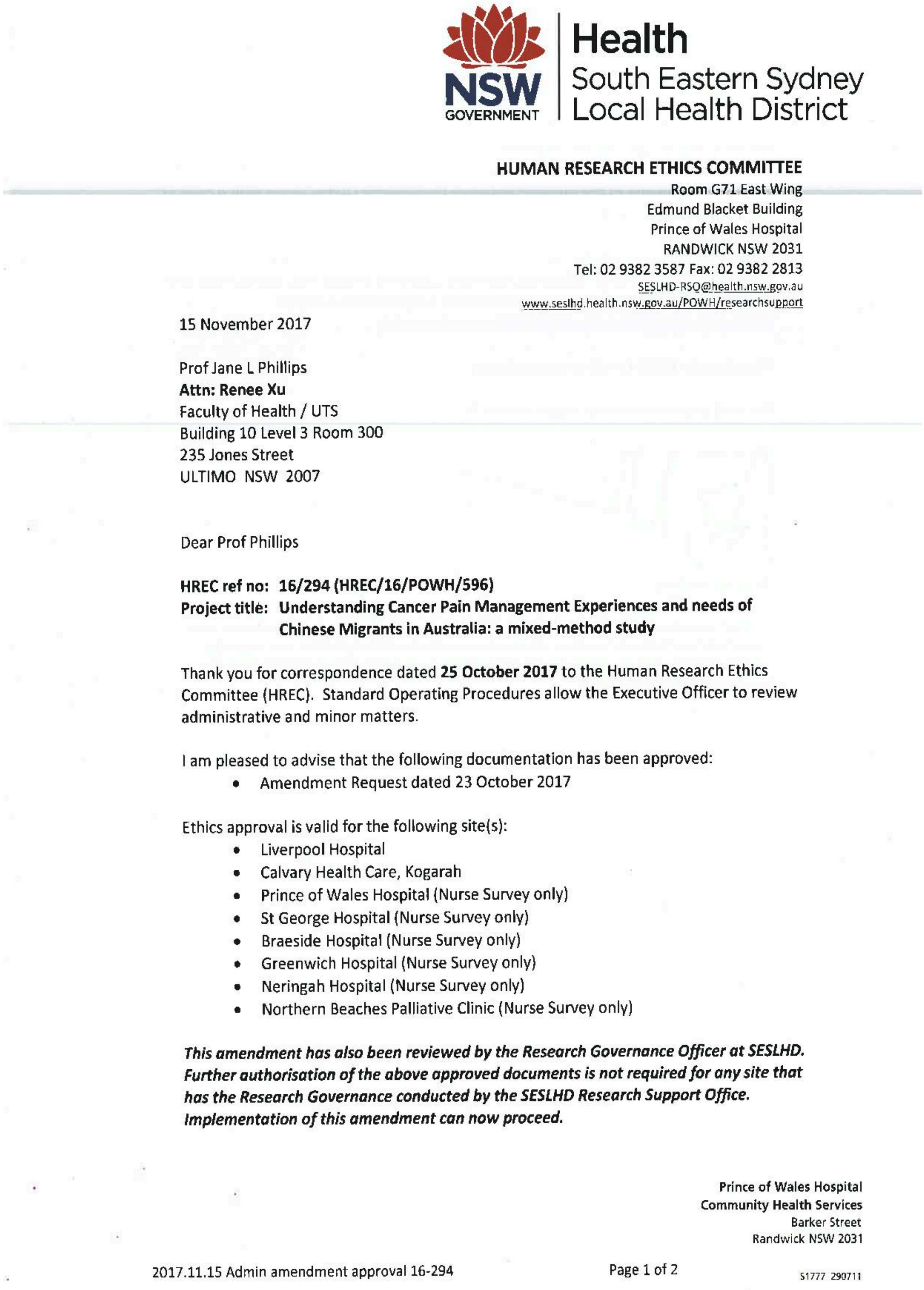
2017.06.14 Amendment Approval 16-294 Page 2 of 2



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15 November 2017

Prof Jane L Phillips
**Attn: Renee Xu**
Faculty of Health / UTS
Building 10 Level 3 Room 300
235 Jones Street
ULTIMO NSW 2007

Dear Prof Phillips

**HREC ref no: 16/294 (HREC/16/POWH/596)**
**Project title: Understanding Cancer Pain Management Experiences and needs of Chinese Migrants in Australia: a mixed-method study**

Thank you for correspondence dated **25 October 2017** to the Human Research Ethics Committee (HREC). Standard Operating Procedures allow the Executive Officer to review administrative and minor matters.

I am pleased to advise that the following documentation has been approved:

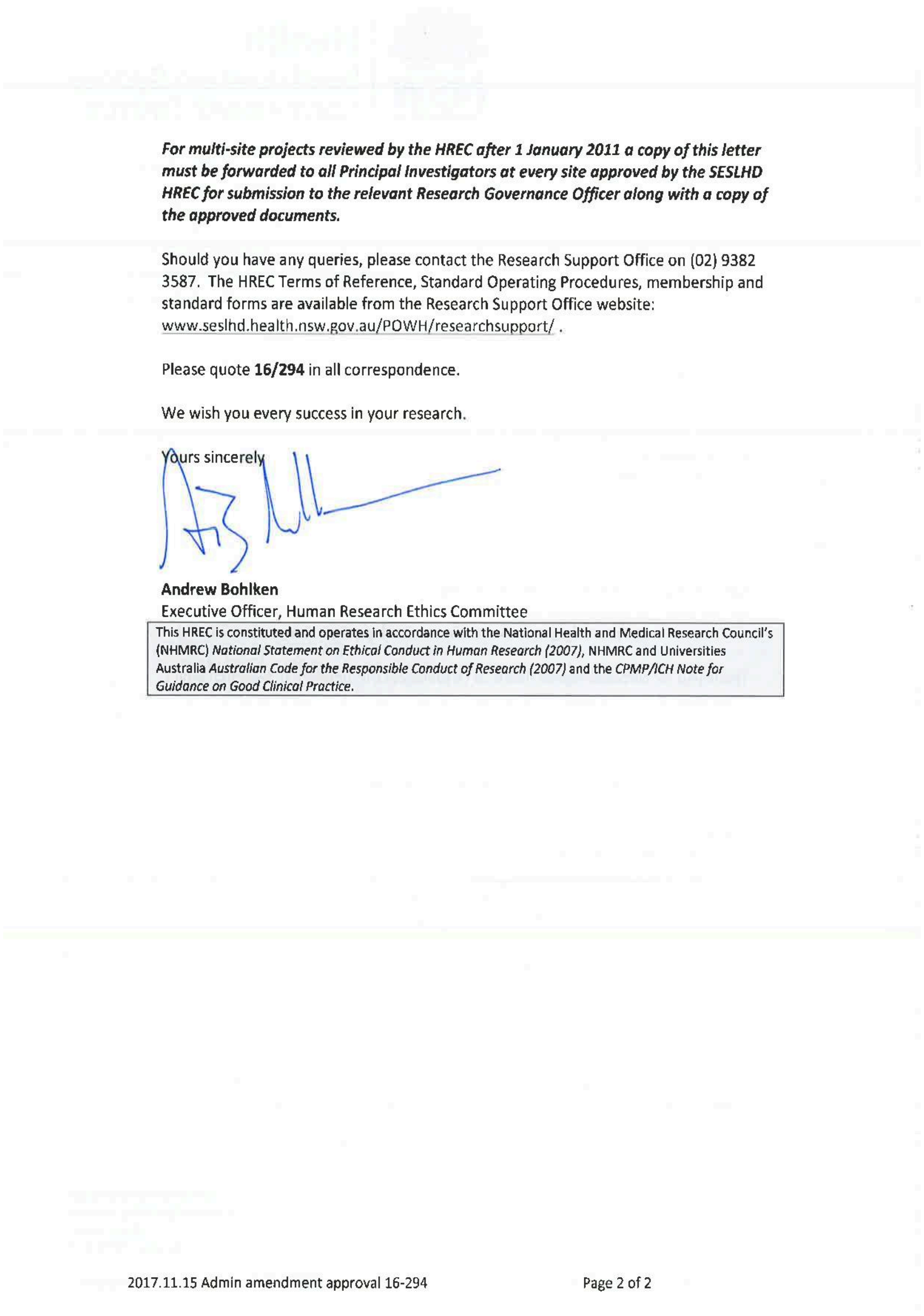
- Amendment Request dated 23 October 2017

Ethics approval is valid for the following site(s):

- Liverpool Hospital
- Calvary Health Care, Kogarah
- Prince of Wales Hospital (Nurse Survey only)
- St George Hospital (Nurse Survey only)
- Braeside Hospital (Nurse Survey only)
- Greenwich Hospital (Nurse Survey only)
- Neringah Hospital (Nurse Survey only)
- Northern Beaches Palliative Clinic (Nurse Survey only)

***This amendment has also been reviewed by the Research Governance Officer at SESLHD. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by the SESLHD Research Support Office. Implementation of this amendment can now proceed.***

**Prince of Wales Hospital**
**Community Health Services**
Barker Street
Randwick NSW 2031



***For multi-site projects reviewed by the HREC after 1 January 2011 a copy of this letter must be forwarded to all Principal Investigators at every site approved by the SESLHD HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.***

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: www.seslhd.health.nsw.gov.au/POWH/researchsupport/ .

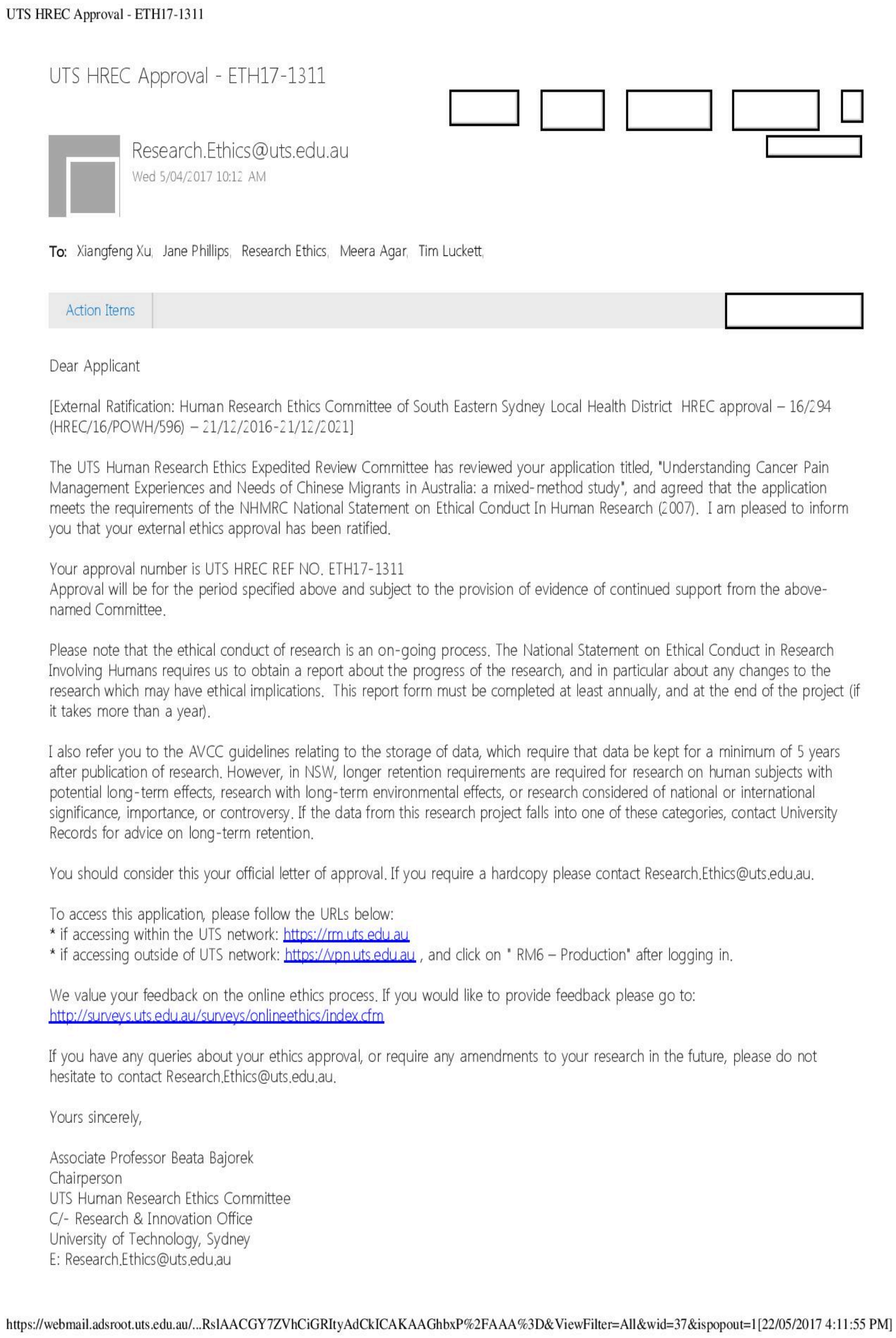
Please quote **16/294** in all correspondence.

We wish you every success in your research.

Yours sincerely

**Andrew Bohlken**
Executive Officer, Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, NHMRC and Universities Australia *Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*



UTS HREC Approval - ETH17-1311

UTS HREC Approval - ETH17-1311

[redacted] [redacted] [redacted] [redacted] [redacted]

Research.Ethics@uts.edu.au [redacted]

Wed 5/04/2017 10:12 AM

To: Xiangfeng Xu; Jane Phillips; Research Ethics; Meera Agar; Tim Luckett;

[redacted]

Dear Applicant

[External Ratification: Human Research Ethics Committee of South Eastern Sydney Local Health District HREC approval – 16/294 (HREC/16/POWH/596) – 21/12/2016-21/12/2021]

The UTS Human Research Ethics Expedited Review Committee has reviewed your application titled, "Understanding Cancer Pain Management Experiences and Needs of Chinese Migrants in Australia: a mixed-method study", and agreed that the application meets the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that your external ethics approval has been ratified.

Your approval number is UTS HREC REF NO. ETH17-1311
Approval will be for the period specified above and subject to the provision of evidence of continued support from the above-named Committee.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year).

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://vpn.uts.edu.au , and click on " RM6 – Production" after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to:
http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Associate Professor Beata Bajorek
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney
E: Research.Ethics@uts.edu.au

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# Appendix K: Joint Display Table One for Research Questions 2

This table presents the joint display for research question 2 in line with the 12 domains of Leininger's 'Semi-Structured Inquiry Guide' and 'Sunrise Enabler': What are the 'cultural and social structural factors' influencing Chinese migrants' cancer pain management experience and needs?

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)** Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences** (Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
| **'Religious/ Spiritual/ Philosophical Factors'** | ***The body can self-heal***<br>• Desire to self-control of pain<br>• Preference for using a healthy regimen to promote self-healing<br>*"I always think that our bodies also have the ability of self-healing. We should take care of ourselves at all aspects of our diet and daily life. Paying attention to doing the exercises may be helpful. You may help yourself in pain management." (P21, female, 53 years old and breast cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Extended** | One of reasons that Chinese migrants tend to accept, endure and/or normalise their pain during pain assessment is because of their philosophical health beliefs about the body self-healing, and that cancer and its pain are the result of their bad health behaviours and/or bad temper. They strongly desire using a healthy way to promote self-healing and control their pain themselves. |
| | ***Cancer pain is self-provoked***<br>• Deserving of the pain as cancer is self-provoked<br>• Acceptance of pain can relieve psychological distress<br>• Endurance and normalisation of pain<br>*"Firstly, it is because of our life style. Secondly, it is because of our diet − we eat everything …The unhealthy things we had would gradually build up in our body…I think my pain is caused by myself…So, we should accept it. It would be fine to bear a little bit of pain. People would not be able to help us even when we tell them. For example, if we tell our children about the pain, they would be worried about us, but they do not have any solutions to help us reduce the pain." (P24, male, 87 years old and pancreatic cancer)* | ***No theme or subtheme identified in nurse survey data*** | **As above** | |
| | ***Lower mean score of 'religious fatalism' ($\bar{x}$ = 1.50, SD ±1.89) in S-BQT***<br>Indicates religious beliefs are not as unlikely to be a major barrier for Chinese migrants to use analgesics | ***Religious beliefs contribute to suffering***<br>*"Cultural needs of Buddhist to have their body 'free' of medications prior to death." (R114, 36 years old, palliative care nurse)* | **Contradicted** | The low score of 'religious fatalism' in S-BQT indicates that religious beliefs have less influence on most Chinese migrants' cancer pain management. However, a few nurses observed that religious practice can be a barrier to receiving analgesics and other pain treatment at the end of life for some Chinese migrant cancer patients. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
| **'Cultural Values, Beliefs, and Lifeways'** | **Cultural values and beliefs influence how Chinese people respond to their cancer pain:** | **Chinese cultural beliefs about cancer, pain, and death shaped their expression of and response to pain:** | **Confirmed and complemented** | Perceptions of both patients and nurses demonstrate that Chinese cultural beliefs about cancer, pain and death influence their expression of care and practice in relation to pharmacological pain management. |
| | ***Cancer pain is inevitable and higher scores of 'fatalism' ($\bar{x}$ = 1.50, SD ±1.89) and 'disease progress'($\bar{x}$ = 4.33, SD ±1.20)***<br>• Survival the more important than the pain relief<br>• Cancer pain indication of cancer recurrence<br>• Acceptance of living with unrelieved cancer pain<br>• Cancer treatment taking precedent over pain treatment<br>• Eager to find the cause of pain but rejecting pain medications<br>• Normalisation of pain<br>*"The most popular words which Chinese people often said to themselves when they go to see the doctor are that "the medication is bitter, but it would be good for the treatment". Sometimes when you take the medication, it could be bitter and may cause pain. This is a part of the process which it happens when you are sick." (P23, female, 63 years old and bowel cancer).* | ***Acceptance of pain reduces suffering***<br>• Pain is inevitable<br>• Under-report and endurance of pain<br>• Rejection to opioids and other analgesics<br>• Using non-pharmacological approaches, e.g. mindfulness for pain<br>*"Suffering is part of disease." (R98, 58 years old, cancer care nurse)*<br>*"They have very strong beliefs that pain is a sign of weakness. Mind over matter – if you think you're not in pain, pain will not exist. So managing pain with their beliefs makes it harder, they will usually refuse treatment." (R104, 57 years old, palliative care nurse)* | **As above** | From both patient and nursing perspectives, a common belief held by Chinese migrants that prevents them receiving or adhering to opioids and other analgesics is their perspective about cancer pain being a part of cancer and its treatment and that it is impossible to take pain medication all the time. They feel that they need to face reality and use non-pharmacological approaches to control their pain. When they put up with cancer pain without reporting it during pain assessment, their eagerness to survive the cancer may drive them to report their pain to oncologists during a clinic visit when they have concerns about cancer pain indicating cancer recurrence. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)** Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences** (Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
| | ***Chinese people express their pain differently compared to local people and higher scores 'fear of distracting physicians' and 'a desire to be good'.***<br>• More reserved<br>• High expectation of bearing pain<br>• Unwilling to ask for help for pain<br>• Normalisation of pain<br>• Endurance of pain<br>*"Local people are very straightforward. Compared to us, they accept life, death and disease easily … I feel that the way how the local people deal with pain is correct. I find they do not care. They would say where the pain is located. We would make self-judgement about the pain first, before we ask the doctor. I feel this is not good … I think we need to learn this from the local people." (P23, female, 63 years old and bowel cancer)* | ***Expression of pain is unacceptable***<br>• Unwilling to bother others<br>• Barely complained<br>• Endurance of pain<br>• Denying of pain<br>• Do not want to bother others with their complaints<br>*"More stoic about pain than Anglo-Saxon patients − sometimes will under-report." (R116, 55 years old, cancer care nurse)*<br>*"…They sometimes will tell the specialist when prompted but on the whole they appear to not want to bother me with their complaints." (R52, 55 years old, palliative care nurse)* | **As above** | While Chinese migrants may report their pain to their cancer treatment team, they may not complain about their pain during their care or when they stay at home. Culturally Chinese society has high expectations about pain endurance, particularly for males, as they are afraid of bothering others with their own problems. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
| **'Cultural Values, Beliefs, and Lifeways' (continued)** | ***Culture-related negative medication beliefs and higher score of 'side-effects' side-effects' ($\bar{x}$4.71, SD ±0.75) of S-BQT***<br>• All medications including anti-cancer and pain medications are toxic<br>• Opioids are poisons and are harmful to the vital organs<br>• Rejection to opioids<br>• Preference to find less harm non-harmful ways to<br>• Endurance of pain<br>*"I think all the medications are toxins. We have already had too many toxins in our body, because we had cancer and we have already used too many chemo and radiation medications which are very poisonous. If you add more toxins, the liver and kidney would not stand them. So, it is better not to take it." (P17, female, 54 years old and breast cancer)*<br>The majority used non-opioid analgesics (e.g. Panadol and Aspirin) (75%, *n* = 18) treating cancer pain<br>Only a third (*n* = 8, 33%) used opioids to manage their cancer pain | ***Myths around opioids and other analgesics***<br>• Rejection to opioids and other analgesics<br>*"Heavy stigma around more use of pain relief the worse and more severe the illness." (R39, 38 years old, palliative care nurse)*<br>*"Fear that taking morphine means that death is imminent." (R50, 48 years old, palliative care nurse)* | **Confirmed and complemented** | From both patient and nursing perspectives, Chinese migrants' cultural-related negative medication beliefs are the main barriers to them receiving opioids and other analgesics for cancer pain, because of the fear of the pain medications would worsen their health conditions. As a result, Chinese migrants may reject taking opioids and use non-opioids for their cancer pain and/or endure the pain. Nurses from palliative care have also observed that Chinese migrant cancer patients reject taking opioids at the end of life because they fear that the opioids may cause immediate death. However, as some nurses mentioned, since most of the time the family members make decisions for the patients, it is hard to tell if the decision for rejection truly reflects the patients' own willingness. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
| **'Cultural Values, Beliefs, and Lifeways' (continued)** | ***Western biomedical model-related opioid fears and higher scores of 'addiction' needed' ($\bar{x}$3.46, SD ±2.69) and 'as needed' ($\bar{x}$3.17, SD ±2.20) of S-BQT***<br>• Concerns about side-effects (e.g. constipation) of opioids<br>• Frightened of severe opioid side-effect experiences<br>• Fear of addiction and rejection to opioids<br>• Endurance of pain<br>*"I endured the pain from time to time, and sometimes I felt that I may overcome the pain by enduring the pain. So, I simply did not use those painkillers. In the questionnaire I did just now, it asked about addiction of the painkillers. I thought it was likely to be addicted to the painkillers, because it may lead to hallucinations. When the pictures that I never saw before appeared in my mind, I felt that my mind seemed to become unstable. I was afraid when my pain was controlled, where my mind would become chaotic. I did not dare to use [the painkillers]. I was afraid that it would become a problem when my mind become chaotic." (P19, male, 67 years old and bowel cancer)* | ***As above*** | **As above** | As above |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
| **'Cultural Values, Beliefs, and Lifeways' (continued)** | ***Opioids extend life for people with terminal cancer pain and higher score of 'tolerate'( $\bar{x}$4.33 ±4.33 ) in S-BQT***<br>• Afraid of losing control to extreme pain<br>• Fear of being tortured to death by the severe pain<br>• Strong pain relief extending life at the end stage of cancer Saving opioids for severe pain<br>*"Taking the pain medications may help relieve the pain for a while. There is no choice when the pain becomes severe. So if he (doctor) gives you medications that may relieve your pain, you would have to take it, no matter what it is. The medications we are taking right now is poison, so it is the same. Therefore, if it is painful, you have to take it even if it is poison." (P12, female, 65 years old and lung cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Contradicted** | The focus group finding suggests that Chinese migrants are willing to use opioids at the end of life or when their cancer is advanced, though they do not want to be told what kind of medications they are taking. This finding contradicted with results of the nurse survey; as previously discussed, the nurses perceived that Chinese migrants focus on active cancer treatment instead of palliation. The difference may be because of the family's inference to Chinese migrant care at the end stage of their cancer. Nurses and other health professionals need to be aware of the difference and promote communication between Chinese migrant cancer patients, their families and health professionals to ensure that the care provided to Chinese migrants meets individual's needs. |
| **'Professional and Generic (folk or lay) Care Beliefs and Practices'** | *Desire to access non-pharmacological pain care:*<br>*Exercises helps to reduce pain severity*<br>*"I have my own approach. My case is that I cannot stay at one position for several hours, so I have to change my position from time to time. So, I would go out to buy a green onion – just going out and walking around. The pain would be reduced after I walk down the street. I use this method to reduce my pain." (P3, female, 55 years old and breast cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Extended** | Regular exercise and movement was considered to be one of the most valued non-pharmacological methods for Chinese migrants to relieve their cancer pain and improve their overall wellbeing. |
| **'Professional and Generic (folk or lay) Care Beliefs and Practices' (Continued)** | *Desire for greater access to physiotherapy*<br>*"Physiotherapy helps me manage the pain..." (P16, female, 48 years old and nasopharyngeal cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Extended** | They are eager to access physiotherapy care services, to receive training about doing exercise properly and/or adopting other complementary approaches, to restore their physical functioning and reduce their pain. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
|---|---|---|---|---|
|  | Desire for more psycho-oncological support<br>*"Psychological support is important – it is more important than pain." (P17, female, 54 years old and breast cancer)*<br>*"I also had seen the psychologist. However, the downside was that he did not understand what the cancer is … How he could help me release my stress when he didn't even know about the cancer…" (P3, female, 55 years old and breast cancer)* | ***As above*** | **As above** | They also need access to psycho-oncological services and ongoing psychosocial support to help them relieve their psychological distress associated with their cancer diagnosis and caner pain. However, the needs were not reported by the nurses. |
|  | Beliefs and barriers to use of TCM for cancer pain:<br>Benefits of TCM<br>*"I took Chinese herbal medicines to recuperate my body. I hope it may help me improve my health conditions holistically and make me feel better." (P16, female, 48 years old and nasopharyngeal cancer)*<br>*"I did acupuncture and massage myself to control my pain. I looked at internet and found a lot of points can stop the pain. So, I did it myself at home." (P21, female, 53 years old and breast cancer)*<br>A half of participants used traditional Chinese medicine (TCM) (50%, n = 12) to manage cancer pain.<br>The most (n = 23, 95.8%) used complementary approaches (massage, heat, Qigong and etc.) to manage cancer pain | Believing in traditional pathways rather than western medicine<br>• Preferences to use TCM and/or other alternative methods without informing health professionals<br>*"Reliance on traditional Chinese medicine, rather than western medications or safe use of both." (R45, 57 years old, palliative care nurse)*<br>*"Use of alternative therapies without informing physician/nurses. Declining services for fear of treatment with western medicine." (R9, 59 years old, palliative care nurse)* | **Contradicted** | Nurses and most of the participants in the focus groups suggested that Chinese migrants would like to adopt TCM to treat their cancer pain and restore their health, particularly when they receive cancer treatment, because TCM can be used as an adjunct therapy to help people recuperate their body from the side-effects of cancer treatment, and restore their physical functions. In return, it will relieve physical discomfort. Therefore, they preferred to:<br>• use acupuncture, massage and other complementary approaches to treat cancer pain<br>• use herbal soups to improve their health conditions and treat pain<br>• self-administer TCMs to control their pain and/or to improve their health conditions.<br>However, it seemed that nurses misunderstood that Chinese migrants only trust TCM and would hide their use of TCM and other alternative approaches for their cancer and pain treatment. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'Professional and Generic (folk or lay) Care Beliefs and Practices' (Continued)** | Concerns regarding qualifications of TCM Practitioners<br>*"I am very conservative and do not really trust TCM practitioners in Australia. I would not trust unless someone who is very famous. So, I have never seen them. If I have pain, TCM would not be my first or final choice. I would go to see my western medicine doctor (the oncologist)." (P15, female, 49 years old and lung cancer)* | *"Distrust of some pain care/comfort methods; wanting to use traditional methods alone." (R89, 55 years old, cancer care nurse)* | **Contradicted** | When the nurses had a perception that Chinese migrant cancer patients only trusted TCM and other alternative approaches, some Chinese migrants hesitated to see TCM practitioners and/or use Chinese herbal medicines because of their concerns about the qualifications of TCM practitioners and the quality of Chinese herbal medicines. Nurses and other health professionals need to be aware of Chinese migrants' concerns, referring them to qualified TCM practitioners for consultation. |
| | Concerns regarding quality of Chinese herbal medicines<br>*"With regards to Chinese herbal medicines, I heard from the radio which said that the soil and weather is crucial in cultivation of the herbs which may have impact on the effects. Now Chinese herbs are planted but there are no such effects. Besides, I do not want to put a lot of stuff in the pot; spend a lot of time to watch the fire pot; and drink it; and find it does not have effects. So, I am not keen about it." (P13, female, 45 years old and breast cancer)* | As above | **As above** | |
| | *Fear of contradictions between western medicine and TCM*<br>*Some did not dare to take TCM after receiving warnings from their oncologists about potential drug−drug interactions.*<br>*Time conflict between cancer treatment and TCM*<br>*Stopped seeing TCM practitioner and/or using of TCM when seeing western medicine physicians and/or receiving cancer treatment*<br>*"I took Chinese herbal medicines before I had cancer, but I do not dare to take it now." (P7, female, 70 years old and lung cancer)* | ***No theme or subtheme identified in nurse survey data*** | **As above** | Although most Chinese migrants prefer to use TCM for cancer pain, they discontinue seeing TCM practitioners and using TCM for cancer pain once they start receiving cancer treatment. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)** Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences** (Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'Economic Factors' & 'Political and Legal Factors'** | *Unaffordability of TCM and other pain treatments*<br>*"The medications are very expensive." (P1, female, 62 years old and breast cancer)*<br>*"I visited three TCM practitioners and I have to pay all the costs for the consultations and the medications … Also, it is not cheap to see a TCM Practitioner." (P4, female, 61 years old and breast cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Extended** | Due to the influence of financial and legal factors, most Chinese migrants face financial difficulties in accessing TCM and pharmacological pain treatment. As a result, they:<br>• discontinue using TCM and other pain medication<br>• are in desperate in need of help to receive acupuncture and other TCMs to control their pain, so they are not help up from receiving their anti-cancer therapies<br>• need financial support for cancer pain treatment.<br>The involvement of social workers in their pain care to assess their financial needs are crucial. |
| | Ineligibility for financial assistance<br>*"It would have already helped us if the government may let us use Medicare to treat our pain." (P1, female, 62 years old and breast cancer)* | ***As above*** | **As above** | |
| **'Educational Factor' & Technological Factors'** | **Cancer pain education shapes Chinese migrants' capacity to self-manage their pain:**<br>***Too little education and information makes it difficult for Chinese migrants to self-manage their cancer pain***<br>*"No one taught us about the pain management." (All participants in Focus Group 1, n = 8)*<br>*"We have very limited information of cancer pain management ... Nobody tells us this information." (P7, female, 70 years old and lung cancer)* | ***No theme or subtheme identified in nurse survey data***<br>Only one nurse mentioned*:*<br>*"Misunderstanding or complete lack of knowledge on pain ladder." (R39, 38 years old, palliative care nurse)* | **As above** | Only one nurse reported that Chinese migrant cancer patients had a lack of knowledge of cancer pain treatment, while most Chinese migrant cancer patients had concerns about a lack of knowledge and skills and had very limited information to help them self-manage their pain.<br>Because of lack of education and information about cancer pain and its pain management, Chinese migrants perceived that they were incapable of self-managing pain and unable to make informed decisions. As a result, they rejected opioids and/or had poor adherence to pain treatment. They were eager to learn knowledge and skills about cancer pain, analgesics, pain assessment and pain treatment options to manage their own pain at home. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'Educational Factor' & Technological Factors' (Continued)** | Preferences for cancer pain information formats vary<br>*"I think that the resources should to be developed in many ways, but not just focus on the internet. I do not mean it does not help, but just feel that it should be in a range of styles … Just like me, usually the cancer patients are elderly. We would be very tired when we have pain. We do not have much time to search information online like young people. We only need some general information and we should reduce the time surfing on internet." (P15, female, 49 years old and breast cancer)*<br>*"We're not interested in apps and we have not had much education." (P2, female, 54 years old and lung cancer)* | *No theme or subtheme identified in nurse survey data* | **Extended** | Due to safety concerns and difficulty in searching, reading and/or making judgement about the quality of electronic information online or via apps on the smart phone, all Chinese migrants, particularly the older generation, prefer to receive bilingual written materials. Electronic versions and other online materials should also be accessible via reliable government websites for the younger generation. In-person and/or online real time consultation at cancer treatment centres and face-to-face bilingual pain educational workshops were desired to help them self-manage their pain. |
| **'Language and Communication Factors'** | ***Communication barriers and enabler***<br>***Poor communication discourages pain reporting***<br>*"I went to see the doctor for solution whenever the pain struck, but the doctor did not explain to me anything." (P1, female, 62 years old and breast cancer).* | ***No theme or subtheme identified in nurse survey*** is relevant to Chinese migrants' report about poor communication between physicians and nurses. Only one nurse mentioned that:<br>*"Even after repeat explanations, Chinese patients tend to believe and trust unofficial sources (such as what the neighbours or others say) more than health professionals." (R39, 38 years old, palliative care nurse)* | **Contradicted** | Nurses' comments about Chinese migrants seeming to not trust them more than unofficial sources is likely because Chinese migrants could not understand what the doctors and/or nurses said, or their explanations did not address Chinese migrants' concerns about analgesics. Eventually, they stopped expressing concern about pain during medical consultations. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'Language and Communication Factors' (Continued)** | ***Medical jargon impedes expression and comprehension***<br>*"There may be problems with ourselves. For example, we may not be able to communicate or speak out our question precisely. If we cannot make ourselves clear, when you want people to help you, it would be hard for you to make the request. If you say the pain lightly, he would say to you that is normal. If you say it seriously, he would make it as a big deal, using the whole set of instrument or tests which make the things complicated" (P19, male, 67 years old and bowel cancer).* | ***Unable to clearly describe pain and treatment needs***<br>• Rely on their family to communicate and make decision for them<br>*"Language barrier makes it difficult for them to verbalise pain and their needs." (R60, 27 years old, palliative care nurse)* | **Confirmed and deepened** | Both Chinese migrants and nurses perceived that language, especially medical jargon, poses a big barrier in clearly expressing and understanding their pain. As a result, they lost confidence discussing cancer pain and pain management with their oncologists and other health professionals. |
| | ***Inappropriate translation causes confusion***<br>*"The interpreter cannot help you at all." (P4, female, 61 years old and breast cancer)*<br>*"Sometimes I cannot understand the words interpreters translated. Because there are slight differences in interpreters' languages which depends on their backgrounds − whether they come from Malaysia, Mainland of China or Hong Kong. Also, there are slight differences in both Chinese and English. For example, in Malaysia people say 'baxian', but here we would say 'percentage'. This is very basic vocabulary, but it can be interpreted differently." (P15, female, 49 years old and breast cancer)* | ***Challenge of using interpreter service***<br>*"Need to have good interpreter available to discuss in depth about pain types, frequency, duration and response to analgesia." (R118, 55 years old, cancer care nurse)*<br>*"Getting interpreters after hours is always a challenge − phone is never good." (R114, 36 years old, palliative care nurse)*<br>*"Most patients I have come in contact with are older people. So there is a generational issue; communication of feelings, pain and other intangible aspects are often difficult to describe … They prefer to rely on family rather staff to assist them; much of this is related to language as well." (R52, 55 years old, palliative care nurse)* | **As above** | Both Chinese migrants and nurses perceived that the quality of interpreter services is another major issue affecting effective communication. There is a need to involve both a Chinese−English speaking family member and an interpreter in clinic consultations for mutual understanding between health professionals and patients. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'Language and Communication Factors' (Continued)** | ***Involvement of Chinese-speaking health professionals supports communication***<br>*"A Chinese-speaking nurse worked there who may help. There is no problem with the communication … I did find this was helpful because we often contact each other via emails and keep in touch for many years. She always reminds me of upcoming activities." (P20, female, 47 years old and breast cancer)* | ***No theme or subtheme identified in nurse survey*** is relevant to Chinese migrants' report about poor communication between physicians and nurses. Only a nurse mentioned that:<br>*"In my experience Chinese patients often only want to speak to nurses who speak their language." (R104, 57 years old, palliative care nurse)* | **Extended** | As language posed a big barrier to informed decisions, from Chinese migrants' view point, involving Chinese-speaking health professionals when it is possible would be helpful to promote effective communication for better cancer pain management. |
| | ***Bilingual educational information as communication tools promotes shared understanding***<br>*"Sometimes when I told doctors about my pain, they asked me to speak English, but I cannot speak English. So it would be much clearer if I let them look at the booklet." (P12, female, 65 years old and lung cancer)*<br>*"Chinese-English information are very important. Sometimes I cannot understand the words interpreters translated. Because there are slight differences in interpreters' languages which depends on their backgrounds…We may read the English and then we will know its original meaning when we do not understand the Chinese translation." (P15, female, 49 years old and breast cancer)* | ***No theme or subtheme identified in nurse survey data*** about Chinese migrants' needs for bilingual education information but nurses have made suggestions about using translation tools to promote communication which is discussed under research question 4 about strategies. | **As above** | Bilingual education resources need to be developed and provided to Chinese migrants to promote their communication with health professionals for their cancer pain. |
| **'General and Specific Care Factors'** | 'Physicians' and nurses' attitudes to cancer pain and its management:<br>"Pain is normal'<br>*"When I went to see the oncologist, I said my hands and feet had slight pain ... The doctor said to me if I did not feel pain it meant the medications I was taking for the chemotherapy did not have effect." (P11, female, 62 years old and breast cancer)*<br>*"In short no pain is not good" (all participants in focus group 2 summarised their physicians' words).* | ***No theme or subtheme identified in nurse survey data*** | **As above** | Chinese migrants were keen to consult with their oncologists and other physicians involved in their cancer pain treatment about their cancer pain. Physicians' attitudes and perceptions about cancer pain discouraged Chinese migrants seeking help for their cancer pain during the clinic consultation and acted as a barrier for them to take action about their cancer pain. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'General and Specific Care Factors' (Continued)** | "Take Panadol"<br>Most of participants were told to take Panadol for cancer pain without pain assessment<br>*"In short, you do not need to see the doctor when you have pain, because they would tell you to take the Panadol." (P7, female, 70 years old and lung cancer)*<br>*"If the medications are used for chemo or radiotherapy, they would tell you in detail. However, if you have had pain in hospital, they would give you Panadol or other medications, but they would not tell you about the side-effects. You just need to take the medication when you feel pain." (P9, female, 69 years old and colorectal cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Extended** | Chinese migrants were disappointed that physicians and nurses in hospitals, and GPs, failed to assess their cancer pain and treat their pain effectively. The ineffective cancer pain treatment led to rejection or poor adherence to opioids and other analgesics, and/or discontinued pain treatment after discharge. |
| | **Barriers and enablers to navigating with health care services for cancer pain:**<br>Uncertainty about where to seek help<br>*"I do not know which one (health professionals) I should to ask when I have pain. Besides, they will shift the responsibilities to each other. After the treatment is finished, they will not care about you anymore. You have to resolve the problems and find the answers yourself…" (P2, female, 54 years old and lung cancer)* | ***No theme or subtheme identified in nurse survey data*** | **As above** | Chinese migrants were unfamiliar with health care systems and had difficulty accessing the pain treatment service after discharge. As result, they struggled to cope and deal with pain at home and/or discontinued pain treatment after discharge. Some went to the emergency department for pain treatment. |
| | Difficulty accessing pain treatment service<br>*"The barrier would be the inconvenience. When I have pain, I have to find a doctor before I may go to the hospital. This is a barrier. When I had pain in the evening at home, I would bear it and did not go to see the doctor until dawn … I wish I would stand the pain for several hours. You would have to wait even when you went to the emergency room. They would ask you to wait. The pain was still there." (P9, female, 69 years old and colorectal cancer)* | ***As above*** | **As above** | |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)** Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences** (Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'General and Specific Care Factors' (Continued** | ***Needs of continuing support***<br>*"I hope there is a department where it provides specific support and help people like us to resolve the problems, no matter the problems are after-effects of the surgery or the chemotherapy. Sometimes we have pain as well as other distress. If there is a specific department where we can ask the questions directly and they can help us to resolve the problems. It would be more helpful. So we do not have to wonder if we should ask our specialists or GPs or chemotherapists." (P2, female, 54 years old and lung cancer)* | ***As above*** | **Extended** | Most of the Chinese migrants did not receive follow-up services and found it very difficult to cope with their cancer pain treatment. They suggested that there should be follow-up services and a department at the hospital to provide continual support to all cancer patients when they start cancer pain treatment and after their discharge from the hospital. |
| **'Kinship and Social Factors'** | **Family and peer support:**<br>***Fear of being a burden***<br>*"Because the disease is my own, they are not able to understand how much I was suffering. I would make them worry; and everyone's feelings are not the same, so they may not be able to help us. I feel like this. I would like to do my best to resolve my own problems. It is nice if the family care about you. However, it would become a burden, if they could not understand you. For example, if I woke up my family that night, I would feel very embarrassed and feel very uncomfortable." (P9, female, 69 years old and colorectal cancer)* | **Dependence on family for decision-making about pain care:**<br>***Family rejecting analgesics for the patient***<br>*"Family members make decisions on behalf of the patient and sometimes deciding whether the patient needs pain management or not; thereby interfering with care needs." (R47, 48 years old, palliative care nurse)* | **Contradicted** | Patient and nurse perspectives about the family member's role related to Chinese migrants' cancer pain treatment is contradictory. There is no doubt that family members are very important for Chinese migrants to cope with their pain at home, by providing daily care, financial and emotional support, and assisting with communication between health professionals. The nurse observed that somehow this kind of support could interfere with Chinese migrant cancer patients' pain management. Particularly for those family members with concerns on the side-effects and safety of opioids and other analgesics, their negative attitudes to analgesics could influence Chinese migrants' cancer pain treatment and lead to rejection of opioids. Importantly, the Chinese migrants did not want to become a burden to their family. They were eager to consult with their oncologist and other health professionals involved in their cancer treatment to find a solution for their cancer pain. |

| **Domains of Leininger's 'Semi-Structured Inquiry Guide'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Themes/subthemes/key elements, results of Patient Questionnaire including results of S-BQT and sample quotes | **Study 3: Nurse Survey (Quant+qual)**<br>Themes/ subthemes/ sample quotes of open-ended question<br>Results of closed-ended questions | **Convergence label** | **Meta-inferences**<br>(Dimension of Leininger's 'Sunrise Enabler': Influences on Care Expressions, Patterns and Practices) |
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| **'Kinship and Social Factors' (Continued)** | ***No theme or subtheme identified in focus group data*** | ***Family withholding information about diagnosis and prognosis from the patient***<br>- Unable to make informed decision for their own pain management<br>*"Concealing of information by family members protecting patients etc." (R99, 55 years old, cancer care nurse)* | **Contradicted** | Nurses had a perception that family members of Chinese migrant cancer patients often withheld information about cancer diagnosis and prognosis. This is contradictory to the findings of the focus group, as all participants were aware of their cancer diagnosis and would like to receive information and take active action to manage their pain at home. |
| | ***Importance of peer support***<br>*"Because everyone has experienced the pain; it would make us feel better knowing that everyone is in the same boat. I do not need to explain to them about my feeling. Sometimes it is hard for healthy people to understand our situation." (P1, female, 62 years old and breast cancer)* | ***No theme or subtheme identified in nurse survey data*** | **Extended** | Sharing experiences and feelings with peers from the same cultural background and having the same disease and problems is an essential way of Chinese migrants maintaining social interaction and functioning, assisting them to overcome barriers and cope with cancer pain. |
| | ***Role of Chinese cancer support groups***<br>*"We come here listen to the lectures. Here we meet some friends who had cancer and exchange ideas. Besides, all volunteers and other people at Chinese cancer support groups are very nice. They provide us information and support which are not available from the community or other place." (P21, female, 53 years old and breast cancer)* | ***As above*** | **As above** | Chinese cancer support groups played a crucial role in supporting people from Chinese background cope and deal with their pain at home by providing a series of educational resources, organising group activities and providing assistance for their daily living. Joining a Chinese cancer support group is beneficial for Chinese migrants so they receive support to help them restore their physical, physiological and social functions. |

## Appendix L: Joint Display Table Two for Research Questions 4

The joint display for research question 4 in line with three 'Cultural Decision and Action Modes' of Leininger's 'Sunrise Enabler': What strategies are optimal to promote culturally congruent cancer pain management for Chinese migrants?

| **Leininger's 'Cultural Decision and Action Modes'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Inferences summarised based on of the results of Chapter 5-7 | **Study3: Nurse Survey (Quant+qual)** Themes/Subthemes/key elements of the results summarised in Chapter 8 | **Convergence label** | **Meta-inferences** Culturally-appropriate interventions |
|---|---|---|---|---|
| **'Cultural Care Preservation and/or Maintenance'** | Desire to self-control of pain<br>Preference for using a health regime to promote self-healing<br>Preferences about using opioids may change as they approach the end-of-life<br>Well educated physicians and nurses provide better care meeting their cancer pain management needs.<br>3. | ***Providing education the nurses and other health professionals about influences of Chinese cultural beliefs on patients' pain care***<br>A cultural awareness campaign should be initiated at health care settings to help nurses and other health professionals better understand Chinese migrant cancer patients' cultural care needs of patients and their families, and<br>The reasons for rejecting analgesics, is essential to promoting mutual understanding and respect and avoiding any potential conflict between patients and staff. | **Complemented and enhanced** | Providing culturally-congruent pain care with understanding and respect:<br>To their philosophic health beliefs about using a health regime, to manage pain and promote body's self-healing.<br>Acknowledge Chinese migrants' preferences about using opioids may change as they approach the end-of-life |
| | Involve family member into their shared-care decision for their pain treatment, but<br>Prefer to seek medical help from their oncologists and/or other physicians involving in their cancer treatment to find solution to manage their own pain.<br>Prefer to report their pain to oncologists and/or other physicians involving in their cancer treatment during clinical consultations.<br>Assumed that they should follow these physicians' instructions about pain treatment. | A cultural awareness campaign should be initiated at health care settings to help nurses and other health professionals better understand Chinese migrant cancer patients' cultural care needs as well as the family's role in their pain management | **As above** | Involve Chinese migrants' family member into their shared-care decision-making about their pain treatment, but need to acknowledge the patients' wishes to manage their pain themselves |
| | | Education on what and how Chinese cultural beliefs have shaped the patients' perceptions and responses to cancer pain and pain management would enable the nurses and other health professionals to obtain a better understanding about their pain reporting and help-seeking behaviours. | **As above** | Screening Chinese migrants' cancer pain at clinic visits<br>Offer opportunity for Chinese migrants to express their concerns about cancer pain and offer options for pain management |

| **Leininger's 'Cultural Decision and Action Modes'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Inferences summarised based on of the results of Chapter 5-7 | **Study3: Nurse Survey (Quant+qual)** Themes/Subthemes/key elements of the results summarised in Chapter 8 | **Convergence label** | **Meta-inferences** Culturally-appropriate interventions |
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| **'Cultural Care Preservation and/or Maintenance'** | Refer Chinese migrants living with cancer pain to physiotherapy and psychological-oncological care services<br>Provide social and psychological support to help Chinese migrants build self-efficacy engaging with and implementing their individualised cancer pain management plan<br>Involve social worker to assess Chinese migrants' financial difficulties and provide finical support for cancer pain treatment<br>Refer Chinese migrants to TCM practitioners in accordance with their needs and concerns using TCM for pain treatment | ***Providing education the nurses and other health professionals on Chinese traditional pathways in pain management***<br>Education/information about Chinese traditional pathways in pain management is critical to enable nurses and other health professionals to integrate these pathways in clinical practice to improve pain care outcomes. | **As above** | Offer non-pharmacological interventions address to Chinese migrants' needs of access to physiotherapy and psycho-oncological care services, TCM and other complementary approaches for care pain.<br>Involve social worker to assess Chinese migrants' financial difficulties and provide finical support for cancer pain treatment<br>Refer Chinese migrants to TCM practitioners in accordance with their needs and concerns using TCM for pain treatment |
| | **Not identified** | ***Compulsory cultural education to the nurses and other health professionals in various formats***.<br>Cultural education in relation to Chinese migrants' cancer pain management should be compulsory as an important component of nurse annual continued professional training for those who working in cancer care.<br>Access to various training and academic education resources about cultural care and access to Chinese-language tools may help nurses enhance their competences in managing Chinese migrants' cancer pain.<br>The training could be delivered via face-to-face formal education (lectures/workshops), in-service | **Enhanced** | Develop multiple cultural educational resources to promote nurses and other health professionals' understanding and confidences in providing culturally congruent pain care to Chinese migrants and their family. |

| **Leininger's 'Cultural Decision and Action Modes'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Inferences summarised based on of the results of Chapter 5-7 | **Study3: Nurse Survey (Quant+qual)** Themes/Subthemes/key elements of the results summarised in Chapter 8 | **Convergence label** | **Meta-inferences** Culturally-appropriate interventions |
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| | | and/or via online training programs, to suit nurses' needs and schedules. | | |
| **'Cultural Care Accommodation and/or Negotiation'** | Involvement of Chinese-speaking health professionals supports communication and providing continual support to them for their pain management after discharge.<br>Assess to Chinese cancer support groups to assist them coping and dealing with their pain at home and restoring their physical, psychological and social function. | ***Promoting culturally congruent pain care to Chinese migrant cancer patients and their family using a collaborative approach***<br>Involving Chinese migrant cancer patients and their families, Chinese-speaking health professionals and Chinese committees (e.g. cancer support groups) for informed, and shared health decisions about pain treatment. | **Complemented and enhanced** | Adopt a collaborative approach and involve Chinese-speaking cancer care coordinators, their oncologists and other physicians, Chinese cancer care support group, Chinese migrant cancer patients and their families for informed and shared health decisions about pain treatment, and promote the patients' physical, psychological and social function. |
| | Access to follow-up services and in-person/online real-time consultations.<br>Access to a department at cancer care centres for in-person and/or real-time online clinical consultation to help cancer patients to resolve the problems associated with the after-effects of cancer treatment and pain. | **Not identified** | **Enhanced** | Provide follow-up visits by the community nurses and/or follow-up calls addressing Chinese migrants' pain and analgesic-related issues increased their confidence and ability to deal with their cancer pain and daily life at home.<br>Consider offering in-person and/or real-time online clinical consultation services to help cancer patients to resolve the problems associated with the after-effects of cancer treatment and pain. |
| **'Cultural Care Accommodation and/or Negotiation' (Continued)** | Appropriate explanation about pain medications prior to discharge prompted better pain control at home.<br>Chinese-English educational information materials may be used as a mean of communication, to | ***Promoting culturally appropriate communication between Chinese migrants cancer patients, their family and health professionals using simple and translated communication tools***<br>Nurses and other health professionals need to be encouraged to listen to their Chinese patients and | **Complemented and enhanced** | Implement therapeutic communication with caring, assisting with Chinese-English educational tools and in plain and simple language to promote help-seeking and active interactions with clinicians, to enhance their self-efficacy in making- |

| **Leininger's 'Cultural Decision and Action Modes'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)**<br>Inferences summarised based on of the results of Chapter 5-7 | **Study3: Nurse Survey (Quant+qual)**<br>Themes/Subthemes/key elements of the results summarised in Chapter 8 | **Convergence label** | **Meta-inferences**<br>Culturally-appropriate interventions |
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| | enable Chinese migrants actively interact with clinicians during their clinic visit for better understanding about cancer pain and its management.<br>For those who spoke limited English, Chinese-English booklet is a useful communication tool to help them clearly describe the pain to their physicians and consults with their physicians about their concerns and option for pain treatment. | the families' concerns related to opioids and other analgesics; and use simple language to explain the effects of pain medication to alleviate their fears.<br>They also need to encourage their patients to ask help for their pain and to actively contribute to their pain management plan.<br>Visual/written resources, such as communication books and translated cards with simple English−Chinese words about cancer pain and options for pain management would be beneficial in promoting culturally appropriate communication between patients and their health care teams. | | decision for their own pain management plan. |
| | Given concerns about the quality of interpreter service, participants suggested that involving both Chinese-English speaking family member and interpreter into the care (e.g. clinic visits) may lead to a better mutual understanding between health professionals and patients. | ***Better access to interpreter services***<br>Increasing accessibility to after-hour interpreter and telephone interpreter services, and<br>Offering an interpreter service at each clinic visit to promote mutual understanding between patients/family and health professionals | **Confirmed** | More well-trained interpreters are needed to provide accurate translation assisting Chinese migrants during clinic consultations to promote mutual understanding<br>Involving both interpreter and family in clinic visits |

| **Leininger's 'Cultural Decision and Action Modes'** | **Study 2: Focus groups and 'Patient' Questionnaire (QUAL+quant)** Inferences summarised based on of the results of Chapter 5-7 | **Study3: Nurse Survey (Quant+qual)** Themes/Subthemes/key elements of the results summarised in Chapter 8 | **Convergence label** | **Meta-inferences** Culturally-appropriate interventions |
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| **'Cultural Care Repatterning and/or Restructuring'** | Recognize Chinese migrants' 'Culture-related negative medication beliefs and high level of barrier in using analgesics<br>Recognize Chinese migrants' complex pain reporting and help-seeking behaviours – prefer to report pain during clinical consultations to find the cause but deny or normalize their pain during a pain assessment.<br>Needs education addressing Chinese migrants' opioid concerns, particularly during cancer treatment.<br>Desired to learn more about how to assess their pain and what methods they may be used to control their own pain.<br>Having better cancer pain knowledge enable them to more readily differentiate acute and chronic pain and take appropriate actions to management their own pain.<br>A booklet using the same format of those for cancer treatment with detailed information such as side-effects and immediate actions would be very helpful. | **Providing education to Chinese migrant cancer patients and their family member to eliminate misunderstanding around cancer pain management**<br>Such as pain, types of pain medication and side-effects, and pain management options.<br>Education should be available and delivered regularly, accurate and consistent, and in a culturally appropriate format that would encourage pain reporting and dispel the many opioid myths, and thus reduce misunderstanding and opioid-related concerns.<br>The education should be to clarify health professionals' role in pain management and address the benefits of pain relief in improving patients' quality of life. | **As above** | Provide regular patient education addressing to Chinese migrants' 'culture-related negative medication beliefs' and their education and information needs about cancer pain and its management, to enhance their capacity of self-managing for their own cancer pain and adherence to analgesics.<br>Reassure importance of acute pain assessment and report and benefit of pain reliefs. |

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| | **Not identified** | Involving Chinese migrant cancer patients' families and interpreters into their education would be beneficial to relieve patients' psychological distress, and<br>Help them fully understand the effectiveness of pain medications and the importance of cancer pain management. | **enhanced** | Involve both Chinese-English speaking family members and interpreters in to Chinese migrants' pain management education to promote better pain management education outcome. |
| **'Cultural Care Repatterning and/or Restructuring' (Continued)** | Bilingual educational materials written materials for all, particularly the older generation<br>Electronic version and other online materials accessible via reliable websites for young generation; and government<br>In-person and/ online real-time consultation at cancer treatment centre<br>Face to face bilingual pain educational workshops | Increasing access to Chinese educational resources and pain assessment tools<br>Developing and implementing Chinese pain assessment tools in clinical practice might enable their patients to accurately assess and appropriately manage their cancer pain themselves.<br>Various types of educational tools (e.g. visual aids and information booklets) and online official resources (e.g. the eviQ website) should be available to help address their educational needs.<br>Access to Chinese educational resources and pain assessment tools would help patients cope with their cancer pain and actively engage with their pain treatment. | **Complemented and enhanced** | Develop and Increase accessibility to multiple –bilingual educational resources to enable Chinese migrants take actively roles and effectively assess and manage their pain at home. |
| | Oncologists, nurses and other health professionals who are caring for Chinese migrants need to foresee the barriers in using TCM approaches for cancer pain.<br>4. | ***Providing information on interaction between Chinese and western medicine***<br>Having health professionals on the team who are qualified in both TCM and western medicine to educate Chinese migrants with cancer pain about the complementary aspects of Chinese and western medicine, as well as the unintended interactions that can occur and the importance of informing the medical team when they are taking Chinese medicine/herbs. | **As above** | Refer Chinese migrants to health practitioners with dual qualifications in TCM and western medication for consultation, to eliminate their concerns on the contradictions and ensure their safety. |

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| | | All health professionals should encourage their patients to discuss their Chinese medicine use and/or needs with the medical team. | | |