

**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)

‘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).

‘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).

'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).

‘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

Thesis

Publication in peer-reviewed English journal

Xu, X., Lockett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (2018). Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature. *Palliative and Supportive Care*, 16(6),785-799. doi:10.1017/S1478951517001171

Peer-reviewed conference (oral) presentations

Xu, X., Phillips, J. L., Lockett, T., & Lovell, M. (Sep 2019). *Exploring cancer and palliative care: Nurses' experiences of caring for Chinese migrants with cancer pain*. Accepted for oral presentation at The 2019 Oceanic Palliative Care Conference (19OPCC), Perth, Australia.

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Xu, X., Phillips, J. L., Lockett, T., & Lovell, M. (June 2019). *Exploring cancer and palliative care: Nurses' experiences of caring for Chinese migrants with cancer pain*. The 21st Cancer Nurses Society of Australia (CNSA) Annual Congress, Melbourne, Australia.

Xu, X., Phillips, J.L. Lockett, T., Lovell, M., Agar, M, & Lobb, L. (Sep 2018). Pain management experiences and needs of Chinese migrant cancer patients. The 2018 International Conference on Cancer Nursing (ICCN 2018), Auckland, New Zealand.

Xu, X, Phillips, J. L., Lockett, T., Lovell, M., Agar, M., & Lobb, L. (June 2018). Pain management experiences and needs of Chinese migrant cancer patients. The 20th Cancer Nurses Society of Australia (CNSA) Annual Congress, Brisbane, Queensland, Australia.

Xu, X, Phillips, J. L., Lockett, T., Lovell, M., Agar, M., & Lobb, L. (May 2018). Pain management experiences and needs of Chinese migrant cancer patients. The 2018 Palliative Care Nurses Australia (PCNA) Biennial Conference, Brisbane, Queensland, Australia.

Xu, X., Lockett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (June 2017). Implementing culture care theories and models in cancer care research. The 20th Cancer Nurses Society of Australia (CNSA) Annual Congress, Adelaide, Australia.

Xu, X., Lockett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Oct 2016). Cultural influence on pain-related perspectives, beliefs and needs of cancer patients from Chinese backgrounds: A systematic review of both Chinese and English language research literature. The 2016 Palliative Care NSW Biennial State Conference, under the theme Transforming Clinical Care. Broken Hill, Australia.

Xu, X., Lockett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Sep 2016). *Cultural influence on pain-related perspectives, beliefs and needs of cancer patients*

from Chinese backgrounds: A systematic review of both Chinese and English language research literature. The Palliative Care Nurses Australia (PCNA) 6th Biennial Conference, Canberra, Australia.

Peer-reviewed conference (poster) presentations

- Xu, X., Luckett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Nov 2017). Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature. Clinical Oncology Society of Australia's (COSA) 44th Annual Congress, Sydney, Australia.
- Xu, X., Phillips, J. L., Luckett, T., & Lovell, M. (Sep 2017). Implementing culture care theories and models in practice and research. 2017 Australian Palliative Care Conference, Adelaide, Australia.
- Xu, X., Luckett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (June 2016). *Cultural influence on pain-related perspectives, beliefs and needs of cancer patients from Chinese backgrounds: A systematic review of both Chinese and English Language research literature.* Cancer Nurses Society of Australia (CNSA) 19th Annual Congress, Cairns, Australia.
- Xu, X., Luckett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Sep 2016). *Cultural influence on Chinese background cancer patients' pain management beliefs, needs and practices: A systematic review of both Chinese and English language research literature.* Abstract presentation (print only), the 9th World Research Congress of the European Association for Palliative Care, Dublin, Ireland.

Oral presentations at institution level

- Xu, X. (Jan 2018). Strategies of conducting focus group at hospital settings: Tips and lessons learnt from my doctoral project. 20 minutes oral presentation at 2018 Summer School, IMPACCT, Faculty of Health, University of Technology Sydney
- Xu, X., (Dec 2017). *Pain management needs and perspectives of Australian Chinese migrant cancer patients: Preliminary focus group data.* 3 minutes e-poster oral presentation at 2017 Spring Research Student Forum, Faculty of Health, University of Technology Sydney.
- Xu, X. (Dec 2016). *Implementing culture care theories and models in cancer care research.* 20 minutes oral presentation at 2016 Spring Research Student Forum, Faculty of Health, University of Technology, Sydney.
- Xu, X. (Jan 2016). *Overview of cultural care theories/models.* 20 minutes oral presentation at 2016 Summer School, the Centre for Cardiovascular and Chronic Care (CCCC), University of Technology, Sydney.
- Xu, X., Luckett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Dec 2015). *Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature.* 2015 Spring Research Student Forum, Faculty of Health, University of Technology, Sydney.

Invited oral presentations at health institutions

- Xu, X., Luckett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Sep 2017). Cancer pain management needs and perspectives of patients from Chinese backgrounds:

A systematic review of the Chinese and English literature. HammondCare Research Meeting, Greenwich Hospital.

- Xu, X. (Apr 2017) Understanding cultural influences on Chinese migrant cancer patients' cancer pain management – highlights of the findings of my doctoral project. HammondCare Research Meeting/Community Nurse Education Meeting, Greenwich Hospital.
- Xu, X., Lockett, T., Wang, A. Y., Lovell, M., & Phillips, J. L. (Sep 2016). Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature. Oncology Teaching Session, Royal North Shore Hospital, Sydney.