UTS UNIVERSITY OF TECHNOLOGY SYDNEY

Understanding the Multi-faceted Patient Experience after Spontaneous Coronary Artery Dissection (SCAD)

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Master of Nursing (Research)

under the supervision of Associate Professor Michelle DiGiacomo, Dr Serra Ivynian and Professor Louise Hickman

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Certificate of Original Authorship

I, Elizabeth Anne Turner, declare that this thesis is submitted in fulfilment of the requirements for the award of Master of Nursing (Research), 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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Elizabeth Turner

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Abstract

Background

Spontaneous Coronary Artery Dissection (SCAD) has emerged as an important cause of acute myocardial infarction (AMI). SCAD accounts for 1–4% of all AMI, but disproportionally affects younger to middle-aged women; SCAD accounts for 31% of AMI in women under 60. There is a considerable burden of adverse psychosocial outcomes including anxiety, depression and post-traumatic stress disorder in people after SCAD, yet research is limited on the experience of SCAD and its effects from the patient perspective. Understanding the person's experience of SCAD is critical to the provision of patient-centred care. An integrative literature review revealed a limited but growing body of research regarding the experience of SCAD from the person's own perspective.

Aims and Research Questions

The SCAD-Insights study aimed to gain a better understanding of the multifaceted patient experience and the impact of SCAD on people and their families for the purpose of informing supportive resources and services after a SCAD event. The questions that guided this research asked how people experience and make meaning of having SCAD, what facilitators and barriers exist in their recovery and how existing resources and services that support recovery from SCAD are perceived.

Methods

A feminist social constructionist approach underpinned the research design, and Interpretive Description was the methodology that informed the conduct of 17 individual semi-structured interviews with people who had experienced SCAD. Reflexive thematic analysis and a patient-centred care theoretical framework guided the data analysis.

Findings

In the first theme ‘SCAD is a mystery’, study participants reported experiencing a range of emotional responses including shock, denial, loss and loneliness. Emotional responses were exacerbated by a perceived lack of information about SCAD and the recovery process. All participants resorted to searching the internet for information. Study participants also described the perceived effects on their families and social circles. In the second theme ‘SCAD is life changing’, study participants reported on the ways in which they adapted to their lives after SCAD. Participation in cardiac rehabilitation had mixed reviews of its appropriateness and effectiveness. In the third theme ‘Finding the SCAD community’, participants described their experience in social media support groups, which provided both benefits to and disadvantages in their recovery.

Conclusion

A SCAD event is followed by uncertainty and frustration, with a fear of recurrence and changes to identity and lifestyle. Social media support groups fill a void in the information gap for people after SCAD. The experience of people after SCAD mirrors that of women after a ‘traditional’ AMI and people with rare disease conditions. People report a lack of information and support for recovery. The findings reinforce the need for patient-centred care that better supports people after SCAD and that may serve to reduce adverse negative mental health outcomes.

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I wish to acknowledge that the literature review presented in Chapter 2 was part of a co-authored paper with my supervisors.

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I conducted the review and was the primary author of this work.

Chapter 1 Introduction

Spontaneous Coronary Artery Dissection (SCAD) has emerged as an important cause of acute myocardial infarction (AMI). Historically SCAD was thought a rare and fatal event, and only diagnosed at autopsy (Franke et al., 2019). With the advent of coronary intravascular imaging technology, the understanding of the pathophysiology, prevalence and management of SCAD has advanced (Franke et al., 2019). Despite this progress, research pertaining to the psychosocial outcomes after SCAD has remained limited. After SCAD, people experience uncertainty surrounding their recovery. Ongoing research into understanding people's nuanced experiences is critical to the implementation of high-quality patient-centred care. The SCAD-Insights study conducted in this thesis aims to provide increased insight into the under-researched area of the person's experience after SCAD.

Chapter 1 presents an overview of the pathophysiology and epidemiology of Spontaneous Coronary Artery Dissection (SCAD). This chapter also describes the longer-term outcomes with an emphasis on psychosocial responses after SCAD and available support for people after SCAD. The importance of patient-centred care (PCC) after SCAD and the significance of this study will be discussed.

1.1 Introducing SCAD

1.1.1 Pathophysiology of SCAD

SCAD develops when bleeding into the wall of the epicardial coronary artery occurs. This creates an intramural haematoma that causes the wall of the artery to bulge into the lumen, obstructing blood flow (Iismaa et al., 2021). In the majority of cases, disruption to the

vasa vasorum of the coronary artery causes a haematoma, which can cause rupture of the vessel as it expands and pressure builds (Iismaa et al., 2021). In all types, the obstruction to coronary blood flow can cause acute coronary syndrome (ACS), ranging from unstable angina to ST-segment elevation MI (STEMI) and sudden cardiac death (Iismaa et al., 2021).

The cause of SCAD remains largely unknown; however, there is a growing body of research into the aetiology of SCAD. Susceptibility to SCAD may be associated with various genetic factors, particularly those related to the development of arteriopathies (e.g., fibromuscular dysplasia [FMD]) (Amrani-Midoun et al., 2021). Hormonal factors and inflammatory conditions may also play a role (Franke et al., 2019). Additionally, up to 80% of people with SCAD reported an emotional or physical stressor prior to the event (Franke et al., 2019). Emotional stressors prior to their SCAD event were more frequently reported by women, while physical stressors such as lifting heavy weights prior to SCAD were more commonly reported by men (Fahmy et al., 2016).

The occurrence of SCAD may not be associated with traditional risk factors observed in atherosclerotic coronary artery disease, such as smoking, diabetes or dyslipidaemia; 33.9% of a large multi-centre prospective observational study (n = 750) reported no cardiac risk factors (Saw et al., 2019). Recent research into SCAD genomics suggests that high blood pressure may have a causative role (Adlam et al., 2023)

1.1.2 Presentation with SCAD

The majority of people with SCAD present with chest pain as their primary symptom and have elevated serial biomarkers (e.g., troponin) and ECG changes indicative of STEMI or non-ST-segment-elevation MI (NSTEMI) (Hayes et al., 2020). However, the initial troponin level may be negative, so there is a risk of an early discharge and a lack of ongoing surveillance (Giyanani & Som, 2021).

People with SCAD present with diagnoses across the ACS spectrum ranging from angina to sudden cardiac death (Iismaa et al., 2021). Between 26% and 87% of individuals present with the more serious STEMI, while 13–69% of people present with NSTEMI. Ventricular arrhythmias or sudden cardiac death are present in 3–11% of people who have experienced SCAD (Hayes et al., 2018).

1.1.3 Prevalence of SCAD

It is now known that 1–4% of all AMIs are attributable to SCAD (Franke et al., 2019). A high proportion of SCAD is observed in women; 84% of people with SCAD were women in one systematic review (n = 2172) (Franke et al., 2021), and greater than 90% of cases were women in other reports (Iismaa et al., 2021). SCAD disproportionately affects younger to middle-aged women; it accounts for up to 31% of AMI in women under age 60 and up to 43% of pregnancy-related AMI (Franke et al., 2019). A small proportion of people with SCAD are men. In one study (n = 288), 25 (8.75%) people with SCAD were male and were, on average, younger than women with SCAD (48.6 years vs 52.3 years) (Fahmy et al., 2016). However, due to under-reporting and under-diagnosis, efforts to estimate the prevalence of SCAD may be limited (Hayes et al., 2020).

SCAD generally presents in people between 45 and 53 years of age, but it can occur at any age, from teenage years into the 80s (El Hussein & Blayney, 2020). SCAD has been reported in all ethnic groups and across geographical locations (El Hussein & Blayney, 2020).

1.1.4 Pregnancy-associated SCAD

Pregnancy-associated SCAD (PASCAD) has been most commonly reported to occur within the first month postpartum (Tweet et al., 2018). PASCAD has been reported to be more serious, with up to 50% of women with PASCAD presenting with STEMI due to left main coronary artery or multi-vessel dissections (Hayes et al., 2018). A review by Havakuk et

al. (2017) (n = 120 women) found a significant rate of complications associated with PASCAD, including up to 25% of women in cardiogenic shock, 16% with ventricular arrhythmia and 4% mortality. As a consequence of STEMI and left ventricular involvement, there is a significant number of women with PASCAD with a reduction in left ventricular function compared to non-pregnant women with SCAD (Havakuk et al., 2017).

1.1.5 SCAD in the Context of Cardiovascular Disease

Cardiovascular Disease (CVD) is the leading cause of death for both women and men globally (Di Cesare et al., 2023). Within CVD, coronary heart disease is the most common condition, with ischaemic heart disease being the most common cause of death (Khan et al., 2020; World Health Organization, 2021). Traditionally, CVD has been understood as a 'disease of men' (Geraghty et al., 2020, p. 9). This perception has negatively affected the awareness of the risk of CVD in women and, consequently, its prioritisation in health policy in research and clinical practice (Geraghty et al., 2020, p. 9). Research and clinical trial evidence for CVD treatment and management has largely been based on data gathered from male participants (Humphries et al., 2017). In women, there is greater mortality and morbidity after cardiac events relative to men (Geraghty et al., 2020).

Despite similar proportions of chest pain being reported by both men and women, women's CVD symptoms may be perceived as atypical and are less well recognised (Humphries et al., 2017). In the case of SCAD, women of relatively younger age or who lack traditional cardiac risk factors are at greater risk of misdiagnosis (Hayes et al., 2018).

1.1.6 Acute Management of SCAD

Current clinical guidelines for the treatment of atherosclerotic AMI recommend revascularisation or clearing the occluded coronary artery through the use of thrombolysis to disperse the blood clot or through the invasive procedure of placing coronary artery stents in

a process known as percutaneous coronary intervention (PCI) (Chew et al., 2016). However, given that the primary pathophysiology of SCAD is haematoma, thrombolysis may increase the risk of further bleeding (Hayes et al., 2018). Invasive treatments such as PCI can be unsuccessful and lead to further complications, such as an extension of the dissection or damage to an already fragile arterial wall (Hayes et al., 2018). In one study (n = 750), PCI was unsuccessful in 30.1% of SCAD cases (Saw et al., 2019). Further, the majority of patients treated conservatively show complete healing of the affected artery a month after their index event (Giyanani & Som, 2021).

The management of a SCAD event, therefore, depends on the person's clinical condition at the time. In the absence of randomised clinical trials investigating the use of PCI for SCAD, conservative (non-invasive) management is currently recommended unless the patient is haemodynamically unstable (Franke et al., 2019). Further, guideline-directed medical therapies used in the treatment of ACS have not been studied in SCAD, and the use of commonly used CVD medications such as aspirin, antihypertensives and statins in the management of SCAD remains controversial (Bullock-Palmer et al., 2019).

1.1.7 SCAD Recurrence

An extension of the SCAD lesion within the first 7 days that causes recurrent AMI may occur in 5–10% of people (Hayes et al., 2018). A large cohort study of SCAD (n = 750) found that major adverse cardiac events over a subsequent 30-day period occurred in 8.8% of the sample (Saw et al., 2019). Mortality rates after SCAD have been reported in different studies as 1.2% in a 3-year period and 7.7% in a 10-year period (Garcia-Guimarães et al., 2020).

Recurrent SCAD events are not uncommon; however, there are varying reported figures. Tweet et al. (2012) reported a 47% risk of recurrence, AMI, heart failure or death in

the 10 years following the index event. An Australian study (n = 40) (McGrath-Cadell et al., 2016) found that over a (median) 16-month follow-up, 8% of people had a recurrent SCAD event, although no deaths were reported. Given the relatively young age of the affected population and the lack of treatments to prevent SCAD recurrence, the effect of these uncertainties regarding the person's future is an important consideration in the prognosis and the ongoing management of patients after SCAD (Hayes et al., 2018).

1.1.8 Recurrence of Symptoms

In addition to the recurrence of SCAD events, the recurrence of SCAD symptoms, most notably chest pain, can occur following a SCAD event (Adlam et al., 2018). Hayes et al. (2018) reported that recurrent chest pain occurs in more than half of people post-discharge from hospital. An evaluation of chest pain in this context must consider the possibility of an extension of the SCAD lesion or recurrent SCAD (Hayes et al., 2018). Additionally, recurring chest pain can contribute to patient psychosocial distress (Hayes et al., 2018). There may also be chest pain occurring in pre-menopausal women with SCAD at predictable times of their menstrual cycle (Hayes et al., 2018). The frequency of chest pain after SCAD has been reported to reduce over time, which is potentially due to the healing of the SCAD lesion or a reduction of psychosocial distress (Hayes et al., 2018).

1.1.9 Long-term Outcomes

Given the unexpected nature of the event, the gravity of potential outcomes and the fear and uncertainty about recurrence, the psychosocial effect of SCAD can be substantial. Younger people and women are already at a higher risk of mental ill-health (Giyanani & Som, 2021), and a SCAD event may precipitate (further) anxiety, depression and post-traumatic stress disorder (PTSD) (Giyanani & Som, 2021; Johnson et al., 2020; Liang et al., 2014).

A large quantitative study (n = 512) investigated psychosocial outcomes after SCAD. Of these participants, 41% presented mild, and 15% presented moderate levels of depression, with similar results for anxiety (32% mild and 16% moderate) (Johnson et al., 2020). Those with lower resilience scores and those with a more recent SCAD event were observed to have higher scores in depression and anxiety measures (Johnson et al., 2020). In a separate study (n = 158), younger people after SCAD were reported to be more likely to have scores consistent with severe anxiety ($p = 0.02$) (Liang et al., 2014). Where SCAD occurred during the postpartum period (n = 19), scores for both depression ($p < 0.0005$) and anxiety ($p < 0.0026$) were significantly higher than in non-postpartum people who experienced SCAD (Liang et al., 2014).

High stress levels were reported in the majority (93%) of another SCAD sample (n = 14), and symptoms consistent with PTSD, such as re-experiencing and hyperarousal, occurred in 43% of the sample (Edwards et al., 2019). It was reported that there was no resolution of these high stress levels within 6 to 12 months following the SCAD diagnosis (Edwards et al., 2019).

Given the potential for this psychosocial burden, people who had experienced SCAD have unique needs in their ongoing management. However, a lack of understanding about SCAD, and a reliance on atherosclerosis treatment guidelines, may result in people with SCAD being managed incorrectly (Franke et al., 2019). People after SCAD may also be inappropriately advised to change their lifestyle to reduce traditional CVD risk factors (Hayes et al., 2018). This is not to say that targeted lifestyle management after SCAD is inappropriate (Saw et al., 2019), but increased pressure to reduce the traditional CVD risk factors may cause frustration and risks diminishing trust in healthcare professionals.

The life stages of people when SCAD typically occurs, specifically younger to middle age, may create challenges for recovery after SCAD. Caregiving responsibilities in families

and careers are important factors at this age. During middle adulthood, between 40–65 years, there are complex social and emotional interactions between individuals and the contexts in which they operate, specifically in relation to family, peer groups and work (Kuther & Burnell, 2017). Changes to these contexts created by events such as an illness can initiate responses that can be perceived by the person either as a crisis or as a turning point (Kuther & Burnell, 2017). A SCAD event could be such a trigger. Family relationships may become complicated in midlife, which is when many adults provide support to various generations of their families. This ranges from emotional support to caregiving and can bring about an emotional toll and create vulnerability (Kuther & Burnell, 2017). Women with PASCAD, often younger than the 'midlife' cohort, are faced with the new role of mother and caregiver. Consequently, they face unique challenges in adapting to life after a cardiac event (Hutchens et al., 2022).

The work context is fundamental to most adults' sense of competence, achievement and identity (Kuther & Burnell, 2017). Disruption of this important aspect through a sudden and unexpected illness such as SCAD can challenge a person's identity and well-being. Current workplace systems are associated with increased stress, increased workloads and poor job security (Dickson et al., 2021). The workplace environment can place a burden on people recovering from illness, which may limit their ability to participate in their own self-care, impair their work–life balance and instil a fear of discrimination (Dickson et al., 2021). Given the life stage at which SCAD often occurs, people after SCAD might, therefore, be expected to experience additional stress regarding their potential return to work.

1.2 Support After SCAD

1.2.1 Cardiac Rehabilitation After SCAD

As SCAD is a relatively rare condition, people who have this experience may lack peer support and community resources to manage their recovery (Giyanani & Som, 2021). One potential avenue for the provision of psychosocial support after SCAD is through participation in cardiac rehabilitation (CR). CR programs aim to improve well-being and health-related quality of life following a cardiac event (Taylor et al., 2020). International guidelines recommend that CR programs should provide psychological support and education in addition to physical exercise components for all patients following a cardiac event (Piepoli et al., 2014; Taylor et al., 2020; Woodruffe et al., 2015). Referral to, and participation in, CR is also recommended after SCAD (Adlam et al., 2018; Hayes et al., 2020). However, current rates of both referrals to and participation in CR are low despite evidence supporting the benefits of CR after SCAD (Hayes, 2014). Low rates of referral to, and participation in, CR after SCAD are consistent with the literature regarding suboptimal participation rates in CR generally. A lack of CR referral is associated with non-participation (Resurrección et al., 2019). Where people received recommendations from their healthcare provider to attend CR, they were more likely to do so (Khadanga et al., 2021). Moreover, women are less likely to be referred to CR than men (Supervía et al., 2017).

1.2.2 Online Support Groups After SCAD

Since the mid-1990s, a range of digital technology platforms have emerged that enabled the sharing of health and medical information (Lupton & Maslen, 2019). The use of social media allows users to generate, share, receive and comment on health-related content; in particular, social networking allows two-way communication (Moorhead et al., 2013). Members of social networking support groups can gather information, construct an

understanding of their illness experience and gain social support (Radin, 2006). The groups are also used to 'pool collective intelligence', where advice is provided on aspects of the illness condition, for example, on how to cope with day-to-day concerns (Radin, 2006, p. 591). As a consequence, patients become more empowered, and in the course of group interactions, goals for social action might be developed, for example, for fundraising or to target policy changes (Radin, 2006).

Support groups across a range of conditions, including cancer and diabetes, have become prevalent on social media (Moorhead et al., 2013). Patients with rare diseases have also used social media for a variety of purposes, including information sharing, social support and research advocacy (Miller et al., 2021). SCAD support groups have also been active in this space (Tweet et al., 2011) and are recognised as a valuable source of support for patients after SCAD (Garcia-Guimarães et al., 2020).

1.2.3 Effect of SCAD on Families

There is limited literature that reports on the experience of the family or carers of people who experienced SCAD and how this affects a patient's recovery after SCAD. Social support, particularly from family members, is associated with improved disease management (Rosland et al., 2010). Family members can also be negatively affected by an illness event (Rosland et al., 2010). Carer stress can result in physical or mental health burdens, and support for carers may be less available (Knowles et al., 2014). Cardiac disease, as a chronic illness, has a profound effect on couples in terms of communication difficulties, intimacy, changes in the domestic relationship and social disruption (Dalteg et al., 2011). Partners who witness a cardiac event may be at risk of developing PTSD themselves (Vilchinsky, 2017). The relatively rare and unexpected nature of SCAD, its severity and the risk of recurrence

coupled with the relatively younger age of people with SCAD, suggests that families and partners will also be affected.

1.3 Patient Experience

Patient experience, clinical effectiveness and patient safety are the three major factors affecting the quality of healthcare provision (C. Doyle et al., 2012). Needham (2012) describes the patient's experience as being concerned with the management of their emotional and physical changes while undergoing treatment and maximising the patient's physical, emotional and social well-being. The delivery of personalised care and partnership with patients is associated with an engaged patient cohort, leading in turn to better outcomes. Similarly, an engaged clinical staff who understand their patients also enhance the quality of care (Needham, 2012).

In an examination of patient perceptions of, and satisfaction with, healthcare services in Australia, good communication and the delivery of high-quality information was shown to be of central importance to patients (Rapport et al., 2019). When communication is poor, patients reported feeling isolated, disempowered and frustrated (Rapport et al., 2019). Satisfaction with care provided after AMI, including aspects such as communication, staff skill and person-centred care, was found to be an independent predictor of lower inpatient mortality rates (Glickman et al., 2010). In particular, satisfaction with nursing care provided after AMI was a critical determinant of overall patient satisfaction (Glickman et al., 2010). With more information about the patient experience of SCAD from the perspectives of the individuals affected, there can be enhanced PCC after SCAD and improved outcomes expected for people who have experienced SCAD.

1.3.1 A Framework for Understanding SCAD Patient Experience: PCC

Closely linked with patient experience is the concept of PCC. Patient-centred medicine was first described by Balint in 1969, who urged clinicians to consider each patient to be a unique human being (Langberg et al., 2019). The concept of PCC was developed from a recognition of the shortcomings of the traditional biomedical model of patient care, that is, the reduction of a patient's illness to a set of signs and symptoms to be investigated and interpreted with the intent of curing (Mead & Bower, 2000). PCC has evolved over time to focus on the person's knowledge and experience and to involve them in the decision-making process (Mead & Bower, 2000). In response to the growing interest in the concept of PCC and the lack of an agreed definition of PCC, Mead and Bower (2000, pp. 1088—1091) developed a PCC framework consisting of five dimensions that encompass various aspects of the patient – healthcare professional relationship (Mead & Bower, 2000): (1) the biopsychosocial dimension combines the aspects of the psychological and the social perspectives of an illness that extend beyond the biological perspective only, (2) the patient-as-person dimension focuses on the personal meaning that a patient brings to the illness experience, (3) the dimension of sharing power and responsibility evolved from critiques of the medical hierarchy's power into a position where patients bring their own knowledge to a collaborative relationship with the healthcare professional, (4) the therapeutic alliance dimension explores the relationship between the patient and the healthcare professional and (5) the doctor-as-person dimension relates to the personal qualities the healthcare professional brings to clinical practice (Mead & Bower, 2000). Factors that affect the dimensions, such as cultural and societal norms, communication barriers and previous life experience, and attitudes of both the clinician and patient, are also considered within the framework (Mead & Bower, 2000). Taking into account a person's psychological and social

background in addition to the purely biological conditions of their particular illness is now understood to be crucial to holistic care (Mead & Bower, 2000).

A systematic review has been conducted to examine the literature since the publication of the Mead and Bower Framework; it reviews the evolution and relevance of the PCC model to contemporary patient care (Langberg et al., 2019). The review concludes that the dimensions of the PCC framework remain relevant to understanding the concept of PCC, although not all dimensions were studied with the same frequency in the research examined (Langberg et al., 2019). Sharing power, including shared decision-making and therapeutic alliance, was the most commonly studied dimension in the literature as the PCC model has evolved over time. In addition, the concept of coordinated care was proposed as a new dimension in PCC (Langberg et al., 2019). Coordinated care concerns the need for the integration of the various aspects of the patient's care plan, including accessibility and timely delivery, to achieve 'cohesive and connected patient care' (Langberg et al., 2019, p. 1233). The review concludes that there are three main aspects to PCC in the contemporary literature: the professional's relationship with the patient, the coordination of care over the wider context of the treatment and, importantly, an understanding of the patient's experience of the illness (Langberg et al., 2019).

1.4 Justification for the SCAD-Insights Study

While research on SCAD has grown over the last decade, the body of literature consists largely of case reports and research into pathophysiology (Saw et al., 2019). Studies are largely retrospective, and because of low case numbers and ethical considerations, randomised controlled trials investigating treatment options for SCAD do not exist (Adlam et al., 2018; Franke et al., 2021; Hayes et al., 2018).

The SCAD-Insights study is situated within the context of the slow progress of increasing the attention given to women in CVD research (Humphries et al., 2017; Jin et al., 2020). CVD is still perceived to be a male disease (Chandrasekhar et al., 2018; Geraghty et al., 2020), yet it is the leading cause of death in women (Vogel et al., 2021). After having an AMI, women reported that they perceived that their healthcare professional's knowledge was dominated by stereotypical notions of heart disease as a male disease (Galick et al., 2015, p. 1129). CVD health outcomes are poorer for women along the illness trajectory from risk and symptom recognition, diagnosis and treatments to longer-term outcomes (Geraghty et al., 2020). Clinical guidelines for CVD screening and management are less likely to be followed for women. Women are less likely to receive guideline-indicated coronary interventions and are less likely to be discharged from the hospital on guideline-directed secondary prevention measures, including medications and referral to CR (Geraghty et al., 2020).

SCAD, as a condition occurring primarily in women at mid-life and characterised by uncertainties in aetiology, management and recurrence, has a considerable effect on patients' mental health outcomes (Hayes et al., 2020). While quantitative research on the psychosocial effect of SCAD has demonstrated elevated scores on psychosocial screening (Edwards et al., 2019; Johnson et al., 2020; Liang et al., 2014), data from self-reported psychological screening tests do not fully capture the individual's experience of an illness event (Serber & Rosen, 2010). What is less clear are the nuanced details of the person's holistic experience and how they are affected by SCAD. This can include physical, social and emotional well-being, the effect the SCAD event has had on their lifestyle, their family's lifestyle, their financial well-being and the meaning attributed to the SCAD event. The presence of any unmet needs in recovery may also be of significance to the SCAD experience. The effect that SCAD has on patients' families and carers remains unknown. Perspectives from men who have had SCAD are also limited in the current literature. Understanding the SCAD patient

experience from their own perspectives will provide comprehensive information about the effect of SCAD on the person's daily life and well-being and provide information about unmet needs in their recovery.

To address this gap, the SCAD-Insights study aimed to gain a better understanding of the multifaceted patient experience and the effect of SCAD on people and their families. Without nuanced information regarding people's experience of SCAD, we cannot fully appreciate the person's support and recovery needs from a patient-centred perspective. Thus, the SCAD-Insights study contributes to the body of literature on SCAD by providing detailed insights from a patient-centred perspective for healthcare service provision to meet the needs of people recovering from SCAD. Findings from this study reinforce the need for the provision of quality PCC that better supports patients, which may serve to reduce adverse negative mental health outcomes.

1.5 Thesis Outline

1.5.1 Aim

The aim of the SCAD-Insights study is to ascertain an in-depth understanding of the experience and impact of SCAD from the perspective of patients for the purpose of informing the design of supportive resources and services.

1.5.2 Research Questions

1. In what ways do people experience and make meaning of a SCAD event?
2. In what ways do people negotiate life after SCAD?
3. In what ways does engagement with an Australian online SCAD survivor support group affect the experience of SCAD?

1.6 Thesis Structure

This introduction has described SCAD as an uncommon form of AMI and presented the current understanding of its pathophysiology, management options and outcomes for patients after SCAD. Options for existing longer-term support after SCAD were presented. The PCC framework was introduced, and justification for the study was described.

Chapter Two presents an integrative literature review that explores the current research regarding people's perspectives of their experience after SCAD. This review was published in *Heart, Lung and Circulation* (Turner et al., 2023). Findings demonstrate that the current literature reporting on the patient experience after SCAD from the patient perspective is limited. The review presents themes in the literature concerning recovery needs and challenges after SCAD, and emotional responses to SCAD are reported.

Chapter Three describes the study methodology. A feminist social constructionist approach underpins the research design, and Interpretive Description is the methodology that informed the conduct of individual semi-structured interviews with people who had experienced SCAD. Reflexive thematic analysis guides the data analysis.

Chapters Four, Five and Six present the qualitative findings from semi-structured interviews conducted with people who had experienced SCAD. Each of these chapters presents findings pertaining to the following themes:

- SCAD is a mystery; emotional shock and loneliness are compounded by an information void.
- SCAD is life-changing; adapting and finding one's place in the world.
- Seeking the SCAD community; online groups are a 'double-edged sword'.

Chapter Seven discusses the findings from the study in relation to the wider research landscape concerning SCAD and CVD in general. This chapter will conclude with the implications for future research and for clinical practice.

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Chapter 2 Literature Review

The previous chapter introduced, defined and discussed considerations for the SCAD patient experience in the context of what is already known about SCAD. Building on these insights, this chapter presents the integrative review conducted to investigate the current state of the literature regarding the patient experience of SCAD and consequences for patients following a SCAD event from the patient perspective. This integrative review was online published ahead of print in *Heart, Lung and Circulation* on 28 November 2023. The review presented here contains some editorial changes made since publication.

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2.1 Abstract

Objective: There is considerable burden of anxiety, depression, and post-traumatic stress disorder in people with Spontaneous Coronary Artery Dissection (SCAD), yet research is limited on the experience and impact of SCAD from their perspective. This literature review sought to describe the current state of the literature on the patient experience of SCAD and consequences for people following a SCAD event from their own perspective. To better understand how people's experiences of SCAD impact their well-being, quality of life,

lifestyles, and identity and what would be useful from the patient perspective, an integrative review was performed.

Review Methods: An integrative literature review was conducted to understand the experience of SCAD and the post-event implications. Four data bases were searched. Search terms included “spontaneous coronary artery dissection”, “SCAD”, “patient”, “experience”, “perspective” and “opinion”. English language, peer reviewed primary research in people with a diagnosis of SCAD that reflected the patient experience was included. Data indicating the SCAD experience including distress prevalence were extracted into an Excel spreadsheet and narrative synthesis of included studies followed.

Findings: From 325 identified studies, five were included for review, yielding a combined sample of 447 participants. People after SCAD reported a lack of information about SCAD and the recovery process, and use of the internet for information. People after SCAD reported challenges in recovery including anxiety associated with fear of recurrence and uncertainty, and a need for greater support. A wide range of negative emotions was reported during and after the SCAD event. Participants reported participating in support groups, with mixed reviews of its appropriateness and effectiveness.

2.1 Key Words

Spontaneous Coronary Artery Dissection, SCAD, psychosocial, experience, perspective

2.2 Introduction

Spontaneous coronary artery dissection (SCAD) is increasingly recognised as a cause of acute myocardial infarction (AMI) cases (Hayes et al., 2020). First described in 1931, SCAD was thought to be a rare and fatal condition (Franke et al., 2019). Technological advances in coronary angiography and intravascular imaging have revealed that SCAD accounted for up to 4% of AMI overall. (Franke et al., 2019). A systematic review investigating the clinical characteristics and outcomes of people with SCAD found that 84% were women with a mean age of 51.1 years (Franke et al., 2021). Cases of SCAD have also been reported among younger men after intense exercise (Adlam et al., 2018).

The cause of SCAD is unknown, but it is thought to be related to various triggers including emotional stress, strenuous physical stress (e.g., Valsalva manoeuvre or intense isometric exercise), or hormonal changes, such as those occurring during pregnancy (Kim, 2020). Genetic changes related to migraine, fibromuscular dysplasia and cervical artery dissection have been documented in people after SCAD (Kim, 2020). However, a large prospective multicentre study (n= 750) conducted by Saw et al. (2019) concluded that in 50.1% of cases, SCAD was idiopathic. In the absence of clinical trials, current treatment guidelines are based on expert opinion, and recommend conservative (i.e., non-invasive) management of SCAD, except in cases of clinical instability (Franke et al., 2021). There is no current treatment to prevent SCAD recurrence (Franke et al., 2021) which is reported to occur between 5 and 30% over a 2-year period (Franke et al., 2019). Further, there are no specific guidelines for longer-term physical activity after SCAD (Chacin-Suarez et al., 2021).

Consequently, people who have experienced SCAD are unique in that they are a younger cohort with an under-researched potentially life-threatening heart condition. Psychological distress, identified as an individual's internal experiences considered to be troubling, disturbing and confusing (Chaddha et al., 2016), can be heightened after SCAD in

the context of a lack of evidence to guide treatment, reduce recurrence, and to inform secondary prevention (Hayes et al., 2020). Following a SCAD event, people may struggle to accept diagnosis of an unexpected and potentially life-threatening condition, particularly if young and without traditional cardiovascular risk factors (Adlam et al., 2018). People may feel alone, unable to find appropriate information to support their recovery, and may live in fear of SCAD recurrence (Chou et al., 2016). Indeed, there is a substantial psychosocial burden of anxiety, depression and post-traumatic stress disorder (PTSD) in people after with SCAD (Edwards et al., 2019; Franke et al., 2019; Liang et al., 2014), suggesting the need for psychosocial support after SCAD.

Developing a deeper, more nuanced understanding of how people experience SCAD will contribute to improved support and health care after a SCAD event. Patient experience, along with clinical effectiveness and safety, is recognised as a major factor impacting on the provision of quality health care (C. Doyle et al., 2012). Patient experience is a broad concept related to both managing emotional and physical changes, as well as examining and maximising the patient's physical, emotional and social well-being (Needham, 2012). Additionally, an examination of patient experience explores the interactions patients have with the health care system (Larson et al., 2019). To better understand how people's experiences of SCAD affect their well-being, quality of life, lifestyles, and identity and what would be useful from their perspectives, an integrative review was performed.

2.3 Methods

An integrative literature review model was used to allow for the inclusion of a diversity of research for the purpose of exploring differing perspectives to understand a complex phenomenon such as the patient experience after SCAD (Whittemore & Knafl, 2005). The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)

reporting guidelines were followed (Page et al., 2020). In consultation with the university librarian, a systematic search strategy was designed (see Supplementary Information). Search terms used were “spontaneous coronary artery dissection” and its abbreviation “SCAD” combined with terms including “patient”, “experience”, “perspective” and “opinion” to capture the patient experience or perspective. Additionally, search terms for research methods including interview, questionnaire, survey, focus group and fieldwork were added to capture research on the patient experience. Databases searched were CINAHL, Embase, Medline, and Scopus, and were searched for relevant literature up to June 2023. The results from these searches were downloaded into the citation management software EndNote (Clarivate, London, UK). Reference lists of full-text articles were also reviewed.

Studies were included if they were peer-reviewed and reported primary research studies written in the English language that described the patient experience following a SCAD event. This included studies that reported perceived physical and / or emotional responses or changes after SCAD, changes to well-being, identity, and perspectives or opinions on personal experiences in management strategies after SCAD. Qualitative, quantitative and mixed-methods studies were considered for inclusion if they reported on participant perspectives of their experiences. Publications such as case reports (such as a single-patient case study), pathophysiology report articles, letters, editorials, conference abstracts, poster presentations, clinical guidelines and grey literature were excluded. One author (E.A.T) conducted title and abstract review, and full-text eligibility was established by the first and final authors. Any disagreements on inclusion were discussed between authors until consensus was achieved. Quality assessment was conducted to assess the authenticity of the included literature and value of the information presented (Whittemore & Knafl, 2005), and to examine the methodological coherence (Hannes et al., 2010), rather than as a basis for exclusion. Quality assessment was conducted by the first author (E.A.T) with the use of the

appropriate quality assessment tools from the JBI (formerly, Joanna Briggs Institute) (Joanna Briggs Institute, 2020).

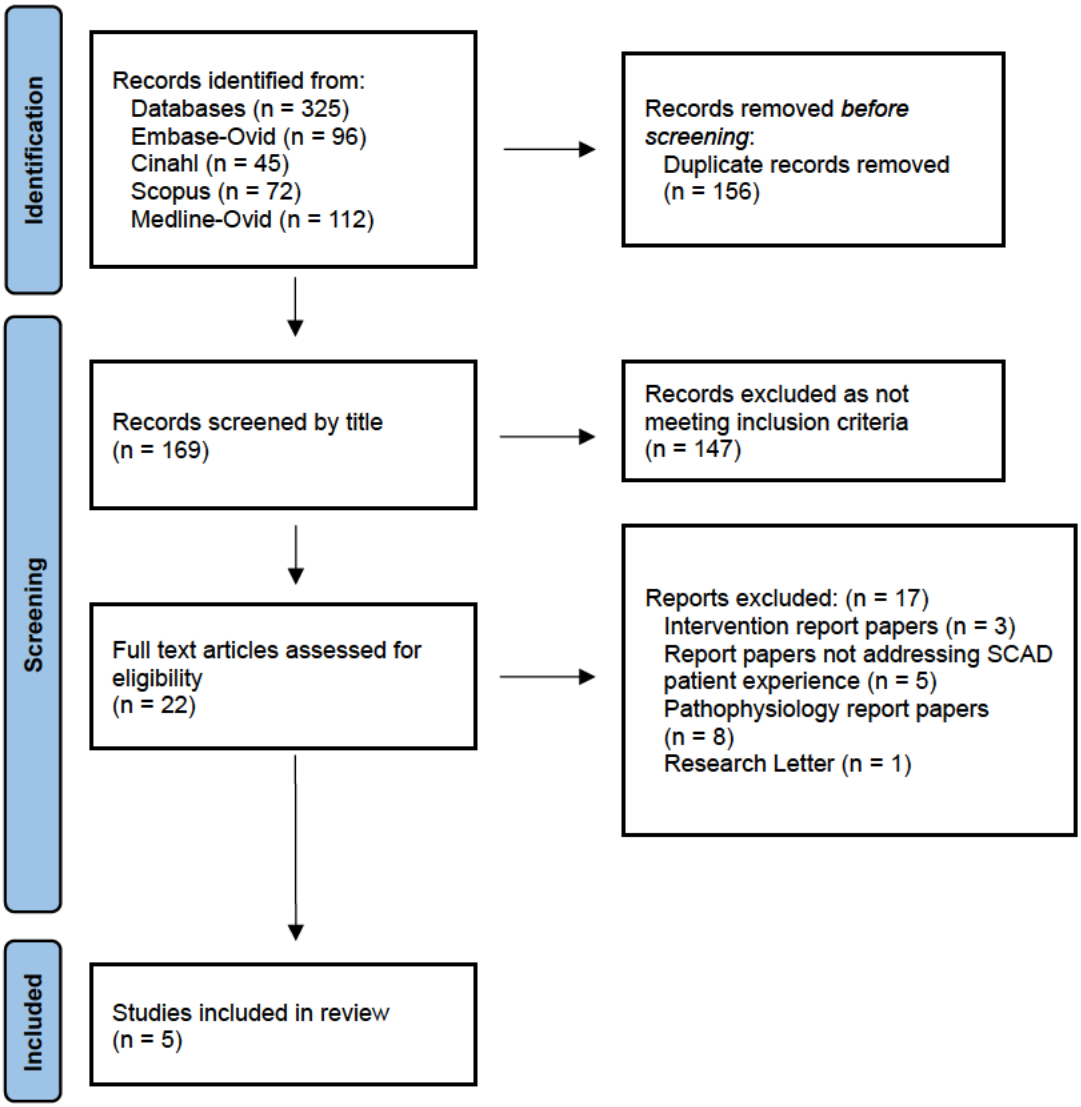
Initially, data were extracted from each study into an Excel spreadsheet, to populate columns depicting aim, study design, participant characteristics, results, and limitations. Integrative data analysis was performed on results extracted, through a process of identifying important patterns and themes to summarise the literature on the SCAD patient experience (Whittemore & Knafl, 2005). An iterative process of analysis was then conducted following the steps of ordering, coding, categorising and summarising to create a cohesive conclusion about the review's aim to describe the current body of literature on the patient experience after SCAD (Whittemore & Knafl, 2005).

2.4 Results

The first author conducted the search wherein 325 articles were retrieved. After removing duplicates, 169 articles remained. Following screening against inclusion criteria by the first author and in consultation with the final author, 22 articles remained for abstract screening. Another 17 articles were excluded after full text review, leaving 5 articles (Figure 1). Reference lists of full-text articles did not yield further relevant material.

Figure 1

PRISMA diagram (Page et al., 2020)



Quality assessment scores indicated variable quality. Studies were scored positively across aspects including ethical standards, representation of participants and interpretation of data. However, there were some negative scores on methodological considerations including a lack of clarity around congruence of the methodological position underpinning the research with research methods used and researcher reflexivity. In view of the debate as to the requirement of quality appraisal within qualitative reviews (Hannes et al., 2010; Whittemore

& Knafl, 2005), the small number of relevant papers and the various aspects of the SCAD experience represented, all papers were included following quality assessment.

2.4.1 Study characteristics

One article used a cross-sectional study design (Wagers et al., 2018). Three articles reported on qualitative studies that included interviews with people after SCAD about their perspectives of the SCAD experience, including psychosocial and emotional responses and effects on well-being, identity, lifestyle changes and recovery needs (Binnie et al., 2023; Bouchard et al., 2021; Clark et al., 2021), while one reported on qualitative data collected from the conduct of focus groups (Murphy et al., 2022).

2.4.2 Participant characteristics

The included studies were conducted in the United States (Wagers et al., 2018), Canada (Bouchard et al., 2021; Clark et al., 2021), Australia (Murphy et al., 2022), and the United Kingdom (Binnie et al., 2023). All included studies were conducted within large tertiary hospital centres for cardiology or major SCAD research settings. Participants were recruited from specialised SCAD programs or treatment centres (Bouchard et al., 2021; Clark et al., 2021; Murphy et al., 2022) or through advertisements placed on social media SCAD support groups (Binnie et al., 2023; Wagers et al., 2018). Participant sample size ranged from 7 to 367, with a total of 447 participants. Participants ranged in age from 30 – 71 years and were mainly female, ranging from 60% to 100% of participants. All studies reported on populations that were mainly White. Participants reported that time since SCAD event ranged from 2 weeks to 27 years.

2.5 Findings

People's perspectives on the impact of SCAD on their lifestyle and their well-being, the challenges they faced in recovery after SCAD, and their opinions on service delivery were reported. A summary of findings is shown in Table 1. A perceived lack of information about SCAD was a prominent theme of this review. Minor themes included living with emotional responses after SCAD and recovery needs after SCAD.

2.5.1 Perceived lack of information

One study reported that a quarter of participants stated that they received no information about SCAD after diagnosis, while most (82%) of the remainder of participants described the information they did receive as 'insufficient or inadequate' (Wagers et al., 2018). People after SCAD perceived a lack of information on the aetiology of SCAD both in terms of their own experience, for example the 'triggers' of their own event, and in the broader context of SCAD (Bouchard et al., 2021). In qualitative studies, participants described a lack of information across a range of areas, in regard to the cause of their SCAD, management strategies and the prognosis after SCAD (Binnie et al., 2023; Clark et al., 2021; Murphy et al., 2022). They described a lack of knowledge held by health professionals from the time of their diagnosis right through to continuing management later in their experience (Murphy et al., 2022). Participants also described inconsistency within the information they were provided (Clark et al., 2021). They noted informational content pertained more to atherosclerotic AMI, with less specific relevance to SCAD, which left an unmet need for information around physical activity and medication treatment after SCAD (Binnie et al., 2023). Indeed, very few SCAD participants (9% of n= 367) indicated that information from a health care professional was the most helpful source they received (Wagers et al., 2018).

People after SCAD reported that they felt the provision of more information would alleviate anxiety related to the uncertainty they experienced following the SCAD event (Bouchard et al., 2021). Furthermore, they felt a lack of control over their condition and feelings of being isolated and alone arising from insufficient information (Bouchard et al., 2021). To overcome this problem and allay uncertainty and anxiety, SCAD participants advocated for the rapid dissemination of research to health care providers and to people with themselves (Bouchard et al., 2021).

In the face of this perceived lack of information, SCAD participants explained that they conducted internet searches to find information specific to SCAD (Binnie et al., 2023; Clark et al., 2021; Murphy et al., 2022). Reputable sources such as the Mayo Clinic or the Victor Chang Cardiac Research Institute were particularly helpful (Murphy et al., 2022). Social media support groups were also described as beneficial in recovery from SCAD for some participants, although there were some mixed reports due to an inconsistency of information provided, a lack of support or negative interactions within the groups (Binnie et al., 2023; Clark et al., 2021; Murphy et al., 2022).

2.5.2 Living with emotional responses after SCAD

Participants with SCAD also described living with a range of emotions during and after their SCAD event. One study asked SCAD participants (n=367) to describe their experience in one word: ‘scary’ was the most often used word at 30.24%, while other words used were ‘surprising’ (13.90%), ‘life changing’ (12%) and ‘traumatic’ (10.35%) (Wagers et al., 2018, p. 5). Other SCAD participants reported they were “caught off guard” because of the sudden nature of SCAD, and that they felt they did not “fit” the image of a person after an AMI (Clark et al., 2021, p. 8). A wide range of emotional responses were reported to have occurred at the time of the SCAD event (Murphy et al., 2022). Participants with SCAD had

believed themselves to be fit and healthy before their event, and described a “roller-coaster of emotions” including shock, disbelief, confusion, fear, and anxiety in the aftermath of a SCAD event (Murphy et al., 2022, p. 5). Emotional responses after SCAD had had a negative impact on participants’ mental health and could persist for months or years after SCAD (Binnie et al., 2023). Emotional responses such as anxiety accompanied a fear of recurrence and a sense of uncertainty, particularly in the context of a paucity of research and understanding about SCAD itself, it’s aetiology and management as well as a perceived lack of control (Bouchard et al., 2021). People after SCAD described feelings of frustration and exasperation as a result of a lack of knowledge about SCAD among health care professionals (Murphy et al., 2022)

People after SCAD described changes to their identities and lifestyles, and a sense of isolation. Participants reported restrictions on their lifestyles were the “most confronting” feature of having SCAD, together with a sense of grief and loss (Murphy et al., 2022, p. 8). They described a loss of confidence in carrying out daily activities, of trust in their bodies and of their identities in terms of being “not the same person as before” (Murphy et al., 2022, p. 7). People after SCAD also reported that they reduced their participation in perceived stressors such as employment and home responsibilities in an effort to reduce their perceived risk of recurrence (Bouchard et al., 2021). Other SCAD participants spoke of the difficulties in balancing several roles within families and employment that continue despite their having had SCAD, and in managing the emotional effects of SCAD on family members (Murphy et al., 2022).

Table 1

Characteristics of Included Studies

Author Year Country	Aim	Design Method / Methodology Measures or analysis	Participant characteristics (n, gender, age range, time since SCAD	Results
Wagers et al., 2018, USA	To examine the role of stressful events, and patient perceptions of stress associated with SCAD pre- and post-diagnosis; and to assess patient perceptions of the helpfulness of post-SCAD resources	Cross-sectional survey Online survey Stressful events: Social readjustment rating scale (modified)	n=367 97% female International cohort, mainly from USA Age 26 – 71 years Range 2 weeks to 27 years after SCAD	SCAD event was rated as highly stressful, with stressful events or extreme / unusual physical exertion in week prior to event. Post SCAD: received verbal information from providers (72%); inadequate support (82%); most helpful information came from internet (52%); interest in an online support group with professional leader (42%)
Bouchard et al., 2021 Canada	To investigate challenges with recovery and the intervention needs of patients with SCAD	Qualitative semi-structured interviews Thematic analysis	n= 15 86.7% female Age 30 – 70 years	Major themes “Challenges in recovery” involved navigating uncertainty; living with anxiety, changes to identity and social isolation: “Intervention needs” involved unique needs include provision of additional psychosocial and peer support, and dissemination of information
Clark et al., 2021 Canada	To explore women’s descriptions of recovery after SCAD, with a focus on lifestyle management.	Qualitative semi-structured interviews Interpretive Description	n=7 100% female Age 44 – 54 years Range 3 – 18 months after SCAD	Major theme “Being lost in an unfamiliar diagnosis”. Sub-themes: Being diagnosed with a rare disease Swirling in an information vacuum Finding support Adjusting to and resuming a more normal life

Author Year Country	Aim	Design Method / Methodology Measures or analysis	Participant characteristics (n, gender, age range, time since SCAD	Results
Murphy et al., 2022 Australia	To investigate the experiences of SCAD survivors with a focus on the psychosocial impacts of SCAD. Aims to provide an in-depth understanding of the stresses and concerns faced by SCAD survivors and to identify support needs and preferences.	Qualitative focus groups Thematic analysis	n= 30 in 7 focus groups 90% female Age 35 – 71 years (mean 52.2 years) Mean 6.9 +/- 3.4 months after SCAD	Major theme “Lack of information” Major themes: Emotional impacts Issues with self-management Issues with family Impacts on work life Support needs
Binnie et al., 2023 UK	To explore preferences of SCAD survivors for their recovery	Qualitative semi-structured interviews Thematic analysis	n= 20 95% female Age 54.6 +/- 8.5 years Less than 3 years since SCAD 60%	Major themes: Education and information Physical activity Psychosocial support

2.5.3 Recovery needs after SCAD

In terms of recovery after SCAD, support for both physical and emotional recovery was deemed paramount. Participants with SCAD suggested that the ideal recovery program would reflect both their preference for web-based resources and a tailored cardiac rehabilitation program specifically for people with SCAD (Wagers et al., 2018). They wanted current information about SCAD delivered in an accessible manner that addressed their information needs (Wagers et al., 2018), and a tailored recovery support program with greater psychosocial support for people after SCAD (Binnie et al., 2023).

Online support groups provided the opportunity to meet others with SCAD and allowed participants to feel supported and not as alone in their recovery (Clark et al., 2021). Conversely, participants in focus groups reported that they did not gain emotional support from social media groups and would prefer health care professional facilitated face-to-face support groups (Murphy et al., 2022).

2.6 Discussion

To date, the literature regarding the patient experience after SCAD is limited. Contained within the five articles were experiences and perspectives of people with SCAD who accessed specialist services. Perspectives of individuals not affiliated or volunteering for research is absent. Although four in-depth qualitative studies have now been conducted with people after SCAD (Binnie et al., 2023; Bouchard et al., 2021; Clark et al., 2021; Murphy et al., 2022) the nuanced SCAD patient experience outside developed English-speaking countries such as the USA, Canada, the United Kingdom and Australia has not been described. The included studies reported on largely White cohorts, despite SCAD having been reported in most geographical locations and within most ethnic groups (El Hussein &

Blayney, 2020). Perspectives missing from the literature were those of men after SCAD and of families and unpaid caregivers of people with SCAD.

This review contributes to a greater understanding of how SCAD affects wellbeing, quality of life and lifestyle after SCAD, from their own perspectives. The included studies reported on the profound effect SCAD had on survivors' psychosocial health and well-being: a wide range of emotional responses were reported including shock, uncertainty, anxiety and loss (Clark et al., 2021; Murphy et al., 2022). This is consistent with existing SCAD research which highlights negative psychosocial outcomes. The development of PTSD is of particular concern in survivors, with a 43% rate of PTSD reported in one SCAD sample (Edwards et al., 2019). Furthermore, younger people with SCAD have been reported to have higher scores on both depression and anxiety measures (Liang et al., 2014).

This review found that in addition to known negative mental health outcomes such as depression and anxiety, psychological distress including social isolation and loneliness experienced after SCAD was also of concern, in particular among younger people (Bouchard et al., 2021). However, regardless of age, participants from included studies reported negative effects on their wellbeing and quality of life after SCAD (Binnie et al., 2023; Clark et al., 2021; Murphy et al., 2022). Participants reported an impact on their quality of life in terms of loss of identity, confidence, social roles and relationships (Murphy et al., 2022), and difficulties in managing changes in their identity after SCAD (Bouchard et al., 2021). These reported effects on people after SCAD are consistent with the literature on "cardiac distress", describing not only widespread emotional responses but also changes to people's sense of self and independence (Jackson et al., 2022).

The review found that a perceived lack of information exacerbates the negative effects of SCAD on well-being and quality of life. Higher rates of distress after SCAD may be attributed to a lack of understanding of the disease process and uncertainty about why SCAD

occurred, further compounded by lack of information from health care providers (Bouchard et al., 2021). Indeed, this mirrors the literature pertaining to uncertainty in illness across both acute and chronic health conditions, including cancer and cardiovascular disease. Illness uncertainty is viewed as a stressor, and the associated anxiety reflects the fundamental negativity of the illness experience (Kuang & Wilson, 2017).

Education and psychosocial support can be key to addressing challenges in SCAD recovery (Binnie et al., 2023). Participants with SCAD in qualitative studies observed the need for a tailored approach to management programs, and for the provision of both psychological and peer support, as well as support for the family members (Binnie et al., 2023; Bouchard et al., 2021; Murphy et al., 2022). A tailored approach to management is important given the feasibility of providing a SCAD specific service to a small group (Bouchard et al., 2020) particularly for those who do not have access to a major SCAD referral centre. Additionally, given the higher pre-AMI event functioning observed in people with SCAD, tailored intervention for recovery after SCAD seems particularly important (Murugiah et al., 2022). A tailored approach could also incorporate resilience training; people with SCAD with higher resilience had lower rates of anxiety and depression (Johnson et al., 2020). A cognitive behavioural therapy-based program was reported to be beneficial to people after SCAD for coping and adjusting following the event. Such non-pharmacological initiatives may be useful in recovery programs (Vaca et al., 2021).

Peer support groups were recommended as generally beneficial by people after SCAD, both in-person and online. Support groups provide the opportunity to meet fellow survivors of SCAD who could understand their experience, although the recommendations were given with the caveat that they can be overwhelming or negative (Binnie et al., 2023; Bouchard et al., 2021; Clark et al., 2021; Murphy et al., 2022). Health providers reported they refer people after SCAD to such groups, but cautioned against misinformation that could

arise from a lack of group moderation from health professionals or if the support group has unskilled peer group leaders (Bouchard et al., 2020). Greater education opportunities for health care professionals in supporting people with SCAD can play a role in increasing the psychosocial support professionals can offer. Communication of high-quality information to both people and their family members throughout a hospital stay is expected, and when communication is poor, people reported feeling isolated, disempowered, and frustrated (Rapport et al., 2019). The delivery of personalised care and partnership with patients is associated with an engaged patient cohort, which in turn leads to better outcomes (Needham, 2012).

2.7 Limitations

There are several limitations to this review. The review was limited to studies reported in the English language and the databases searched. Consequently, papers reporting on the SCAD experience in non-English speaking cultures may have been missed. The heterogeneity of the study designs of the included articles limited the data analysis to an integrative literature review model. However, these limitations serve to underline the importance of research into psychosocial distress after SCAD and the unique needs of SCAD survivors.

2.8 Conclusion

The review found that people with SCAD have only recently been given opportunities to provide the nuanced and detailed information that will inform service delivery and the SCAD research community at large. A perceived lack of information provided to people with SCAD is the major theme in existing qualitative research. People after SCAD report a range of emotional responses in the aftermath of their condition. Psychosocial interventions, such

as cognitive behavioural therapy-based groups and online peer support, have been shown to benefit people after SCAD and can be integrated into standard care after SCAD.

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2.10 Supplementary Information

Integrative Review: The patient experience after a SCAD event.

Supplementary Material: Search Strategy

1. Embase Ovid

12	limit 11 to (article or article in press or "review")
11	3 and 10
10	4 or 5 or 6 or 7 or 8 or 9
9	((patient* or personal or healthcare or survivor*) adj3 (experience* or perspective*)).ti,ab.
8	personal experience/
7	exp questionnaire/
6	qualitative analysis/
5	health survey/
4	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire* or survey*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw. or qualitative research/
3	1 or 2
2	SCAD.tw.
1	Spontaneous coronary artery dissection.tw. or coronary artery dissection/

☑	12	limit 11 to (article or article in press or "review")	96
☑	11	3 and 10	179
☑	10	4 or 5 or 6 or 7 or 8 or 9	1940115
☑	9	((patient* or personal or healthcare or survivor*) adj3 (experience* or perspective*)).ti,ab.	337575
☑	8	personal experience/	62087
☑	7	exp questionnaire/	920087
☑	6	qualitative analysis/	83828
☑	5	health survey/	227249
☑	4	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire* or survey*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw. or qualitative research/	605192
☑	3	1 or 2	5272
☑	2	SCAD.tw.	2691
☑	1	Spontaneous coronary artery dissection.tw. or coronary artery dissection/	3972

2. Medline Ovid

12	limit 11 to (article or article in press or "review")
11	3 and 10
10	4 or 5 or 6 or 7 or 8 or 9
9	((patient* or personal or healthcare or survivor*) adj3 (experience* or perspective*)).ti,ab.
8	personal experience/
7	exp questionnaire/
6	qualitative analysis/
5	health survey/
4	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire* or survey*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw. or qualitative research/
3	1 or 2
2	SCAD.tw.
1	Spontaneous coronary artery dissection.tw. or coronary artery dissection/

Ovid MEDLINE(R) and In-Process, In-Data-Review & Other Non-Indexed Citations and Daily <1946 to June 28, 2023>

1	Spontaneous coronary artery dissection.tw. or coronary artery dissection/	1540
2	SCAD.tw.	1501
3	1 or 2	2341
4	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire* or survey*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw. or qualitative research/	471594
5	health survey/	66903
6	exp questionnaire/	1210794
7	((patient* or personal or healthcare or survivor*) adj3 (experience* or perspective*)).ti,ab.	206285
8	patient satisfaction/ or patient preference/	99433
9	4 or 5 or 6 or 7 or 8	1826380
10	3 and 9	112

3. Scopus

(TITLE-ABS-KEY ("Spontaneous coronary artery dissection" OR scad) AND TITLE-ABS-KEY ((("semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide) W/3 (interview* OR discussion* OR questionnaire*)) OR (focus AND group* OR qualitative OR ethnograph* OR fieldwork OR "field work" OR "key informant" OR survey*) OR (((patient* OR personal OR healthcare OR survivor*) W/3 (experience* OR perspective* OR opinion*)))))

72 results found

4. CINAHL

S11	S3 AND S10
S10	S4 OR S5 OR S6 OR S7 OR S8 OR S9
S9	((patient* or personal or healthcare or survivor*) N3 (experience* or perspective* or opinion*))
S8	(MH "Life Experiences+")
S7	(MH "Questionnaires+")
S6	(MH "Surveys+")
S5	(MH "Qualitative Studies+")
S4	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) N3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or survey*)
S3	S1 OR S2
S2	SCAD
S1	spontaneous coronary artery dissection

S11	S3 AND S10	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (45) | Viev
S10	S4 OR S5 OR S6 OR S7 OR S8 OR S9	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (1,206,083)
S9	((patient* or personal or healthcare or survivor*) N3 (experience* or perspective* or opinion*))	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (104,863)
S8	(MH "Life Experiences+")	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (56,298)
S7	(MH "Questionnaires+")	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (483,578)
S6	(MH "Surveys+")	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (261,000)
S5	(MH "Qualitative Studies+")	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (180,290)
S4	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) N3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or survey*)	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (721,570)
S3	S1 OR S2	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (852) | Vie
S2	SCAD	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (344) | Vie
S1	spontaneous coronary artery dissection	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (688) | Vie

Chapter 3 Methods

3.1 Overview

The integrative literature review in the previous chapter presented findings on the current literature regarding the patient experience after SCAD. The review found that the SCAD patient experience has only recently been qualitatively studied. Indeed, much of the SCAD literature consists of case studies and pathophysiology reports located within the biomedical model of research (Saw et al., 2019). Only limited research regarding the qualitative patient experience of SCAD has been published (Turner et al., 2023). The SCAD-Insights study has its origins in my years of clinical nursing experience working with people after SCAD in the CR setting. In this clinical context, people after SCAD appeared psychologically distressed after SCAD, yet little evidence-based clinical guidance is available to clinicians managing SCAD in CR.

This SCAD-Insights study seeks to understand the multifaceted experience of people after SCAD to facilitate the development of patient-centred clinical care following SCAD. This chapter will present a discussion of the philosophical positions underpinning the study. SCAD does not occur in a vacuum but rather in the context of the lives of people living within contemporary culture. A social constructionist approach underpins this research project, which seeks to understand the SCAD experience from the person's own perspectives. The research plan for the collection and interpretation of qualitative data pertaining to the SCAD patient experience will be outlined and the ethical responsibilities discussed.

3.2 Philosophical Approach

3.2.1 Ontology and Epistemology

Ontology and epistemology describe the philosophical 'paradigms' (Malterud, 2016) that have been called the 'architecture' of how researchers view the world and knowledge production (Collins & Stockton, 2018, p. 5). Thus, they form the basis of research design. Ontology and epistemology are inseparable: to discuss the construction of reality *is* to discuss the construction of knowledge about that reality (Carter & Little, 2007).

Ontology refers to the models by which we view reality. These models could be described as lying on a continuum between positivist—where there is objective and verifiable knowledge—to interpretive—where knowledge can come from interpretations based on culture, history and theory (Malterud, 2016). Epistemology refers to the study of how we produce knowledge: can knowledge be produced as the truth, or is knowledge always created from different perspectives that create more than one truth (Braun & Clarke, 2013)? Within the interpretive paradigm, social constructionism emphasises the role of society and culture as critical elements in the production of knowledge and understanding (Malterud, 2016). From the position of social constructionism, knowledge about a phenomenon is constructed from within social and cultural contexts where such phenomena occur (Malterud, 2016).

Social constructionism recognises that the meaning of illness and even the experience of illness is constructed by social and cultural structures (Conrad & Barker, 2010). Clearly, illness and disease have biophysiological aspects, but illness events are also 'shaped by social interactions, shared cultural traditions, shifting frameworks of knowledge and relations of power' (Conrad & Barker, 2010, p. S69).

Research from a social constructionist position provides a detailed understanding of the experience of SCAD from the persons' own perspectives. There is currently a paucity of this perspective in the SCAD research literature. Social constructionist research recognises

that such perspectives are established within the dominant culture in which the people operate. A social constructionist perspective also recognises the importance of the researcher's background (Malterud, 2016). In reflexive social constructionist research, the researcher acknowledges their background and the contexts in which the research is undertaken (Malterud, 2016).

Carter and Little (2007) posit that epistemology influences the methods of research in three ways. First, it plays a role in how the researcher–participant relationship develops in terms of how the participant is regarded as a contributor to the research (Carter & Little, 2007). Participants in this study were regarded as contributors of appropriate and valuable knowledge, not merely as subjects to be observed. Secondly, epistemology affects how the quality of the research is displayed and demonstrated (Carter & Little, 2007). Finally, epistemology governs the ways in which the research is communicated and the ways in which the researcher, the audience and the participants interact (Carter & Little, 2007).

3.2.2 A Feminist Research Perspective on Women's Heart Conditions

Feminist authors have drawn attention to women being excluded from the development of knowledge and women's life experiences and inherent value being systematically discounted (Hesse-Biber, 2014). Feminist perspectives challenge knowledge claims made by those in dominant and privileged positions and aim to remove barriers to what can be known and by whom (Hesse-Biber, 2014). Feminist perspectives reveal that biases appear throughout the research process that serve to maintain 'an unjust status quo' (Wigginton & Lafrance, 2019, p. 4).

Feminist research perspectives argue that the ways in which we understand ourselves and the world are contextual and always changing in response to these contexts (Wigginton & Lafrance, 2019). To ignore such political and cultural contexts is to ignore the power dynamic in which they operate (Wigginton & Lafrance, 2019). Gender is socially constructed. *Gender*,

in this sense, is defined as ‘the social relationships between males and females in terms of roles, behaviours, activities, attributes and opportunities and which are based on different levels of power’ (Manandhar et al., 2018, p. 644). As such, gender is an important social determinant of health (Alcade-Rubio et al., 2020, p. 1). Gender inequities remain in place across the healthcare system, and despite increased awareness, unconscious gender biases persist (Alcade-Rubio et al., 2020).

Moreover, the tacit understanding of humans as male by default has rendered female bodies invisible to medicine (Criado Perez, 2019). Thus, there is ongoing concern that women have been, and continue to be, less well represented in cardiovascular research (Geraghty et al., 2020; Humphries et al., 2017; Jin et al., 2020). In addition, there is an increased awareness that there are gender biases in the management of CVD. Not only has there been under-recognition of the physiological differences in women (e.g., smaller coronary arteries), but diagnosis and treatment differences for women with heart conditions persist (e.g., treatment delays and less frequent invasive intervention) (Geraghty et al., 2020). The treatment and management of CVD, for example, the use of certain cardiac medications based on data derived from predominately male research participants, can be inappropriate for women and lead to poorer outcomes (Humphries & Pilote, 2018). Indeed, managing people after SCAD on pathways more appropriate for traditional CVD may be harmful (Geraghty et al., 2020), for example, through the prescription of inappropriate medication regimens or due to a lack of appropriate education and psychosocial supports.

Notwithstanding that this research project was open to any person who had experienced SCAD, female or male, to participate, a feminist epistemological perspective was adopted to further support the research into SCAD as a cardiac syndrome predominately affecting women. Moreover, feminist research perspectives recognise that oppression is not

exclusively exercised on women, and in the healthcare system, the person, female or male, is a position where disempowerment may be encountered (D. Jackson, 1997).

A feminist perspective prioritises the recognition of participant's autonomy and agency to be included in the research into the ways an illness experience affects their lives (Felzmann, 2020). Feminist research perspectives demand engagement with 'care ethics' whereby participants are understood as unique individuals with a need for empathy and care for their well-being (Felzmann, 2020, p. 5). This care extends to the portrayal of the participants in the research and how the researcher might interact with the community after the research has been completed (Felzmann, 2020).

3.2.3 Methodology

Qualitative research, with its emphasis on meaning and contexts (Braun & Clarke, 2013), is ideally placed to answer the kinds of research questions nurses ask about people's experiences of illness. Indeed, Braun and Clarke (2013) argued that qualitative research is an appropriate means for understanding the meaning people ascribe to their experiences through a focus on life's complexity. Through the collection and analysis of text-based data rather than numerical data, qualitative research aims to answer research questions about people's experiences and actions (Carter & Little, 2007). Where people are obliged to respond in a categorical fashion to standardised psychosocial questionnaires, the more nuanced and detailed nature of their experience is not captured (Serber & Rosen, 2010). Qualitative research into the patient experience of SCAD provided a more holistic view and is aligned with social constructionism through its focus on how culture influences people's understanding and how they construct meaning of their experiences. In turn, this information can inform the multidisciplinary and PCC model for people after a SCAD event.

The SCAD-Insights study used a methodology founded on Interpretive Description (Thorne et al., 1997). The development of Interpretive Description as a research methodology

was necessitated by an increasing recognition that neither quantitative nor qualitative methodologies used in other disciplines were appropriate for the particular needs of nursing research (Thorne et al., 1997). Nursing research is interested in the 'shared components of experience' that a population broadly shares in similar illness circumstances, often the focus of quantitative (biomedical) research (Thorne et al., 1997, p. 179). But nursing research is also interested in knowledge that is specific to the individual's lived experience (Thorne et al., 1997, p. 179). Thus, Interpretive Description recognises both the context and construction of the health experience in addition to both the individual and commonly held experiences of participants (Thorne et al., 1997). In this recognition of the 'constructed and contextual nature of human experience', Interpretive Description is aligned with naturalistic social constructionist research methodology (Thorne et al., 2004, p. 3).

For the SCAD-Insights study, the Interpretive Description methodology was selected to enable the research to describe both the common themes and patterns that characterise the experience of SCAD and to note the individual differences within the cohort of people after SCAD (Thorne et al., 2004). Importantly for nursing research, Interpretive Description recognises that such complex and constructed phenomena must be studied from a holistic perspective (Thorne et al., 2004). Interpretive Description methodology addresses questions such as 'What is it like to have a certain disease? What kinds of thoughts and feelings do people experience when they encounter certain challenges? How do people comprehend their need for our service?' (Thorne et al., 2004, p. 4). These types of fundamental questions are being posed by CR clinicians when considering how best to approach the nursing care of people after SCAD.

In Interpretive Description, knowledge and experience in clinical practice is welcomed, as it brings to bear the researcher's wider range of knowledge to be used in the analysis of the data (Thorne, 2016). Clinical experience and knowledge gained from having

worked with people after SCAD in the CR setting can be important both for recognising the complexity of the data and for recognising when variation in the data might bring important insights that can contribute to the establishment of credibility (Thorne, 2016).

3.2.4 Patient-Centred Care Theoretical Framework

Additionally, a PCC framework (Mead & Bower, 2000) was employed to facilitate data collection and analysis in this research. In this framework, introduced in Section 1.3.1, five interlinking aspects called 'dimensions' are acknowledged: biopsychosocial, patient-as-person, sharing power and responsibility, the therapeutic alliance and doctor-as-person (Mead & Bower, 2000, p. 1087).

Consistent with the social constructionist paradigm underpinning this project, the PCC framework acknowledges external factors that shape the delivery of patient-centred health care (Mead & Bower, 2000). Factors such as cultural and societal norms, communication barriers and the previous life experience and attitudes of both the clinician and the patient affect the delivery of PCC (Mead & Bower, 2000). In line with the PCC framework (Mead & Bower, 2000), the design of the interview questions and the analysis of the data were undertaken with a focus not only on the patient as a person and their illness experience but also on the broader socio-cultural environment in which they are located, and the partnership between healthcare provider and patient.

These factors in PCC resonate with the feminist perspective. Feminist researchers consider the politics and power relations within the research process, including asking the interview questions and the language deployed and emphasising the reflexivity of the researcher, who must reflect on how they understand the participants' accounts and how the research can be used to make change (Wigginton & Lafrance, 2019).

3.2.5 Researcher Position Statement

Guiding the development of any research study is the set of philosophical assumptions that a researcher carries (Creswell & Poth, 2018). These assumptions are developed through the researcher's life experiences, and they influence the choices made in the research design process. As an experienced CR nurse with a passion for social justice and a feminist worldview, it was appropriate for me to conduct a project on the SCAD experience to contribute to the under-researched area of women's CVD experience.

I brought to this study my clinical experience of having worked for eight years as a CR nurse. In line with the Australian Cardiovascular Health and Rehabilitation Association (ACRA) core components guidelines (Woodruffe et al., 2015), CR nurses provide expert cardiac nursing care to CR participants, including clinical assessment, the provision of education on cardiac health management and risk factor management, psychological support, patient advocacy and case management within a multidisciplinary team.

The clinical experience of observing and working with women attending CR (or not) fostered an interest in conducting research in this area. I observed first-hand the socio-economic cultural barriers women face in attending CR. In comparison to their male counterparts, women received fewer referrals, attended less often, dropped out more frequently and generally reported greater barriers to CR participation (such as caregiving responsibilities). Similar experiences are reflected in the literature of women in CR (Resurrección et al., 2019; Supervía et al., 2017).

In addition to working with a relatively small cohort of women in CR, I have clinical experience working with people after SCAD, although few presented to the CR program. I observed that people after SCAD displayed considerable psychological distress in the aftermath of their SCAD event. However, there were no clinical guidelines and little information available to my CR team to use in supporting people after SCAD. Similar to the

wider female cardiac population, people after SCAD also reported greater barriers than men to CR attendance. This phenomenon piqued my feminist sensibilities. Additionally, I felt an affinity with women after SCAD, who were often of a similar life stage; similar to many of these women, I am a working mother juggling competing demands.

I was required to attain new skills in the research journey of interviewing participants. I needed to convey I was performing the role of researcher, not that of clinician when interviewing research participants (Felzmann, 2020). In nursing, allowing a person to vent their concerns and providing that space to be heard is a key aspect of my PCC practice. In the development of trust and rapport as a nurse, I would sometimes share a personal anecdote or detail. However, as a researcher, it was necessary to cultivate researcher neutrality and to balance my natural empathy and belief in sharing emotional experiences with the researcher role. Researcher neutrality extended to the avoidance of asking nursing questions or providing nursing advice. However, my years of nursing experience were invaluable in creating rapport with participants and being at ease in conducting interviews. Participants appreciated the opportunity to talk about their experience with a researcher who was empathic and interested in their illness experience.

In this research, I looked beyond my habitual nursing practices of taking someone's testimony at face value and looked at the data in a much deeper and more analytical manner. Reading and re-reading the data and asking myself questions such as 'What is this participant telling me?' was critical to the analysis. One important strategy was to remember during these interviews with people after SCAD that I was privileged to hear their stories and that I had a responsibility to represent their honest accounts and perspectives in my research. Regular debriefing with supervisors was critical to the development of the research. Finally, the recognition that researcher values and perspectives will colour the data analysis was important. An understanding that findings do not 'emerge' but instead are constructed by the

researcher in a creative process was to recognise that researcher values influence the end result (Braun & Clarke, 2022, p. 233).

3.2.6 Aim of the Project

The aim of the SCAD-Insights study is to ascertain an in-depth understanding of the experience and impact of SCAD from the perspective of patients for the purpose of informing the design of supportive resources and services.

3.2.7 Research Questions

1. In what ways do people experience and make meaning of a SCAD event?
2. In what ways do people negotiate life after SCAD?
3. In what ways does engagement with an Australian online SCAD survivor support group affect the experience of SCAD?

3.3 Methods

Semi-structured interviews allow for the exploration of participants' perspectives and the meanings they make of their experiences in such detail as to construct knowledge about these experiences (Roberts, 2020). The semi-structured interview format enabled participants the freedom to contribute any concepts or information they felt appropriate while allowing the researcher to cover important predetermined points and to probe for deeper information (Roberts, 2020).

Individual interviews maintain participant privacy and allow a rapport to develop. Rapport development is important to allow participants to feel comfortable in discussing potentially sensitive information (Roberts, 2020). Individual interviews were conducted by telephone or on online platforms such as Zoom. Remote interviews allow for greater flexibility and accessibility and increased participant comfort, and they recognise the

participants' autonomy and dignity, for example, by enabling participation at their own selected time and place (L. Doyle et al., 2020). The conduct of online or telephone interviews was also Covid-safe for both participants and the researcher.

3.3.1 Development of the Interview Protocol

The interview topic guide (see Appendix 1) was designed to be open-ended to allow participants to speak freely about their experiences. Questions were informed by the gaps identified in the literature review (Turner et al., 2023) and the patient-centred framework (Mead & Bower, 2000) from the perspective of the feminist social constructionist position adopted. Open-ended questions, therefore, focused on the nuanced personal experience of the SCAD event. Aspects of the person's life that influenced their responses to SCAD or aspects of their lifestyles that were affected by the SCAD event were of particular interest. The questions also asked about the relationships with healthcare providers and the healthcare system. Pilot interviews were trialled with supervisors to ascertain whether the questions were relevant, appropriately phrased and could effectively elicit information.

After the introductions, the interview typically began with the open-ended question: 'Can you tell me about the experience with your heart?', a question designed to elicit information about the SCAD experience generally. From there, the participant could elaborate as they wished, and the researcher could probe for more details as appropriate. Other questions were asked about the participants' well-being since the SCAD event and if they perceived any effects on their identity or lifestyle, and perceived effects on their partner and family members. Their experiences engaging the healthcare system and aspects of their recovery were also discussed. The participants' experience of their membership of online support groups was also a topic for discussion within the interview. The interviews concluded by asking for the participant's advice for people who will experience SCAD in the future.

3.3.2 Sampling and Recruitment

Online support groups for people after SCAD are noted to have been instrumental not only in providing peer support, but also in research advocacy (Tweet et al., 2011) and in the creation of databases (Krittanawong et al., 2016). Given the relative rarity of SCAD presentations, participants for the study were sampled through an online support group, a richer source of potential participants than the general CVD setting. Moreover, recruitment from an online group where members interact, make meaning of their experience and manage their recovery together in collaboration is a good fit with the social constructionist approach adopted.

After contacting the convenor of the SCAD Research Inc Australia (https://scadresearch.com.au/), who is known to me through my membership to ACRA, and gaining permission from the board to do so, the study advertisement was placed on their Facebook page (https://www.facebook.com/SCADResearchAust). SCAD Research Inc Australia is an Australian not-for-profit charity that aims to raise awareness about SCAD and to raise money for SCAD research. The SCAD Research Inc Australia Facebook page is followed by 1550 people and is a public page followed by people after SCAD, their families and friends and healthcare professionals with an interest in SCAD. The SCAD Research Inc Australia Facebook page publishes information to raise awareness about SCAD and details about the group's activities, for example, fundraising activities.

Additionally, a study advertisement was placed on the SCAD Survivors Australia private Facebook group (URL omitted for reasons of privacy). This group is a private group with 1100 members who have been accepted for membership by virtue of their diagnosis with SCAD and is a private space for people after SCAD to share stories, ask questions and 'vent' (SCAD Research Inc Australia, personal communication, February 9, 2023). Questions commonly asked in this space concern medications, ongoing chest pains, heavy menstrual

periods on blood thinners, length of recovery and recommendations for SCAD-knowledgeable cardiologists. Placement of the study advertisement on these groups purposively targeted people who have had direct experience with SCAD. This is necessary to provide information that can answer the research aims (L. Doyle et al., 2020). Inclusion criteria were that the participant had a medically confirmed diagnosis of SCAD at any point in time or were family members or caregivers of people who had had SCAD, were able to speak English and, thus, provide informed consent. Exclusion criteria were that the participant was not able to provide informed consent. No family members or caregivers came forward, and study participants were exclusively people who had experienced SCAD.

The Facebook advertisement (see Appendix 2) asked people who had experienced SCAD to volunteer to share their stories through participation in a study designed to understand the SCAD experience from their personal point of view. The advertisement asked interested people to email the researcher directly. Posts on the Facebook advertisement and the researcher's email account were monitored for any responses to the advertisement. All respondents were contacted individually. Any questions regarding the study were answered, and additional information was supplied where necessary. Participant information and consent forms were provided, and negotiations for appointments for interviews were made with each participant at a time suitable to them. There were no pre-existing relationships between the researcher and the participants.

3.3.3 Sample Size

The information power model of qualitative research sample size recognises a number of elements that play a role in determining an appropriate sample size for a qualitative research project (Malterud et al., 2016). The aim of the study, the specificity of the sample, the use of theory, the quality of the interview dialogue and the strategy for the analysis all affect the information power of the sample (Malterud et al., 2016). Due to the relatively

uncommon prevalence of SCAD, there were limited numbers of eligible participants for this study. A smaller sample size can provide rich-enough data and, thus, be adequate for information power (Malterud et al., 2016).

Researcher experience can also affect the number of participants required to bring sufficient information power (Malterud et al., 2016). The researcher is an experienced registered nurse with skills in creating rapport with patients and years of clinical experience in working with people who had experienced SCAD. Qualitative research interview training was undertaken prior to conducting the interviews to increase specific research interviewing skills. Pre-existing clinical experience and knowledge is recognised in the implementation of the Interpretive Description methodology insofar as this knowledge can contribute to the eventual strength of the findings (Thorne, 2016). Clinical experience and knowledge leads the researcher to understand where further detail might be required: 'What else might there be to see, and how would I know that?' (Thorne, 2016, p. 179), thus, building information power.

Importantly, the quality of the theoretical underpinnings of the study plays a part in determining the sample size and information power (Malterud et al., 2016). Interpretive Description (Thorne et al., 1997) allows flexibility in understanding when a rich understanding of the SCAD experience has been achieved. Appraisal of the information power is conducted during the phases of data collection and early data analysis (Malterud et al., 2016). It was determined that an acceptable information power was achieved at the point of 17 interviews. In consultation with the supervisory team, it was felt that the data obtained from these participants was rich in material, and that enough information had been gleaned to answer the research questions in an interesting and comprehensive manner.

3.3.4 Data Collection

The recruitment and data collection was conducted from March 2022 to January 2023 after gaining approval from the UTS Research Ethics Committee (ETH21-6703) (see Appendix 3). Data were collected via individual in-depth semi-structured interviews conducted via Zoom (https://zoom.us/; n = 16) and telephone (n = 1). Participants were met in a private online Zoom meeting room at the agreed time with the researcher located in a private office. Interviews were audio recorded and detailed notes were written both with the explicit permission of the participants. At the beginning of each interview, the participant was reminded of the purpose, given the opportunity to ask any questions and reminded of their informed consent. Each interview closed with the option to summarise or reassess the information and an opportunity to add any further information they may have felt was important.

The researcher checked in with how the participant was feeling during the interview and, if consented to, the researcher checked in again via an email after the interview was conducted. Participants were provided with the contact details of support such as counselling options from organisations such as Head to Health (https://www.headtohealth.gov.au/) and the Heart Foundation (https://www.heartfoundation.org.au/) in addition to Lifeline (https://www.lifeline.org.au/) and Beyond Blue (https://www.beyondblue.org.au/). The researcher followed a distress protocol to ensure the participants' safety (see Appendix 4). Some participants did become tearful when discussing the effect SCAD has had on them. The interview was momentarily paused, and the researcher offered words of support and offered to take a break or discontinue the interview. However, no participant required the interview to discontinue, and all were confident that they were feeling well at later contact.

3.4 Data Analysis

There are a range of options available to analyse qualitative datasets in Interpretive Description (Thorne, 2016). One such method is reflexive thematic analysis, which allows for the development, analysis and interpretation of qualitative data. Crucially to Interpretive Description, reflexive thematic analysis includes reflexivity or critical reflection on the role of the researcher (Braun & Clarke, 2022).

Thematic analysis is defined as a method used to identify, analyse and report on patterns known as themes within a dataset and is a method to organise, describe and interpret meaning within the data (Braun & Clarke, 2006). Thematic analysis is viewed as a 'foundational method' for qualitative research, and its flexibility has meant that it has been applied across 'a range of theoretical and epistemological approaches' (Braun & Clarke, 2006, p. 78).

Over time, however, Braun and Clarke have come to term *reflexive* thematic analysis as a distinct method of thematic analysis that emphasises both 'the importance of the researcher's subjectivity as analytic resource, and their reflexive engagement with theory, data and interpretation' (Braun & Clarke, 2021, p. 330). The use of reflexive thematic analysis to work with data in this research on the patient experience after SCAD is appropriate to the theoretical assumptions underpinning the research. It is suitable as an inductive approach where the analysis is 'grounded in' the data (Braun & Clarke, 2021, p. 331). Reflexive thematic analysis also recognises that the coding of the data is a critical part of theme development (Braun & Clarke, 2021). In an interpretive description of the SCAD patient experience, clinical experience and researcher knowledge are valuable resources (Thorne, 2016), but the eventual analysis through reflexive thematic analysis evolves over time and does not come from predetermined themes (Braun & Clarke, 2021). Six phases of reflexive thematic analysis have been proposed by Braun and Clarke (2021) for the analysis

of data, the development of codes and themes and the production of the research report, and can be deployed flexibly as the analysis progresses.

3.4.1 Familiarity with the Data

Transcribing the interviews is part of the first phase in the reflexive thematic analysis data analysis process, and it allows the researcher to become familiar with the data (Braun & Clarke, 2022). The initial three interviews were transcribed manually by the researcher verbatim to include pauses, the use of slang and non-semantic sounds with the aim of producing a clear and thorough version of what was said during the interview (Braun & Clarke, 2013). This approach resonated with Thorne (2016) in that it allowed the researcher to become present and to pay deep attention to what the participants were saying. The transcription was completed after each interview to facilitate the refinement of the interview questions to ensure the study aims and objectives were met (Thorne et al., 2004). The transcription process is critical in Interpretive Description to allow the researcher the time to become familiar with the data being collected and to allow the researcher to pay attention to the nuance within the data (Thorne, 2016). However, manual transcription is time-consuming and can become an 'emotionally complex' experience (Thorne, 2016, p. 158). The remaining interviews were professionally transcribed and verified by the researcher to ensure accuracy while listening to the audio file to edit and correct any transcription errors, distinguish between speakers and add speaker names after de-identification. The participants' names and identifying information (such as treating hospitals or doctors' names) were removed during the editing of the transcription.

Familiarity with the data arises from listening to the audio recordings, making a transcription of the interview and reading and re-reading the text that has been generated (Braun & Clarke, 2022). Immersion or deep engagement with the data allows the identification of important elements and patterns that can exist across the data (Braun &

Clarke, 2022). (Thorne, 2016, pp. author-year) posits that the first phase of data analysis requires that the researcher allow themselves the time to react to the data and to take note of what data 'attracts our attention' (p. 157). Critical engagement with the data through immersion requires the researcher to constantly ask questions about what the data represents and the ascribed meaning (Braun & Clarke, 2022). This engagement with the data was achieved through a process of reading and re-reading the interview transcripts, taking notes and constant reflection on the data obtained. Asking myself such questions as 'What is happening here?' (Thorne et al., 2004, p. 7) began a process of inductive reasoning where new information about the data could be built up to describe the experience of SCAD and the individual variation within the cohort. This process of reflection and inductive reasoning allowed an exploration of relationships between the different pieces of data, and this continued back and forth over the next phases of analysis.

3.4.2 Coding

The use of coding is required in Interpretive Description to sort and organise the data (Thorne, 2016). It is recognised that there are various techniques to be considered for this task (Thorne, 2016). The use of reflexive thematic analysis was understood to be compatible, as it recognises both the subjectivity of the researcher and the evolution of codes during the process, as insight is developed during data analysis (Braun & Clarke, 2022). In phase two of reflexive thematic analysis, while reading through the text of each interview, each word or phrase that was relevant to the research question was labelled (Braun & Clarke, 2022). This was done by using the comment function in Microsoft Word. These interesting phrases included my overall impressions of the data or ideas about the data, which then became codes. Codes could have 'semantic' meaning—close to the participant's own explicit language—or could be 'latent'—capturing a more implicit or contextual meaning (Braun & Clarke, 2022, p. 57).

The highlight function was also used to indicate a quotation thought to be of particular interest or a pithy statement that could potentially be used as evidence. Each transcript was also printed out, and coloured pens and highlighters were used to indicate interesting or relevant points in addition to the researcher's own thoughts and ideas. The use of both soft- and hard-copy documents allowed the researcher to take the time to become familiar with each participant's story and to view the data at different times and from different aspects. The research questions were written down and displayed prominently on a card at the study desk or on top of each document for constant referral and to keep the coder focused on the purpose of the study.

The codes were expected to evolve as the researcher's coding experience developed, and adjustments were made if codes were too narrow or too broad (Braun & Clarke, 2022). In reflexive thematic analysis, codes are considered to evolve as the researcher's understanding of the meaning of the data develops and becomes more engaged with the data (Braun & Clarke, 2022). Indeed, in Interpretive Description, it is important to use broader coding to maintain a perspective of the whole dataset and to allow inductive analysis (Thorne, 2016). Additionally, the researcher used the Microsoft Word comment function to create notes of her thoughts and ideas as she progressed through this phase, in addition to keeping a reflexive journal. Such additional notes can include pieces of data considered important to future analysis (Thorne, 2016). Examples of these additional notes includes notes on the context of a particular point raised by the participant or thoughts the researcher might have had in response to a particular piece of data.

Several companion documents were also created during this analytic process. For each interview, a document was created with a table of codes in one column and quotations from the interview pertaining to each code in the second column. Page numbers for each quotation were included for any future cross-reference. A summary of each interview was

also created, which was forwarded to the participant for their approval. This was not strictly necessary or advised as part of reflexive thematic analysis; however, it was enacted to help ensure the credibility of data and the initial interpretation. Several study participants responded that the summary had captured what had been said in the interview.

Before moving to the next phase, the researcher went through each transcript several times to ensure the process was systematic and rigorous and in recognition of the evolution of the codes created. When it was considered that the list of codes gave an accurate summary of the dataset, and in consultation with the supervision team, who are experienced qualitative researchers, phase three began, noting that each dataset could be returned to where necessary (Braun & Clarke, 2022).

3.4.3 Themes

During phase three of reflexive thematic analysis, initial themes in the data were generated. A theme captured a range of data that were united or reflected a shared idea (Braun & Clarke, 2022). To arrive at these themes, the researcher engaged in critical reflection on the codes to explore where there were common meanings across the dataset (Braun & Clarke, 2022). Codes were copied from the comments placed on the interview transcripts into a Word document and then arranged or grouped under headings that seemed appropriate as potential themes. The process of copying and pasting codes was also carried out on paper through the creation of a concept map to enhance the creative process of engaging with the data and critical thinking about what potential themes could be developed. The process was developed iteratively and could be changed as the analysis developed and evolved, and careful attention was paid to the developing themes answering the research questions (Braun & Clarke, 2022). This further phase of analysis allowed a deeper examination of the relationships between the data, which led to conclusions that answered the aims of the project (Thorne, 2013). Taking the time to reconsider different options and critical thinking about what is being observed and

why was crucial to being aware of potential alternatives and having a broader perspective on the data (Thorne, 2016).

Phases four and five in reflexive thematic analysis are concerned with the ongoing development and refinement of the themes. A 'thematic map' was created to allow the researcher to think about potential themes, how they fit together and how the eventual findings might be structured (Braun & Clarke, 2022, p. 85). It was important to remain mindful that themes must have a 'central organising concept' that ensured that the codes were clearly related to the theme (Braun & Clarke, 2022, p. 89).

Phase five involved writing theme definitions to check the quality of the theme and to help consider the eventual organisation of the analysis (Braun & Clarke, 2022). This involved asking questions, including what the theme is about, what is specific to the theme and what it contributes to the eventual analysis (Braun & Clarke, 2022). The repeated refinement and development of themes is consistent with Interpretive Description, where one is urged to think critically about associations between data and test relationships between data and contradictory pieces of data (Thorne, 2016).

3.4.4 Writing Up

Braun and Clarke (2022) stress the importance of the 'writing-up' phase: the writing process plays a critical part in the analysis of the data. The development of data analysis occurs during the writing and is not understood to be a separate part or entity at the end of the whole project but rather part of an ongoing process (Braun & Clarke, 2022). The written presentation of a qualitative study, and, in particular, its findings, is also an important consideration in terms of its value to the clinical readership for which it is intended (Sandelowski & Leeman, 2012). Specifically, the presentation of findings as *thematic statements* can be better understood by the reader and be translated into clinical practice (Sandelowski & Leeman, 2012). In this instance, thematic statements can suggest potential

practice changes to better accommodate people after SCAD into a healthcare intervention such as CR.

In keeping with the inductive approach taken to the data analysis, after the initial interview was transcribed and tentative coding began, writing about the data also commenced. As more interviews were undertaken, transcribed and coded, and codes collated, the process of writing about the findings took clearer shape, and through this process, themes became evident and evolved. Written feedback from supervisors on written documents, in addition to discussion during regular supervision meetings, was critical during the writing phase. Critical discussions with supervisors helped elicit fresh perspectives on the data, and the act of my articulation and writing of my own perspectives on the data for the purposes of supervision propelled the analysis forward.

3.5 Reflexivity

Researcher reflexivity was critical throughout the data collection and analysis process and the final writing-up phase. Thorne (2016) recommended the use of a journal for the researcher to record responses to the data, patterns observed within the data and questions about the data that arise. Through the regular writing of a reflexive journal describing the researcher's own responses and thinking about the process, in addition to regular questioning of the data and the associated notes being taken, critical interpretive thinking about the dataset evolved and contributed to the final research product (Thorne, 2016). Acknowledgement of personal values and assumptions and critical reflection on responses to the research process was essential in creating a useful analysis (Braun & Clarke, 2022). Aligned with the feminist perspective of the project, Wigginton and Lafrance (2019) emphasised the importance of maintaining a reflexive journal to clarify thoughts and

observations during the process, in addition to the continuing focus on the philosophical underpinnings of the project.

A reflexive journal enabled the researcher to record ideas and thoughts that arose during the data collection and analysis, in addition to notes from conversations with supervisors or work colleagues about the work. Journal entries included comments on the research process, insights into the data being collected and notes on associated reading around the topics arising through data collection and data analysis.

3.6 Ethical Considerations

Observing the ethical principles of autonomy, nonmaleficence, beneficence, justice, dignity and integrity were central to this research project and were embedded throughout the study design.

3.6.1 Recruitment

The researcher approached the recruitment process with respect and care for the participants' decisions and autonomy. Response to recruitment advertisements was voluntary and, as such, was passive recruitment. By enabling participants' stories to be heard, the study respected their autonomy and recognised people's sense of altruism.

3.6.2 Informed Consent

Voluntary participation in the study recognised the people's autonomy and inherent dignity. For participants to provide informed consent, they were provided with written and oral information regarding the study and its aims, its objectives, their contribution and how their participation will proceed, in addition to information about the risks and benefits of participating. Contact details of the research team were provided in addition to details of how the study was approved and the data protected and kept confidential according to the data

management plan. When participants were informed and agreed to participate, they signed a consent form. Participants had the option to withdraw their consent at any time and could do so without explanation or repercussion on any future care, again, in recognition of participant autonomy and dignity. No participant withdrew from the study.

3.6.3 Data Management, Storage and Access

The primary researcher was the only person with access to the participants' identities and to the subsequent data sets. These pieces of information were stored securely and separately. Data were held securely according to the requirements of UTS. Any hard-copy data generated, such as handwritten field notes, were held in a private home office that only the researcher had access to. A data management plan was created on UTS Stash. All digital and hard-copy data collected from the project will be held securely for the requisite period of five years, after which time the data will be destroyed.

All data were de-identified by removing names and other identifying features from all documentation other than the signed consent form. Explicit permission was obtained for the recording of interviews. Pseudonyms were used in keeping with conditions of ethical approval.

3.7 Rigour

Strategies are required to ensure that the study is methodologically rigorous. Rigour relates to the accuracy and precision of a research study, the strength of the research design and how appropriate the method is to answer the research question posed (Cypress, 2017). Traditional elements of rigour include credibility, dependability, confirmability and transferability, and were intended to respond to 'questions of truth value, applicability, consistency and neutrality' being applied to naturalistic research (Lincoln & Guba, 1986, p. 76).

Credibility refers to the accuracy with which the research findings represent the participant's lived experience (Cypress, 2017). Credibility can be achieved through prolonged participant engagement, creating rapport and providing detailed descriptions of the setting and the participants (Creswell, 2014). Credibility can be strengthened through peer debriefing (Lincoln & Guba, 1986). In the SCAD-Insights study, regular debriefing with the supervisory team ensured critical thinking about the data collected. Transferability describes the degree to which the findings of a study can be applied to other situations, but Nelms (2015) argued that being able to generalise the findings to other contexts is not within the scope of qualitative research. However, the provision of a 'thick' description allows readers to judge the applicability of the findings (Lincoln & Guba, 1986). Dependability refers to how replicable the study is and how stable the results or findings are (Cypress, 2017). Detailed descriptions of the study procedures enable the ability to replicate the study. To further confirm dependability, the interview transcripts were thoroughly checked for errors and data collection and analysis were discussed through the supervision process (Creswell, 2014). Confirmability relates to the extent to which the findings of the study are moulded by the participant contribution (Nelms, 2015). Strategies to strengthen confirmability included keeping a reflexive journal, a detailed audit trail (Nelms, 2015) and the use of detailed researcher field notes as a valuable resource for data analysis (Phillippi & Lauderdale, 2018; Thorne et al., 1997).

High-quality qualitative research should also demonstrate consistency between the elements of epistemology, methodology and methods (Carter & Little, 2007). In the development of Interpretive Description, Thorne (2016, p. 231) recognised the 'inappropriate application of quantitative quality measures' to research coming from 'an entirely different epistemological enterprise'. To that end, alternatives to ensure sound research in Interpretive Description have been offered. Such alternatives for Interpretive Description studies are

important given that insights and findings will be used in the clinical setting where there are not only research quality considerations but also the moral obligation to be of value to the individual and the community at large (Thorne, 2016).

Importantly, qualitative research must demonstrate ‘epistemological integrity’ insofar as there must be coherence between the stated epistemological position, the research question and the interpretation of the data (Thorne, 2016, p. 233). The SCAD-Insights study researching the understanding of the patient experience after SCAD is situated in a social constructionist position, and the methods used in the research process are appropriate to this perspective.

The SCAD-Insights study demonstrates ‘representative credibility’ (Thorne, 2016, p. 234) in that the findings report appropriate claims from within the specific sample while recognising that knowledge of SCAD exists beyond the particular sample. Having described the rationale behind the research design and the interpretation of the findings, the research demonstrates evidence of ‘analytic logic’ (Thorne, 2016, p. 234). Additionally, by articulating and reflecting on my own life and clinical experience, in addition to presenting knowledge claims that represent both the individual and the shared SCAD experience, ‘interpretive authority’ is established (Thorne, 2016, p. 235).

Further, Thorne (2016) posits that the disciplinary and social contexts of the research impose further quality considerations. A rationale for the ‘moral defensibility’ of the study (Thorne, 2016, p. 236) has been set out in the literature review (Turner et al., 2023), which demonstrated that there is relatively limited qualitative research into the uncommon yet serious health event that is SCAD. Closely related to this quality aspect is the aspect of ‘disciplinary relevance’ (Thorne, 2016, p. 236). A nursing research project aiming to understand the experience after a SCAD event in the context of a limited body of evidence and a lack of clinical guidance in the specialised nursing care of people after SCAD is

particularly relevant to CR clinicians. An interpretive description of the individual differences and shared experiences (Thorne et al., 2004) after a SCAD event, considered in the context of the PCC framework (Mead & Bower, 2000), makes a contribution to the literature and can inform the support of people with SCAD and their families.

3.8 Summary

This chapter has described the development of the research design by describing the epistemological positioning, the rationale for the chosen methodology of Interpretive Description and the methods by which data were collected and interpreted. Ethical considerations and the importance of quality were also outlined. The subsequent chapters will report on the qualitative findings from interviews conducted with people after a SCAD event.

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Chapter 4 The SCAD Experience and Meaning-making

4.1 Overview

Findings from the semi-structured interviews with participants after SCAD are presented in chapters four to six. This, the first findings chapter, presents study participants' descriptions of their experiences and explores the ways in which they construct meaning from their experiences. This addresses the first research question: 'In what ways do people experience and make meaning of a SCAD event?' Participants described their experience and response to symptoms. A common theme in these descriptions was that SCAD was a mystery that resulted in emotional shock and loneliness. Study participants spoke of the emotional effects of having had a heart attack due to SCAD and the effect of SCAD on their identity.

The SCAD diagnosis—that of an uncommon and mysterious type of AMI—led to a sense of increased anxiety, fear, uncertainty and loneliness, which in turn led to a search for information. A perceived lack of information about SCAD served to compound these emotional responses. In turn, this created a sense of urgency regarding the search for information. Longer-term psychosocial consequences were also discussed by study participants.

4.2 The Interviews

Seventeen people who had experienced SCAD took part in in-depth semi-structured interviews. The interviews were conducted online via Zoom, except for a single interview conducted by phone. All were audio recorded. Interview time ranged from 30 to 112 minutes, with a mean time of 76 minutes. Of the 17 participants, 15 were female. Two participants

lived in the United States, and all others lived in Australia. Eleven participants lived in major cities, four lived in regional cities and two participants lived in small townships.

4.3 The Participants

The demographic characteristics of the interviewees are presented in Table 2.

Table 2

Characteristics of Interviewed Participants (n = 17)

Demographic characteristic	n
Sex	
Female	15
Male	2
Age at interview (mean years)	42–68 (53.2)
Age at SCAD event (mean years)	35–67 (56.8)
Current partner status	
Partnered	14
Unpartnered	3
Current employment status	
Employed	14
Not employed in paid workforce	3
Time since initial SCAD event	
< 6 months	7
6–12 months	2
1–2 years	4
>2 years	4
Number of SCAD events	
1	15
>1	2
Location	
Major city Australia	9
Major city USA	2
Regional city Australia	4
Rural town Australia	2

4.4 Symptom Experience and Response

Study participants invariably began their interviews by speaking about the chronology of their SCAD event. Chest pain was the primary symptom reported. Other symptoms reported included shortness of breath, nausea and fatigue. Notably, most participants did not recognise symptoms as potentially cardiac-related. Instead, they ascribed their symptoms of

chest pain to other conditions, such as indigestion or musculoskeletal pain, while other symptoms, such as fatigue, were often attributed to stress. Suggestions that symptoms might represent a heart condition were frequently dismissed:

> My arm's got pins and needles … And I thought oh, this is a really weird feeling right down my arm. And then … I sat up and as I sat up, I immediately got pain in my chest. And my husband said 'Oh my god, I think you're having a heart attack' and I said 'Oh don't be ridiculous' (Kelly, female, age 47)

Kelly did not seek medical attention for at least another 24 hours, never contemplating it could be her heart. She also described a fear of judgement from healthcare professionals: 'I'm thinking to myself, what these people are gonna think I'm crazy … what am I gonna do, just walk in and say, I think having a heart attack, they're gonna think I'm nuts'. (Kelly, female, age 47)

Looking back on her experience, she said that she could not explain her actions at the time:

> I kind of laugh at myself when I tell the story of how I just ignored everything. And I think that is not me. I think I'm an intelligent person. And if you called me and said I don't feel well, I have chest and arm pain, I would drop the phone, drive over and the first one to get you to the hospital. I don't know why I ignored it. (Kelly, female, age 47)

Often, it was at the insistence of another person that they eventually sought medical attention. For example, David called his wife to say he had chest pain:

> I started just feeling my chest, like pressure, heaviness, which I thought … like heartburn or something which would just pass. I didn't think much of it at first. Then it was just getting worse and just wasn't going … I was sweaty and starting to feel sick too. I thought this is not normal. So, I rang my wife and said you better come home … so she came home and actually gave me aspirin … but I didn't know if it was a heart attack. I didn't know what was going on. I had no idea. So, she just said take them. So, I took them and then off to the hospital … So, then we drive there, and then on the way there, pain started going. I'm like 'Just turn around, let's go home'… she said, 'No, no, we'll keep going'. (David, male, age 56)

It was only due to his wife's insistence that he attended a hospital where he was diagnosed with SCAD. In other instances, older children, work colleagues or neighbours who noticed the participant was unwell suggested they seek medical attention. Once a second person had insisted they seek treatment, participants agreed, though often reluctantly.

Only a few study participants took prompt action to seek medical attention, and only one called for an ambulance. The decision to call for an ambulance was fortunate because she had a cardiac arrest just as the paramedics arrived:

> I was very pale around the eyes … had the sweat, so very much looking of shock. So I went back into the main room and sat down again, and I signalled one of [my colleagues], and said, 'I think you need to call for an ambulance' … So I lay down, and it would've been maybe a minute, minute and a half, I went offline, which is, I felt my right foot just go off to the side, and everything went dark … I woke up, the chest pain was gone, and so I was a little bit surprised that they told me they'd actually done CPR for 15 minutes and given me five shocks. So that came as news to me (Terri, female, age 57)

Most participants, however, described pushing through their symptoms. Other life responsibilities regarding family or work were given a higher priority than self-care. Participants described having attended meetings, preparing their children for school

(including driving them to school), taking their dogs for a walk, or going to work, all the while experiencing chest pain or feeling unwell.

4.5 Emotional Reaction and Effect on Identity

The first theme, 'SCAD is a mystery', reflects the participants' emotionally charged reaction to unexpected symptoms indicating cardiac dysfunction and diagnosis with a condition hitherto unknown to them and to their ensuing struggles with identity. Within this theme, study participants portrayed their experience of having SCAD in terms of enduring a range of overwhelming emotions. Emotional responses to the SCAD event included feeling shocked and overwhelmed or entering a phase of denial. Notably, they described a sense of loneliness, particularly in the context of a perceived lack of information about SCAD. Both SCAD itself and the participants themselves were thought of as a mystery. Participants reported feeling a sense of uncertainty and that their identity of themselves as healthy people with complex roles as partners, parents, family members, workers and active members in their social communities was threatened.

4.5.1 Shocked and Overwhelmed: Effect on Identity

After undergoing investigation in the emergency department, all study participants were given an initial diagnosis of having had a heart attack. They described experiencing a range of emotions, including shock and incomprehension, upon hearing this first piece of diagnostic information. All reported that having a heart attack was inconceivable to them. They believed that, given their younger age (study participants' mean age was 56.8 years at the time of SCAD), it was impossible for them to be having a heart attack:

> I was just looking at the ceiling going oh my god, what is even happening here? … I probably thought in my head there is no way I'm having a heart attack. How is even this possible? I am too young. What the hell? (Kelly, female, age 47)

4.5.2 Denial and Doubt

Despite experiencing chest pain symptoms and being given information by the healthcare professionals that they had had a heart attack, some participants went into denial regarding their condition. They questioned the veracity of the information they had been given and believed that they would be discharged from the emergency department because nothing serious had occurred:

> I'm not gonna be here long anyway so I'm just going to go with that, and whatever … denial, just denial really. I was like, nah, they've got something wrong here. It was just a tiny episode, nothing is ever going to come of it (Annelise, female, age 60)

Participants generally believed cardiac disease to be associated with older age and poor health and lifestyle. Thus, despite symptoms such as chest pain, the diagnosis of heart attack was dismissed in favour of a belief that a mistake had been made or that a transient health complaint was responsible.

There were some participant reports of disbelief in the diagnosis of SCAD as the cause of their heart attack over the longer term. Being told that SCAD is a relatively rare occurrence affected the participants' comprehension of the reality of their situation. They reasoned that if it was rare, there could have been a mistake:

> My probably honest opinion is I'm still a bit dubious that it's actually a SCAD event … Because it's so rare, I'm going, has it really been? Has it really been something else? Like a traditional heart attack that the doctors haven't seen? Has it been something else that's happened? (Emma, female, age 47)

4.5.3 Questioning their Healthy Identity

This sense of disbelief led study participants to experience feelings of shock. Study participants identified themselves as healthy people and believed that it was not possible for them to have had a heart attack. They generally followed a healthy lifestyle, including a

nutritious diet, not smoking and consuming limited amounts of alcohol. Most described themselves as fit and most engaged in an active lifestyle of exercising regularly:

> It's just shock. I couldn't believe it. When someone said I had a heart attack, I would never have thought in a million years. I don't smoke, I hardly drink, I play soccer … Just out of the blue. Total shock. (David, male, age 56)

Participants believed that they were all 'doing the right thing' by their health. To be told they were having a heart attack challenged their identity as a healthy person. Franklin recalled, 'There were moments where I was kind of questioning my identity, you know, … I can't think of myself as a healthy person anymore, you know. And I had considered myself fairly healthy' (Franklin, male, age 55).

Some participants described informing their medical teams they were healthy and, in some cases, were concerned they may not receive the care they needed because of this fact. Annelise remembered, 'I'm lying on the bed, you know, saying I'm a runner … I'm extremely fit guys, you know, don't write me off' (Annelise, female, age 60).

She recounted that she asked her husband to bring her running shoes to the hospital for her to place at the end of her bed. Feeling out of place as younger and healthy, and in response to this challenge on her identity, she wanted to signal to the staff and the other patients that she was different.

To be cared for in a hospital ward with other people who were older and, in some cases, more acutely unwell, many study participants felt out of place. Some participants felt embarrassed to be among older and sicker people and disliked the post-heart attack restrictions (e.g., bed rest) placed on them. Restrictions intensified the concept of feeling old and infirm:

> I did feel very affronted that I wasn't allowed out of bed to have a shower or go to the toilet and had to use a chair pan. I was young, fit, active and healthy and hated that I was being treated like an invalid. (Emma, female, age 47)

Seeing older people in the educational materials for people after a heart attack further challenged study participants and caused concern. Daphne recollected 'They showed us a video, me and my husband, about angiograms and stenting. The video itself was about 15 years old. It showed all these old people doing rehab. It was a bit depressing, to be honest' (Daphne, female, age 52).

Participants also described starting to feel old before their time and wondering if this was where the decline into old age started. 'You know, am I gonna be like, is this the first … am I gonna look back in this … that's when … it started. That's when that decline started' (Franklin, male, age 55).

4.5.4 SCAD Diagnosis Compounded Anxiety and Uncertainty

Receiving the news that their heart attack was caused by SCAD was a second shock that intensified distress for the study participants. None of the participants had ever heard of SCAD. Participants were told SCAD was uncommon, that the causes of SCAD were unclear and that there was limited research around treatment and management, '[The cardiologist] walks in and he said, "I can't tell you, this was a one in a million thing. It's called a SCAD heart attack." He explained what it was, he said, "your artery dissected, it flipped open" '. (Kelly, female, age 47)

For a cohort of people who considered themselves to be practising healthy lifestyle behaviours, a lack of comprehensive information to guide recovery was frustrating. Some participants continued to consider their heart attack in terms of traditional heart attack aetiology:

> Yeah, it was a bit of a shock. Umm, a lot of a shock. I couldn't, I mean, I guess I believed it. But I didn't know about SCAD … I just thought it was a fatty deposit type heart attack, because that's what they were telling me and showing me pictures of blocked arteries and all that sort of thing. (Daphne, female, age 51)

This incomprehension was based on the education that she had already received. Daphne had been provided with information about atherosclerotic heart attack; to then have to manage contradictory information about the same health process (i.e., a heart attack) created a sense of uncertainty. She remarked, as several participants did, that she was on a 'steep learning curve'. Some participants recognised that the shock they were experiencing played a role in their ability to comprehend information:

> I wouldn't have the ability at the time to think about that, like, being in shock. You don't know what's happened … but I would have liked to have known what was going on at a higher level because SCAD is something that's not known about. (Emma, female, age 47)

To be told they would never meet another person who had experienced SCAD was a strong reminder that there is a risk of death from SCAD. Naturally, this frequently left participants with a fear of death, all the more so when their personal research also led them to the literature indicating the risk of mortality from SCAD.

SCAD was understood to be unexpected, and when told it was so rare that the healthcare professionals may never have seen it, participants were left to consider it was a chance event they had little control over:

> I just thought how can this be so … random? … I found it very weird that this could be a one in a million chance or whatever they put on it … [The cardiologist] said, we go through our careers and we never see that, you can actually never see something like this. And I'm like, Oh, my god. What is this thing? … Why can't I win the lotto rather than having this, why couldn't it be the lotto? Anyway, I found it hard to believe. (Kelly, female, age 47)

4.5.5 Isolation and Mystery Breeds Feelings of Isolation

Informed by healthcare providers that SCAD is a rare and mysterious condition, study participants began to feel a sense of isolation. Some participants were told they were unlikely ever to meet another person who had experienced SCAD. Participants reported that they felt alone in this journey, which was exacerbated by the perceived lack of information about SCAD:

> I found the hardest out of all of that was the feeling alone. I just felt so alone, because [the treating healthcare professionals had] never come across a SCAD before. I didn't know anyone who'd had it, they didn't know any survivors of it. They didn't know what to do with me, they couldn't really help me. And they just said, you're, you know, one in a million, you're never going to meet another SCAD person. And in a way, that was the worst thing to ever say to me, because I just felt, I felt so alone. And I just felt like, no one was going to get it and no one was going to feel what I felt, and no one had any idea what it was like to go through what I had gone through. (Joanne, female, age 42)

Faced with uncertainty about SCAD, some participants spoke about being labelled a 'mystery'. Chelsea recalled, '[The cardiologist] does say I'm a mystery … I was sort of a bit of a mystery patient. We don't know why this is happening' (Chelsea, female, age 60).

Being labelled in this way affected the participants' ability to comprehend and start to make sense of what had happened to them. A lack of explanations and information about how to prevent future occurrences caused participants distress and put them at risk of further fear and anxiety.

Having read some information that the typical person with SCAD is a woman, one male participant, David, described the effect that being atypical had:

> That's the part that plays with my head. Because it's not like something you can change so it doesn't happen again. They keep telling me, were you stressed? No. Did you lift anything really heavy? No. It's just a mystery. What I've read and what they've told me is that I don't fit any of what they say, the criteria. Like it would affect mainly women; I'm not a woman. Older than what they say (David, male, age 56)

David was very concerned by the idea that he did not fit the characteristic SCAD categories, and this played into his perception of how he could avoid future SCAD events.

Study participants described their healthcare professionals' uncertainty as a signal that they had to advocate for themselves more broadly in terms of obtaining the care and support they needed. Most staff members they encountered were described by the study participants as 'lovely' and 'great', but sometimes healthcare professionals cast doubt on whether they should even be in hospital, and this created increased distress for some participants:

> While … I'm just trying to rest, this nurse came in and went 'You're too young to have a heart attack' and I'm thinking 'Oh my god, you know, where's your … bedside manner?' That's why I'm here in fact. (Betty, female, age 53)

Uncertainty displayed by healthcare professionals also had the effect of adding to participants' psychological distress and increasing their concerns for their safety:

> This doctor just kept looking at me like, not that he didn't believe me. But he was like, you're not going down the road of heart attack … it was like I was the big guinea pig because I think they thought how's this chick at [her] age having a heart attack? … that was that was more of the worry to me that … you do hear freaky things that happen … I'm not blaming anyone, but I'm just glad that nothing happened serious to me that I died. (Kelly, female, age 47)

4.6 Making Meaning of Experience: Need for Information

All study participants recognised that information was the key to making sense of what had happened. Over the days immediately after SCAD, participants began to gather information from the internet using their phones at their bedside. They began to understand that it is a life-threatening condition, and this had a serious effect on their emotional responses in terms of adding to the distress they were experiencing. Some participants described increasing anxiety and fear as they began to appreciate the reality of their situation. Participants became aware of the risk of mortality from a SCAD event:

> I was anxious about not knowing what it means, you know, how, what does this mean for the rest of my life? … I thought, oh, fuck, I could have died. And what's more, I could still die. Now. Like, you know, in the near future. So the first day I didn't think about my death. I just thought about my headache. But the next day after that, I started to think I might die. This could kill me. (Gail, female, age 68)

Some participants began to question the care they were receiving, typically based around a perceived lack of information about SCAD; they were upset that they were unable to make decisions or think about alternative actions, 'I had private insurance, I should have asked to be transferred to a different hospital and get a different cardiologist but to be honest, I was just in shock. I didn't know what to do' (Annelise, female, age 60).

Participants spoke of a sense that their ability to advocate for themselves was negatively affected by their sensed loss of control over their progress and their eventual recovery.

4.6.1 Perceived Lack of Information at Diagnosis of SCAD

The quality of the information the study participants reported receiving about SCAD varied considerably. Those who had had their SCAD event years before their participation in the SCAD-Insights study reported receiving a minimal level of information about SCAD.

Study participants who had had a more recent SCAD event reported that a greater amount of information had been provided to them; some participants reported having received a SCAD-specific pamphlet.

The level of detail in the education provided to participants was a function of the level of expertise of the healthcare professionals delivering their care. Regardless of the quality of information they felt they received, all participants reported they had used the internet to obtain information about SCAD. This patient-driven research occurred regardless of how comprehensive the explanation from their doctor was. Study participants all felt that the information they received about their diagnosis was inadequate for their needs.

Information that was lacking for participants pertained to the aetiology of SCAD. Participants wanted to know why SCAD had occurred as well as how. Participants wanted to know more details about SCAD than simply the anatomical information. By understanding more about why it occurred, participants felt they could understand how it could be prevented in the future and what it meant for them as they recovered.

At the minimal end of this information spectrum, Hayley, whose SCAD event occurred in 2016, was given her diagnosis by means of a Post-it note with the initials SCAD written on it:

> When he did give me the diagnosis, he had written it down on a sticky note. SCAD, right, spontaneous coronary artery dissection on a sticky note, and he goes, you can have a bit of a Google of this … I was the first person, you know, he didn't know anything about it … I felt really, like, he's a specialist, and he didn't know. I felt like, right, I kind of got to have to do my research. (Hayley, female, age 40)

The fact that the specialist suggested Hayley could research SCAD herself indicated to her that he was not knowledgeable about SCAD, and this added to the fear and uncertainty she experienced. She did not understand what had happened to her and what it meant for her life. At this time of uncertainty, online research was critical to her recovery and to her

management of her newly diagnosed health condition. For Hayley, the lack of knowledge displayed by her specialist spurred her into action to research everything she could about SCAD.

Conversely, study participants who had had their SCAD nearer to their participation in the SCAD-Insights study reported a greater level of information about SCAD. Franklin, one of the American study participants, described receiving an in-depth explanation from the hospital cardiologist, complete with anatomical models and diagrams:

> He said was that the inner layer of my right coronary artery … became separated from the middle layer. And when it when it sort of tore and separated, it created a blockage, like flapped down … he had … gone into that coronary artery kind of worked it to kind of get that flap back out, and then use the stent to hold the part of the artery that it separated … in place. He used a model to kind of show me, you know, where the RCA [right coronary artery] is on the heart. And then he drew on a piece of paper with what had happened to the artery and how he had fixed it with the stent. (Franklin, male, age 55)

Australian participants also reported they had received a detailed explanation:

> They bought in a little model of the heart and they said, you know, you've got a break in this part of the heart and then down at the bottom, this part of the heart and then they showed me the scans that showed me, you know, where there was, you know, the breaks. (Chelsea, female, age 60)

More recent participants also received SCAD-specific pamphlets:

> [The hospital staff] gave me that. [Participant held up a copy of the SCAD Research Inc Australia patient information pamphlet] They pretty much knew [about SCAD], I guess … I think a lot of people still don't know a lot about it, but they did. (David, male, age 56).

Yet, all study participants remained uncertain about the diagnosis they had received and unsatisfied with the explanations they had received:

> So, [the cardiologist] left and I got to work with my phone, looking up SCAD. And I'm like, huh? 90% of these happened to women, and pregnant women. And yet here I am. And I really want to know, like, what's the underlying cause, like … why did this happen? … The cardiologist didn't really have great answers. He's like, you know, this, this could have been waiting to happen, be congenital, you know, you could have had this weakness. We just don't know, like, we don't know why this happens … I remember being not thrilled with that. (Franklin, male, age 55)

Perceiving that the treating team had knowledge about SCAD was reassuring to participants:

> It helped getting that pamphlet on SCAD. And then because there was really nothing else really to do in the hospital, I researched as much as I could find on it … just getting a little pamphlet from a nurse … I do feel fortunate because I've read so many people's stories that they go to the [hospital] in their area, or in Europe, or wherever, that they don't even know what SCAD is. So I felt fortunate that the hospital I was at knew about it and hooked me up with the right cardiologist and all that kind of thing. (Susan, female, age 55)

However, those study participants who had received SCAD-specific information often reported that they felt they were given information and then left with it as if the information provision was a tick-box exercise for healthcare professionals. Susan said, 'I just think more education in the hospital about it because it was, it was just, kind of like, here, read this, this is what you had' (Susan, female, age 55).

For these SCAD-educated participants, healthcare professionals simply handing over a pamphlet was not enough. Receiving a pamphlet did not allay the perception that there was an information void about SCAD, nor did it address the participants' need for individualised care.

4.7 Processing Implications for the Future in the Aftermath of SCAD

Study participants described ongoing psychological unease in the period following the SCAD event. They outlined continued anxiety and uncertainty, and they reflected on the effect that SCAD had on their identity.

4.7.1 Anxiously Living with Uncertainty

After being discharged from their hospital, the study participants described increased anxiety due to the possibility of recurrence and uncertainty about what may cause another event. The participants were in shock after the acute SCAD event, and some felt they were in survival mode and just managing day-to-day in the acute phase: 'I feel like it was more survival in those first couple of weeks and then it was after that; the anxiety really ramped up' (Rebecca, female, age 42).

Rebecca went on to describe that, as time passed and as she gained more information, particularly about the recurrence of SCAD, her anxiety increased:

> It's only after I had the angiogram, gone back to work, I started to feel—get really anxious that it could happen again, the recurrences … I guess I kind of just thought, oh, this could have just happened to anyone; any female. But it's only then once I started to get more and more information that I started to get worried that I could have risk factors for having—for it to be more likely to reoccur. (Rebecca, female, age 42)

This increased anxiety was the case even for those participants who described themselves as usually calm and stress free. Living with increased anxiety exacerbated the emotional effect of SCAD on participants' lifestyles. Participants described feeling alone and fearful in the days and weeks following hospital discharge. The presence of ongoing symptoms, such as recurrent chest pain or fatigue, that they may not have been prepared for or expected, intensified anxiety even further. This was particularly true if they had to make decisions about further care-seeking. Emma, who had ongoing complications after her SCAD

event, described the effect this had had on her life and the internal dialogue that occurs when weighing up what to do:

> I would tell you emphatically I'm not an anxious person. And since having this, and even last night, you have [chest pains] … going? Oh, god, is this …? Is this one? Will I have to go to the hospital? … Just sit down … you know, just take it easy. But that, that real initial thought is one of really heightened anxiety. Is it happening again? (Emma, female, age 47)

4.7.2 Grieving the Loss of Health

In the aftermath of SCAD, study participants recalled experiencing grief as they came to terms with what they had lost through being ill. They described feeling a loss of their good health and the independence that comes with being healthy; for example, as Annelise described, 'It's grief … for the loss of your perfect health' (Annelise, female, age 60).

Study participants reflected that they were fit and conscious of living a healthy lifestyle up to that point in their lives. Participants described a sense of SCAD being unfair and coming about through no fault of their own. Advice from healthcare professionals or other sources to make lifestyle changes, such as to reduce stress or change employment, added to a perception of loss, which resulted in grief: 'That process … of grief … I'm only 53 … It's not fair, you know, my choices have been taken away because of a medical condition and … getting really really quite distressed about that' (Betty, female, age 53).

The presence of ongoing complications such as recurrent chest pain added to this sense of grieving a loss of independence and a life of chronic ill-health: 'I guess a bit of a loss too because I've had … the six presentations. I feel like oh my god, is this my life now, of getting like chest pain?' (Emma, female, age 47).

The accompanying stresses of additional presentation(s) to the emergency department and living with a threat of recurrence gave rise to a sense of ongoing grief for a previously independent lifestyle for the participants.

4.7.3 Fear of Judgement

A fear of being perceived as a hypochondriac exacerbated the anxiety the participants experienced and affected their decisions to seek care when needed after SCAD. Increased anxiety, in turn, created a vicious cycle whereby participants became anxious about being anxious. They had read that anxiety may be a precursor to SCAD and were anxious to reduce their risk of recurrence. On experiencing further chest pains and anxiety after her initial SCAD event, Emma described, 'I felt like a hypochondriac going back so soon. There is that anxiety about, you know, am I going to have another incident because I knew my body was under stress' (Emma, female, age 47).

Participants ascertained they were at risk of recurrence if they continued to suffer from anxiety, and that they should seek medical attention. However, they feared both judgement by healthcare professionals and being treated by healthcare professionals who may not know about SCAD:

> To have a heart attack … you know, the discrimination that you get with that, because … you're overweight, you know, you're lazy, you're fat, you've got high cholesterol. So … I think that within the medical profession there is that ignorance there and because … SCAD is not well known it makes it worse. (Betty, female, age 53)

4.7.4 Loss of Control

Through this challenge to their identity as healthy people, and in the context of being in shock, participants struggled to make sense of how they should progress into their future. Good health could no longer be taken for granted and was perceived as beyond their control:

> I was thinking recently about that, the shock factor … part of it is actually, you have to suddenly be less smug about your own health … it's like a de-smugging of one's health … like, you're rolling along, thinking you're doing all the right things, keeping fit, you know, exercising, etc. But then you get something like this that's totally beyond your control. And you can't take anything for granted basically. (Daphne, female, aged 52)

The challenge to participants' identity could also have negative effects in terms of ongoing management and healthy lifestyle. Many study participants wanted to actively work towards recovery. For example, Kelly asked her cardiologist for advice, but none was forthcoming:

> One thing I couldn't get over was, I said, 'Okay, well, what happens now? What do I have to do?' He said, 'Nothing', he said, 'don't change your life'. (Kelly, female, age 47)

Others had an attitude of disillusionment that being healthy did not protect them from a life-threatening condition. Some participants described having discontinued their previous healthy lifestyle that put them at risk of future ill-health:

> Ended up putting on 10 kilos … probably, I thought well, you know … you look after your own [health], you eat well, you don't smoke, you only drink irregularly and yeah, you do all the right things and you still get it, so you end up going 'I'm not walking!' And I don't walk that much now, I am trying to get back into it … I don't feel comfortable at this weight, but how am I going to lose weight? But then I really like that piece of chocolate cake, and because I nearly died, I'm gonna eat that chocolate cake! (Betty, female, age 51)

Some study participants described that they felt they should modify their behaviours and become more cautious. These restrictions were at odds with a previous sense of youth and freedom and put them at risk of developing a more sedentary lifestyle:

> I guess the freedom you had or the luxury you had of just being free to just whatever, doesn't work like that anymore. You've got to stop and process what you're going to do before you go and do it now to make sure that you're not raising your blood pressure too much or over-exerting. (Melissa, female, age 55)

4.7.5 Anger and Betrayal

Study participants also described feelings of anger after SCAD. Recalling their young age and prior perceived good health, some participants became angry that they had had a SCAD heart attack. They felt that, in having a heart attack, their body had betrayed them. Betty recalled that she 'got really angry, going, my body has let me down. It did this, you know, it let me down and now, you know, can I [ever] go back to work?' (Betty, female, age 53).

Through this act of betrayal, study participants felt that their bodies had not responded as they should or that their bodies were no longer serving them in the way they expected, for example, by being able to perform their usual daily tasks. Anger also arose for some participants through the imposition of restrictions on their lifestyles, mainly on lifting and carrying, by their treating healthcare professionals. The participants felt a loss of independence through having exercise and lifting restrictions imposed on them by their medical teams, and that it was unfair to be restricted in this way:

> I just was so angry that [the healthcare professionals] thought it was okay to just take away everything. Like I just could not. I couldn't get my head around that. I was just like, right. So through no fault of my own … I've lost everything. (Joanne, female, age 42)

Laura recalled that she 'felt uncertain in my body. I felt betrayed. So I didn't know how much I could rely on it. But … I just pushed through it really, that's all' (Laura, female, age 60). After feeling let down by their bodies, participants had the choice to carry on as

Laura did or to respond positively to the challenge and react to their bodies in a more encouraging and affirming manner:

> At first … I saw myself as weak, as like, how could my body let me down, how dare you? But I flipped that around and thought, bloody hell, like, you've actually saved me three times. You know, you've done everything you can to save me and, and I'm still here, I've put you through the mill. And I'm still here. (Hayley, female, age 40)

To respond in this more positive fashion marked the beginning of a positive recovery after SCAD for this participant.

4.8 Perceived Effect of SCAD on Others

As with any other serious illness, the experience of SCAD does not happen to the individual in isolation. Study participants spoke of how they thought their SCAD event had affected others in their families and friendship circles. A common thread was that partners and family members were perceived to experience similar emotional responses as the participants themselves did. This included surprise based on assumptions that heart attacks only happened to older people in ill-health. As recovery progressed, there were some mixed reports of how partners in particular continued to provide support. Depending on their ages, children were perceived by study participants to have been affected in different ways. Participants described their parents as particularly upset by the situation. A child having a heart attack went against the 'natural order' of things. Friendship circles too were affected. Friends were generally supportive, but they also held assumptions about who has heart attacks.

4.8.1 Perceived Effect on Partners

Most participants were partnered, and partners were described as being shocked at the time of the event:

> I think for my, my husband … he got a big scare. And I think, I think we both were a bit PTSD after it happened for a while, but I think that's worn off a bit. But he was very … he was great. Actually … he was very busy at work and work was not very helpful in accommodating him … So he was very stressed about that as well as about me. (Daphne, female, age 51)

Study participants described that as time passed, partners seemed to recover from their initial shock and life had slowly returned to normal, and participants described their partners as being supportive and caring. The partners remained cautious about the participants' health and monitored their symptoms and their activity levels. Many participants reported that their partners were protective of them and made sure that they did not lift anything heavy or 'did too much'; some partners reportedly co-opted their children into the effort to protect their mother after SCAD.

For example, Chelsea described frustration in that she wanted to live life normally, was an 'active' person and did not want to be subject to restrictions. Simultaneously, she understood that her partner's caution came from a place of care:

> My husband is very protective of me. Naturally. Like, right, you're stopping work. You're not doing this, you're not doing that. Part of you thinks, you know, that's the way he cares about you. And then part of it's like, well, this is terribly frustrating (laughs) being told that I can't do anything when, you know, my life doesn't has never revolved around not being able to do something. My life revolves around, you know, what more can I do? But I can understand that, you know, obviously, he's concerned about, you know, my health. (Chelsea, female, age 60)

Conversely, Gail said that she liked that her partner was more protective of her than she had been before:

> She's more protective of me than she was before … I quite like it! I don't mind. I don't mind if she says to me don't lift heavy things. That's good. I don't mind, yes. And I have made adjustments in that way. (Gail, female, age 68).

Only one participant specifically mentioned their sex life after SCAD when asked about how SCAD had affected their partner:

> He's been very, very careful with me. Making sure I don't do, do the wrong thing, do too much. He's always saying 'how's the chest?' that sort of thing [lowered voice] Things are quite gentle in the sex department. Which is fine [pause] … But he hasn't said anything like, oh, gosh, … our lives are over. You're an old lady now. And you're impacting my lifestyle or anything like that. He hasn't thought that way at all. He knows it's just the luck of the draw. And he just worries about me and doesn't want to lose me. (Daphne, female, age 53)

Another study participant alluded to the intimate aspects of her relationship:

> It does impact on your marriage … there's a lot of love and support for the first month or so. But because it's an invisible illness, you know, it's kind of slot back into normality again after that … Doing everything again. Being … everything to everybody again. You know, you're fine now, you've survived this. Not that he's ever said that. (Hayley, female, age 41)

Another study participant discussed her thoughts about being a single woman trying to negotiate the dating scene. Susan described having to manage other people's expectations and any potential fears they might have about her health despite feeling well and progressing in her recovery:

> I'm single. I try to date here and there. I don't bring that up, because I don't want—it's like, you had a heart attack; are you're going to die on me? I just don't bring it up because I don't want it to—it's kind of a non-event for me now because I feel so great, but also I don't want to scare somebody away, thinking, I have to take care of her. (Susan, female, age 56)

Conversely, some partners were perceived by the female study participants to be somewhat unhappy with them being 'out of action' after SCAD. For example, some partners were perceived to be unhappy if the participant was unable to attend to usual household tasks

as they had done before SCAD. This created extra emotional work on the women's part. Study participants with male partners felt they had to manage his responses in addition to continuing their role within the family unit:

> I'm guessing a lot of the women are mums and, you know, and there's not many mums … that don't have that Supermum cape on. We got to look after the house, the husband, the kids, the, you know, the bills, the groceries … everything that's going on. And so you don't have time to be sick. (Emma, female, age 47)

Some participants described a perceived inability of their partner to contend with SCAD. Annelise reported that her marriage broke down after her SCAD event. She recalled that her husband had previously demonstrated that he did not 'cope' with illness, and over a period of six months, he drifted away and began a new relationship with a younger woman. Laura described her husband's response of dismissing her concerns:

> My husband seemed to just take the doctor's 'Well, we're not exactly sure'. So you know, just get on with it … he thought downplaying it was the way to go, I think. Oh, well, you know, it hasn't happened again or, you know, you'll be right … It wasn't that he was dismissive entirely, but he, I believe, functions with 'if you don't feed it oxygen, it'll go away … just let's move on'. (Laura, female, age 60)

Without partner support, participants continued to feel alone. Just as SCAD had a range of effects on participants themselves, so too was there a range of effects on partners.

4.8.2 Perceived Effect on Children

All but two participants in the study were parents. Children of the study participants ranged in age from toddlers through to young adults. The perceived effects of SCAD on the children of participants varied according to the age and life stage of the child.

Participants who had younger children thought that their children were particularly affected. Two female participants had year-old babies at the time of their SCAD. The babies were thought to be 'completely oblivious, thankfully', but for one:

> because I was breastfeeding, I had to stop, obviously, all of a sudden, and go on to medication and stuff … poor [baby] missed out on the boob, it was wrenched away. (Hayley, female, age 40)

Young children were thought to be affected by their mother's absence from home while in hospital. For Hayley's children, who both had autism, this was of particular concern:

> I just disappeared out of their lives for a week and then … because they're ten and seven, it did impact on them more … every night, I was in hospital, you know, because they couldn't come and visit me because of Covid restrictions, so I was doing you know, the bedtime stories on FaceTime of a night and … my oldest was a bit teary, and, you know, and when I did come home, he was worried when I'd leave the house, are you going to come back, you're going to hospital. And you know, that kind of fear. You know that something's going to happen. But they've … seemed to settle down but … their autism did regress. Their therapists … were working very intensely with them when I was in hospital because it did, you know, impact on their ability. (Hayley, female, age 40)

After their mothers returned home, the older children noticed that they were no longer being picked up by their mothers or played with as actively as before:

> My oldest, he doesn't remember a lot about it. But at the time … that first year really impacted on him with the restrictions of what I could do, because I was always one of those mums that went on the trampoline with him, I could no longer go on the trampoline, I used to, chuggy back him around the house … and so he did find that really, really hard because his mum changed. Like, she wasn't the fun mum, that was, you know, fun before. But luckily, because he was only five … he doesn't really remember, but it still hurt me at the time, because he used to really get angry with me. And that used to hurt so much. Because it was really through no fault of my own. (Joanne, female, age 42)

Children who were teenagers or young adults were observed to be affected differently by their parent's SCAD event. Some of these older children were the ones who had helped their parent at the onset of the heart attack symptoms, having observed that they looked unwell, or they were asked directly by their parent for their advice. None of the participants discussed any long-term effects they thought the first responder role had on their children. But study participants did recall that their children were scared at the time of their parent's SCAD event, but that they had recovered:

> I think my son was probably, he was in the ED with me when it was all going very south and I remember he was up against the wall … he was in shock and no one was taking any notice of him … He was 18 years old and he was just sliding down the wall, and well I mean … yeah, I think it had some sort of impact on him, it was a delayed impact on him, um but he's good now, he's good now. (Annelise, female, age 60)

Other study participants also spoke of the ways they tried to manage their children's reactions to minimise their emotional responses:

> But my daughter would freak, she would have been only been what, 12 then, and that's not how I wanted her to see me at midnight, tired and emotional and … there's beeping noises and vomiting. And I just thought no, that is this is not a place for her at midnight. My husband was the same. He didn't really want to bring them but they were both going no, no, because they hadn't seen me since they left for school. … my husband picked them up and … had to say this has happened. And we're a very close family and they just went into complete meltdown. (Kelly, female, age 47)

The participants told their children about their heart attack to a greater or lesser extent depending on their ages. Joanne recalled that:

> I haven't told him I've had a heart attack. … I just said to him, … you know, my heart isn't, you know … because I don't want him to be one of those kids that grows up worrying about where his mum is all the time. Yeah, so we've really downplayed it, like really downplayed it. (Joanne, female, age 42)

Older children received a more detailed explanation. However, Susan described that she believed her children did not understand and still expected her to continue her mother role as usual:

> My kids—I'm trying to think how to say this, even with a heart attack, my kids would still expect me to get up and mow the lawn or whatever I'm used to doing because I'm never sick and I don't let things stop me, because it's just as a single parent, there's just stuff I have to do … My kids … they helped a little bit at first, but I think they're just so used to me not being sick and not giving up. … I don't think they understand that I could have died, and so sometimes that's hard. I get they're kids, but it's frustrating sometimes. (Susan, female, age 56)

Some older children also searched for information about SCAD, which prompted them to ask questions of their parent. Regarding their children's risk of having SCAD, there were varying responses, and this depended on whether the participant themselves had had screening. Some study participants chose not to be screened, which in turn prompted questions from their older children:

> My daughter asked me the other day, they are about to try to start a family, and she asked me … did I find out about FMD when I had my SCAD? I told her I chose not to find that out, because if they found out that I had it there was nothing that could be done about it anyway so at that time I don't want to have another thing … I suppose she worried about genetics I guess. (Annelise, female, age 60)

Conversely, other study participants recalled that they thought that it was up to the older children individually whether they would be screened for any risk factors for SCAD.

While SCAD is not as strongly linked to lifestyle factors such as diet and exercise as traditional CVD is, some study participants described that their whole families had adopted healthier lifestyle behaviours in the aftermath of SCAD. For example, Daphne described that when her family come together, they now check their blood pressure on the home blood pressure monitor. Laura described that her older children were active supporters of her adopting a more disciplined meditation and fitness regime after her SCAD. This family participation in healthy lifestyle behaviour was helpful to their recovery.

4.8.3 Perceived Effect on Parents

The parents of the participants is another group that was perceived to have been affected by the SCAD event. As most study participants were in the younger to middle-aged population, they reported having elderly parents. For a child to experience a life-threatening health issue was understood to go against the 'natural order' of things. It is perceived to be normal for parents to experience serious illnesses such as CVD before their child. Study participants felt that their parents didn't cope with the reality of their child having a heart attack. Franklin's parents were described as being 'pretty freaked out' when they heard their child had had a heart attack. Kelly recalled her father's distress:

> My dad was crying. He … just kept talking to me, bursting out crying … He said, I still can't even believe this has happened. And I'm the one who's supposed to be having a heart attack. Not you, you know. (Kelly, female, age 47)

Additionally, study participants' mothers continued to act in a maternal caring way for their child after their SCAD event. Chelsea's elderly mother had to be prevented from coming to the hospital to care for her daughter:

> Everyone just wanted [to visit], you know, my mother in particular, who's in her nineties. She's like, 'order me a taxi, I'm coming straight away'. And I said, 'Mum, you can't come because of Covid'… and I was very tired. And I was often FaceTiming her, just sort of lying there with my eyes closed. (Chelsea, female, age 60)

Despite experiencing ongoing symptoms of fatigue after her SCAD event, Chelsea felt that she needed to manage her mother's responses by trying to reassure her mother that she was being cared for in hospital.

In the longer term after SCAD, mothers of participants were described as having great concern for their child's ongoing welfare:

> I just think … concern, a lot of concern and worry and fear for me. And my mum is one of those people that … feels things probably more than I do. So if the boys—as in her grandkids—been little shits to me, she'll be like, 'No!' She protects me. And not that she doesn't love them. That's not what I'm saying. But she's just very … she feels things very deeply. And … Dad, very much the same. And just that worry. They just want me to be okay. (Hayley, female, age 40)

Hayley described her mother as being ready to intervene with her grandchildren in an attempt to protect her daughter from stress out of fear of another SCAD event.

4.8.4 Perceived Effect on Friends

Outside the immediate family, study participants also described some effects on their friendship circles, with most participants reporting that their friends were generally a helpful support to them in recovery. Without exception, study participants reported that their friends, who were generally similar in age, were surprised to hear of the SCAD diagnosis:

> My friends are completely shocked. They are obviously, most of them are similar age. To me they have been incredibly supportive. Yeah. [Chelsea started to cry] So, you know, wearing masks when they come to visit me. Um, sending me gifts, some flowers, and they're very worried. Yeah. I can't, I can't imagine. I can't imagine life without a lot of my friends. And I think they think the same thing … sorry [Chelsea tearful] … I guess it's a shock too to have a friend who has had a heart attack (Chelsea, female, age 60)

All participants reported that none of their friends had ever heard of SCAD. Chelsea's friends were medical doctors and had never heard of SCAD. Participants' friends were reported to be unaware that young(er) women could even have a heart attack, much less the existence of SCAD. However, Kelly described her perception that some of her friends did not believe that she had had a 'real' heart attack:

> One of my friends said 'so it wasn't really a heart attack … like a full-on heart attack? Like what older [people have], like, a full [heart attack]?' I had to explain to her everything that happened because she just could not believe that it was an actual [heart attack]. [Then] she said, 'so it was kind of like an episode?' No one at our age thinks … that goes on. We're all very naive about it. (Kelly, female, age 47)

Related to this reported lack of knowledge about SCAD, Emma noted that some friends provided inappropriate advice, for example, regarding diet or vaccines:

> A lot of girlfriends are like, so what are you doing about your diet? … are you sure it's not the vaccine? … you know, it's … all sorts of wild assertions from really, you know, well-educated, well-grounded, rational, well-travelled friends and family. (Emma, female, age 47)

These instances gave the study participants the sense that they were not believed and, in addition, that they needed to step in as educators to correct misinformation. Thus, the participants adopted the role of educator within their friendship circle to inform their friends and wider social circles about heart disease and SCAD in particular. In the process of

researching SCAD for themselves, many of the participants obtained information that they passed on to friends and advised them to be vigilant about symptoms and ask for help when needed.

4.9 Theme Summary

Participants in this study reported a range of emotional responses to having a heart attack, including shock, overwhelm, fear and denial, and they were particularly at odds with the concept of the typical heart attack patient who is older and living an unhealthy lifestyle. Such emotional responses increased when diagnosed with the unfamiliar condition of SCAD. Participants all described receiving an inadequate level of information about SCAD. This was felt more acutely by those participants who suspected their healthcare professionals of being less than knowledgeable about SCAD. The lack of information about why SCAD occurred left participants feeling psychologically distressed. In addition, being told that SCAD is a rare condition, one that practitioners may never see, created a sense of isolation and loneliness for participants. Labelled a ‘mystery’, SCAD participants felt alone and vulnerable.

The following chapter will present qualitative findings pertaining to the second theme: SCAD is life-changing. Participants in the present study reported on the various effects SCAD had on their lives beyond the initial event. These included the effects on the roles they played in their families and social lives. Participants offered insights into factors affecting their recovery and changes to their post-SCAD identity.

Chapter 5 Negotiating Life After SCAD

5.1 Overview

The previous chapter presented detailed descriptions of how the SCAD-Insights study participants experienced their SCAD event and the emotional effect it had on them immediately and following their release from hospital. This chapter reports on the ways in which study participants progressed in their recovery after SCAD to answer the second research question: 'In what ways do people negotiate life after SCAD?' The overarching sentiment was that SCAD is life changing. Study participants described having to find ways to adapt and to find their place in the world. Participants spoke of factors they believed affected their recovery and how they worked through these factors to manage their changed life circumstances. Recovery trajectories varied depending on the presence of ongoing health issues. Study participants described the perceived personal characteristics and circumstances they attributed to their recovery. The effects on their life, including work, were discussed. Participants also recounted how SCAD had prompted changes in their identity and, in particular, the development of their self-advocacy capabilities.

5.2 Factors Affecting Perceptions of Physical and Psychological Recovery

5.2.1 Recovery Over Time

The SCAD-Insights study participants described the processes they went through to understand and cope with managing the uncertainty that came with having an uncommon condition. They did this through educating themselves and reaching out for support, but, as several participants noted, it was a process that occurred organically over time. Emotional

responses after the SCAD event were particular to the individual and could be influenced by the input and support of others.

Many study participants had their SCAD event in late 2021 to early 2022 during the COVID-19 pandemic. These participants had some time to reflect, albeit only a few months in some cases, and they described noticing an improvement in their health. Factors affecting their perceptions of recovery included time, expectations of progress, physiological evidence, supportive relationships with health professionals, engagement with formal supportive services and personal characteristics.

All study participants early in their SCAD recovery described the event as having an acute effect on their physical health, which included ongoing fatigue or a loss of energy or strength for some. As described in the previous chapter, the participants generally understood themselves as being physically fit. Therefore, these effects on their health were surprising to them, which gave rise to frustration for participants striving for full recovery. Daphne described herself as 'frail' when she left hospital after her SCAD event. She described being told by healthcare professionals that people after SCAD would 'fully heal in, in 5 weeks, 35 days. So I was like, okay, I'll be better in 35 days. But it hasn't been like that' (Daphne, female, age 52).

In hindsight, she recognised that she was much better but reported remaining frustrated because she perceived that she had not returned to her pre-SCAD health:

> Oh time I suppose. Yeah, that's probably it. And also just being sensible and realistic about the level of physical stuff that I can do. As frustrating as that is sometimes. But I'll get there … your perspective does change over time. (Daphne, female, age 52)

Daphne went on to describe that her cardiologist advised that she would make a full recovery in 6 months, and this had contributed to her expectations of recovery:

> He seemed to think that [recovery] would have sort of happen by itself … which I guess it does. He said, I'll see you in 6 months, at which stage, you'll probably be back to normal. And maybe that's, that's a month away. So maybe I will be … more or less, a lot better. (Daphne, female, age 52)

Study participants who had experienced ongoing physical symptoms after SCAD observed a non-linear process of recovery, and their frustration concerning recovery was even more pronounced. These participants described having chest pains, fatigue or other physical complications after their initial SCAD diagnosis. Some participants attributed such complications to possible side effects from prescribed medications. For example, Emma described her journey as 'five steps forward and one back'. She saw her recovery trajectory as one of making small progress, only to have that progress derailed by another complication that then took time to manage and recover from. This had a negative effect on her. Just when she thought she might be getting better, she became demoralised, and her uncertainty increased.

The study participants who had had their event years prior recognised that recovery from SCAD had been a gradual process over time and reflected positively on their recovery. These study participants were proud of their recovery and described a confident outlook on life after SCAD. Kelly reflected that once she passed the 12-month mark, she believed she had passed a milestone in her recovery. She had not had any recurrence of SCAD, nor had she experienced any serious ill effects. She perceived that she had recovered well enough that she could be confident that she had survived SCAD:

> Now I feel like I'm completely in control. And I know what to look for. I know how to get my mindset into where it needs to be if I'm getting a bit funny, but as the years have gone on, I feel a lot better. But the first 12 months up was the toughest. (Kelly, female, age 47)

Annelise, who had her SCAD event 8 years prior to her interview, reflected that she had gone on a journey to a point where she was now happy in her life. She described having had 'eight bonus years' after her SCAD. She remarked, 'here I am 8 years later, still going strong'. Annelise reported she had experienced feelings across a continuum from shock and denial through grief to a place of acceptance. Over time, she came to believe that SCAD was 'just one of those things'. These recollections suggest that her mindset had shifted over time.

5.2.2 Seeing Evidence of Healing is Believing

Being told that there was clinical evidence of healing of the SCAD lesion contributed to several of the participants' sense of recovery. Evidence of healing was found in subsequent medical investigations, including an echocardiogram, an MRI scan or a second angiogram. The information that there was little to no damage to their heart muscle gave the participants comfort and a belief in the possibility of recovery. Betty recalled, 'They re-angiogrammed me and they actually acknowledged … that the SCAD had healed. So that was really, really good you know, it was good to know that. I needed to know that it had actually healed' (Betty, female, age 52).

Betty also had ongoing palpitations after SCAD and reported that observing her body's responses during a stress test gave her the confidence that she could recover and return to normal. She also learnt how to distinguish and manage her symptoms:

> It actually taught me … to be able to know, when, you know, I feel yuck, once I stopped on the treadmill, my heart went back to normal. So even though it was under stress, it still did all the right things under stress … once I laid down it returned to normal so that gave me … confidence. (Betty, female, age 52)

The evidence of healing also reinforced the participants' identity as being fit and healthy, which was perceived to have contributed to successful recovery. Participants took pride in this: '[I can] give myself a pat on the back and say, yes I was fit and healthy … I

gave myself a great platform for recovery' (Annelise, female, age 60). Tangible evidence of healing provided study participants with confidence, which in turn had positive effects on their emotional state generally.

5.3 Supportive Relationships with Health Professionals

5.3.1 Knowledge about SCAD is Important

Several study participants reported that the relationship they had with their cardiologist was of critical importance to their healing process. Hayley described her cardiologist as:

> just so absolutely brilliant in hospital, just the support he gave me and just that acknowledgement, and that validation. And you know … absolutely pivotal … I just felt I needed to go with someone who was quite passionate [about SCAD]. (Hayley, female, age 40)

All participants reported that they knew that SCAD was an under-researched area of medicine and had a degree of acceptance of this. Gail recalled that her cardiologist told her:

> We don't know enough, we haven't got enough stats about this stuff … and he reminded me that he, he was just guessing he didn't really know. So that was on the one hand, that was kind of unnerving because of course no one knows. But that's true all the time, isn't it? No one knows you could get struck by lightning no one knows. So it was peculiar, I found him very settling. Surprisingly, even though he didn't reassure me at all. Just told me how he saw it. (Gail, female, age 68)

Gail appreciated the cardiologist's honesty. Nonetheless, study participants all sought as much knowledge as they could access.

Some participants reported that they were happy with the cardiologist they had met at their diagnosis and were content to stay with them over the longer term. Wherever participants perceived a lack of understanding about SCAD from a healthcare professional,

this instilled a lack of trust in them and their ability to provide care. A few study participants reported they were unhappy with their medical care for various reasons, most importantly due to a lack of SCAD-specific knowledge on the part of their cardiologist. These participants described actively searching for a cardiologist they thought would know more about SCAD. Annelise reported that she had been under the care of three different cardiologists in one hospital admission and did not have 'faith in any of them'. After hospital discharge, through word of mouth, she found a cardiologist who knew about SCAD and who was supportive of her. She reported that 'he's great and he has been a big part of me getting on with it'. The study participants who reported having more than one admission to hospital said they had met different doctors during their admissions to hospital. Through this process, they reported being able to make an informed choice about who would better fit their needs. Hayley, after multiple hospital admissions, finally found a cardiologist who knew more about SCAD than other doctors she had met, and she advocated for her care to be transferred to him.

5.3.2 More than Knowledge

Having specialist knowledge about SCAD was not the only factor in choosing a cardiologist. The cardiologist's personal characteristics and attributes were reported to be of major importance to the study participants. In the early days after their SCAD diagnosis, when study participants were emotionally distressed, they reported that they valued a cardiologist's patience with having to answer lots of their questions about SCAD itself and its treatment and management options. Having patience and empathy and being honest in admitting they themselves were unsure were characteristics prized by study participants. Annelise recalled that her cardiologist had taken the time to research her case and was patient enough to answer her 'endless questions'. Joanne, who had been a nurse in the cardiac ward where she was treated, was assigned to a cardiologist with whom she had worked. Joanne decided to stay with this cardiologist because she understood that this doctor cared about her

welfare personally and would ‘fight for her’. Through understanding this analogy, Joanne felt that her cardiologist was an active contributor to a collaborative partnership that would enable healing.

A cardiologist’s willingness to admit when they were unsure or needed to research a particular aspect of SCAD was also welcomed by the participants. Laura described that her cardiologist:

> listens to me. He listens. Yeah. He listens to my concerns, whether they’re, they’re founded or not, or grounded, you know … he’ll explain why. So … we have a good relationship in that it’s a communication … he is very respectful. He is really happy to say, look, I’m not real sure. Let me look into it. And I’ll get back to you. And he does and immediately will ring you at home or, you know, and tell you what he’s found or whatever, you know, and there’s just an open honesty … The cardiologist changed my medication the other day because of that bruising. So he’s still open to fine tuning things … like he’s not just here’s the regime one fit one size fits everybody … and yeah, consider the individual. (Laura, female, age 60)

5.3.3 Engagement in Therapy

Several study participants reported they had or were currently undertaking psychological therapy to assist them in their recovery, while other study participants reported that they believed this was something needed in SCAD recovery generally. Betty reported that she had recognised she was struggling and had had some ‘meltdowns’, so she sought therapy sessions with a ‘nuts and bolts’ therapist she had met in her previous cancer treatment. This ‘nuts and bolts’ description was based on her perceived need to focus on goal setting and practical strategies, as opposed to being taught meditation, which she personally did not ascribe to. Space to talk about and acknowledge the fact she had had a near-death experience and the subsequent emotions of grief and anger was important:

> I nearly died. I feel really angry about this … I want that acknowledged, I want to tell my story. And then move from there. And that [therapy] worked really well … I suppose it's the space, it's the space to say, you know, I'm really peeved with this, I'm really angry that my [body] gave up, you know. But it hasn't given up, it gave me the actual symptoms to actually be still alive today, so you know from a really negative, you know, and turning it into that positive. (Betty, female, age 51)

Therapy was perceived by this participant to have assisted her in turning her experience around towards something more positive.

Franklin also spoke of needing space to talk about his feelings to avoid burdening his family and, in particular, his wife. He recognised the need to make long-term changes to his behaviour and the barriers he might face in this. Therefore, he sought a therapist who could work with him on behaviour change specifically:

> I did reach out and engage a therapist. And he was super helpful. He specialised in phase of life changes and chronic medical conditions was one of his areas, and just really, it was just really great to be able to sort of, you know, talk this through, talk it out loud … because my wife was concerned, too, and I didn't want to stress her out and linger on the negative and things like that. So he was really helpful to kind of help me process those feelings. (Franklin, male, age 55)

Psychological therapy was recognised by many participants as a helpful strategy to manage their recovery after SCAD.

5.4 CR and Its Role in Recovery After SCAD

5.4.1 Referral to CR after SCAD

Most study participants recounted that they had been referred by their healthcare professionals to attend CR. However, some participants reported experiencing delays or a lack of acceptance by the CR program itself. Further, a few participants noted they had not been referred to CR at all. Reported reasons for the lack of a referral were varied and

included a lack of access to CR programs, the presence of other medical issues and the decisions of healthcare professionals. For those participants who were referred to CR, there were some individual factors (e.g., childcare requirements) that determined whether they would attend CR or not. Further, some study participants were unable to attend CR due to the COVID-19 pandemic closures of CR services.

Some participants reported that they were told by their local CR staff that the program would not be appropriate due to their lack of traditional heart disease risk factors. Laura, whose work colleague had simultaneously had a heart attack, reported:

> I phoned up and [the CR staff] said, 'no, you don't need to do all of that'… [her colleague] was a large guy, had really high cholesterol, he had massive blood pressure … 'you don't need to do any of that. No, no, you don't fit the category'. (Laura, female, age 60)

CR staff informed some participants that the CR service would not be able to help because they had a SCAD event. Emma recounted that when she called her local CR service, the staff openly doubted her SCAD diagnosis and asked her if she 'wasn't doctor shopping'. This response suggested not only that the staff were unfamiliar with SCAD but also, with such an attitude, that they would not be able to provide the necessary emotional support.

Other study participants reported that they had been referred to CR, but that the CR service did not follow up with them. Participants reported that they became impatient and arranged their own attendance at CR to expedite the process. They felt that the wait was too long, and they were eager to commence their recovery process. The emotional upset they were experiencing reinforced the idea that they needed support and would have to search for it themselves: 'I thought I needed cardiac rehab after I've yelled at my family. I need cardiac rehab. The local area health … has got a cardiac rehab attached to it. So I rang up and did my own self-referral' (Betty, female, age 52).

Eventually, the CR unit to which Betty had originally been referred contacted her, at which point it was clearly too late. This experience prompted her to stress that people after SCAD need timely intervention:

> Six weeks later, I get a phone call in October from [the larger district service] … for the CR. So that distance is too long. I ended up going with [her local CR service] … the lag for someone between August and October managing it by themselves is too long … it needs to be bang bang bang, you know. (Betty, female, age 52)

Several other study participants were informed that attending CR would be inappropriate for them, that they would not benefit from it, and, therefore, they would not be referred. Hayley was told during her original admission that CR would likely not provide any benefit to her. As a mother of two small children, she reported that she then prioritised the care of her children over her potential attendance at CR:

> [The cardiologist said] 'You can do cardiac rehab if you want to, but because it's a tear, you probably not gonna get any benefit out of it. So I don't know whether it's going to do you any good'. And I was thinking, well, gosh, you know, I've got therapies for my three-year-old, I've got a baby now … I didn't see my kids for 7 days … my poor breastfed baby, he was 11 months old …. So I felt okay, well, I won't do I won't do rehab, then it's just going to add to my load. (Hayley, female, age 40)

Non-attendance at CR because healthcare professionals deemed it inappropriate for them, or because CR was delivered in an ad-hoc manner, may delay recovery for participants and add to psychosocial distress. When Hayley eventually did attend CR, she noted its great benefit:

> [A later cardiologist] did refer me to cardiac rehab, which was amazing. And I should have done it the first time; it's sort of helped me get that trust back into my, in my body as well … it was more like, look … you can exercise and it's not, your body's not going to collapse. You can do these things and you're not going to end up in hospital. (Hayley, female, age 40)

5.4.2 Benefits from Participation in CR

Study participants who did take part in a CR program reported varying attendance times, ranging from one single CR assessment through to a complete 8-week program. CR sessions were typically described by study participants as being conducted in a circuit-based structure with other group members exercising together. The benefits of their participation in CR varied, but the experience was generally regarded as positive.

Exercising after SCAD was a major concern to study participants in light of their identity as healthy people. Attending a CR gym, supervised by trained healthcare professionals within the grounds of a hospital, promoted a sense of safety for participants:

> I walked faster there than I had done since the whole thing started because I knew that if I fell down dead, they would revive me. And I felt like that the whole time. Like every day I went there I worked a bit harder. (Gail, female, age 68)

Those participants who attended CR reported that they enjoyed the exercise component. Participants stressed the benefit of being supervised when doing exercise, especially in the hospital environment, which gave them the confidence they needed to return to exercising:

> [CR] was at the hospital, which was the best thing. I'd recommend it to anyone who has [SCAD]. It was great. It gives you the confidence. You get your confidence back because you're in that environment that if something were to happen, you're actually there at the hospital. (David, male, age 56)

However, some participants felt that the rate or intensity of exercise prescribed by CR was low in comparison to their usual exercise regime. For example, Emma described a frustration that her exercise program was less intense than her pre-SCAD exercise regimen. Sometimes, those who asked for guidance on the intensity of their exercise were disappointed that there were no guidelines for exercise after SCAD, and they were given only 'vague' instructions. Non-specific or vague guidance was not felt to be helpful to the participants who were anxious about SCAD recurrence and who were eager to return to normal.

Some study participants also attended the education sessions provided by CR that included topics such as diet, exercise, medications and stress management. Study participants complained that education sessions were not tailored to SCAD. Sessions were described as 'generic' and 'not appropriate'. Every study participant attending education reported that they already knew and were practising the advice provided on healthy lifestyles. However, some study participants reported they benefitted from learning about the heart anatomy and about their medications. Additionally, some participants felt that education sessions about the emotional aspects of having a heart condition were beneficial:

> I did go to the education sessions … which I didn't necessarily need to go to. Because a lot of the talks are around eating healthy and blood pressure and things that don't impact on me, but the other aspect of it is the emotional state and the impacts that it has on relationships that they chat about as well. (Hayley, female, age 40)

To hear about the emotional effects that people with heart disease might potentially experience served to normalise how they were feeling after their SCAD event.

Study participants reported a psychological benefit from attending CR. Many participants described that they attended CR in a state of distress about having had a heart attack despite leading a healthy lifestyle and in a state of uncertainty after SCAD. Participants reported they benefitted from being supported by the CR staff:

> I have to say, from the day that I went from my assessment at the rehab place, my anxiety started to get better. They were just unbelievably helpful to me. I don't think they did anything different for me to what they do for everybody else. I mean … I suppose the different thing was that they acknowledged that I'd had a SCAD and that, you know, I was entitled to feel pretty shocked, that despite all of my preventive health efforts, I still had this bloody heart event. And that might, they have kind of normalised my anxiety. But they also said, 'No, you will recover, things will get better.' And they said that repeatedly. (Gail, female, age 68)

Reassurance from CR staff that being distressed after a SCAD event was to be expected was reported by study participants. In addition, CR staff reassured them that recovery was possible. Overall, study participants who had attended CR reported that they would recommend it to other people after a SCAD event:

> I think I'm pretty hot on the cardiac rehab piece because that's just good for you anyway, right? And anybody with SCAD is encouraged, just statistical risk for other things downstream happening to you, whether it's another dissection or something else. And so I think the that recommendation … you've got to take advantage of that. And if somehow that's not covered or recommended or referred, you've got to make those kinds of changes and get in that setting. But I think cardiac rehab is … like to work with an exercise physiologist while you're being monitored, like, it's totally different than just like, 'you just need to go to the gym, bro'. (Franklin, male, age 55)

Participants based their endorsement of CR on having received positive benefits from CR themselves, such as increased confidence, psychosocial support and support in continuing their healthy lifestyles.

5.4.3 Personal Characteristics are Important for Recovery

Participants talked about the perceived personal characteristics that assisted in their recovery after SCAD. These personal characteristics included positivity and being 'stress-free':

> I'm pretty positive person anyway, so … I don't think I would feel any different from … how I would have been if I didn't have a heart attack … I don't know, it's like a bit of a badge of honour to tell you the truth. You feel like you've dodged the biggest bullet and, and it's like, come and get me. Okay. It's like you've tried and you … you didn't get me. I feel like that. (Kelly, female, age 47)

David described an attitude of stoicism. He described actively avoiding thinking about what happened in an effort to recover: 'I don't dwell on it. But occasionally, you sit there thinking, well, did it actually happen? Because I don't feel any different. But I don't keep dwelling on it' (David, male, age 56).

Conversely, some study participants revealed that they had a history of anxiety and depression, but they identified in themselves personality traits that were helpful in their recovery. Hayley reported having been on anti-depressants for long-standing anxiety and depression, yet described herself as having a personality that needs to make plans so that she could then act. Gail described life-long strategies she had used to reduce her anxiety and her ability to 'contain' anxiety when it occurred.

Joanne reported on her spiritual beliefs as a factor in her recovery from SCAD. She mentioned several times during her interview that she had relied on her faith during her recovery. She talked about she and her husband praying together, and that this had helped them both. Conversely, Franklin described himself as not ascribing to any particular organised faith. However, he recalled that he spontaneously asked a hospital staff member, who had been identified as a pastor, to pray with him, and that this inspired him to relax and accept the treatment he was about to undergo.

5.5 Adapting to Life After SCAD

5.5.1 Evolution of Identity

Several study participants reported an integration of SCAD into a new identity. Participants reported that while they felt that they had returned to normal, SCAD had become an integral part of the way they saw themselves:

> I feel like SCAD is definitely a part of who I am as a person and my identity. And I do identify, like, on my [social media] profile I have … SCAD heart attack survivor, on my description, because I identify with that, that is to me part of who I am and who I am today. It's given me that strength to kind of move forward. (Hayley, female, age 40)

Having an outward sign of a new identity, such as a tattoo, gave participants an opportunity to educate others as part of their own healing process:

> It [participant showed me her tattoo] says SCAD survivor, and it's got the little heart … if somebody asks me about that, I explain it to them … I want to get the word out. (Susan, female, age 55)

Beyond such outward signs, many participants noted they had constructed their new identity through speaking up and raising awareness:

> [I] haven't got a tattoo, I haven't got a bracelet. But, you know, I speak [about] it enough that everybody that's around me knows it … that's all I can do for me. (Laura, female, age 60).

Participants were generally highly motivated to educate others about SCAD. They discussed that being part of the online SCAD community provided them the opportunity to raise awareness of this condition and to develop new capacities. Their involvement and perceptions of the online SCAD community group will be described in detail in the next chapter.

5.5.2 Self-Advocacy After SCAD

A perceived need to advocate for themselves after SCAD was commonly expressed by study participants. As described above, they frequently recalled meeting non-specialist healthcare professionals after their hospital discharge who did not know about SCAD and were even sceptical about it. One strategy participants used to counter the doubt expressed by healthcare professionals was to collate a file of the medical information to present when seeking care. Having the relevant information on hand saved time when having to explain themselves and provided evidence that the study participants had had a genuine health condition that required care and follow-up. Emma described feeling that she had to prove she had a genuine health condition:

> If you had all your notes they might take you more seriously … you need … your notes for them to even see you as a valid and credible, yeah, a valid and credible patient. (Emma, female, age 47)

Betty made sure that she had copies of all her discharge letters and other clinical information from her hospital admissions so that she could manage her own care and 'take control of her health literacy'. In the context of increasing specialisation with different specialists dealing with separate conditions, she felt that she had to assume responsibility for managing the various aspects of her holistic health care. For example, she was able to coordinate different specialists to investigate her SCAD risk factors (e.g., FMD).

In addition to collating their medical records, many study participants made copies of information such as research papers or information brochures that they had come across as part of their own personal research, specifically to take to their treating healthcare professionals. This was done not only to inform the healthcare professionals caring for them about SCAD but also to ensure that education would be provided to future patients.

Participants had a strong sense of being engaged in education and research to benefit people who will experience SCAD in the future.

The perceived need for self-advocacy was occasionally felt to impose an additional burden. In the context of not being believed or feeling dismissed by healthcare professionals, some participants felt pressured to maintain their advocacy, particularly if feeling unwell. After admission at her second SCAD event, Hayley reported that:

> I felt like one of [the doctors] didn't understand. And [he] just said, 'Oh, you'll be right, you'll be fine. You'll be right. Don't worry about it.' How can I not worry about it? I felt like I was fighting for me. And that was definitely a hindrance, when you feel like you've got to advocate yourself. (Hayley, female, age 40)

Hayley described that she felt that asking questions, while necessary, might become a problem. The treating team at that time ordered a CT angiogram. However, she requested an angiogram, which she knew to be the gold standard in diagnosis:

> I remember asking to go to the private hospital because they were saying to me and we're going to take you down for … an angio … what do you call it? Not the proper angio, but the one that's less invasive, [a] CT angio. Yeah, and I knew from my research that CT angio … doesn't show, it looks like a spasm … it's not advanced enough to pick up a SCAD necessarily. And so I said, oh look, I think I need to have a proper angiogram to diagnose this. I don't think this is going to show up. Anyway, I went up, we had it and the dude said, oh, it looks like you're having a spasm. [I said] it's not a spasm. It's a tear. I tell you, it's a tear. And I felt like I was kind of fighting a little bit. (Hayley, female, age 40)

She overheard staff talking in a disparaging manner about her being anxious, where she simply thought she was asking for the most appropriate investigation. She feared her self-advocacy could appear to challenge the methods of the healthcare professionals involved and could risk further negativity and sub-optimal care.

However, self-advocacy was generally perceived by study participants as important and beneficial for recovery after SCAD. Engagement in self-advocacy allowed participants to take on the roles of educators and advocates for the wider SCAD community as they recovered. Hayley said that she realised that 'I'm lucky to be able to advocate for myself', and further:

> I worry about people who you know, who can't do that, you know, people who, you know, non-English speaking background, people with disabilities, people who don't perhaps have the education or feel like they can't speak up when something's not right … I feel … this sense of responsibility … because I can do these things. I need to do something about it. Because there's lots of people who can't, because whatever reason, their circumstances. (Hayley, female, age 40)

Having the personal strength and ability to speak out was understood to be key to recovery after SCAD. Engaging in advocacy enabled the study participants to contribute to the overall SCAD community and educate and support others. Some participants felt a responsibility to contribute to the community and recognised that others could benefit from their contributions.

5.5.3 Return to Work After SCAD

Returning to work was an important way that study participants took control of their recovery and returned to a semblance of normality. Most participants were pre-retirement age (< 67 years in Australia), and many stated they wanted to return to work to regain their independence as part of the recovery process. For example, Daphne described herself as 'needing' to return to work to progress with her recovery. She reported that going to work, where she would not think about 'myself and my chest', would be helpful. To make a meaningful recovery, the study participants recognised that they had to progress to a point

where they did not think about what had happened. Returning to work would provide this respite and, eventually, healing.

Overall, there were mixed reports of when and how study participants returned to work. Return to work was complicated by medical advice to reduce stress and avoid lifting. In some cases, participants were given medical advice to stop work entirely. This was challenging. Nicole described that she closely identified as someone who had always worked and provided for herself and her family:

> A lot of my identity has been wrapped up in my work, my independence, my financial security, my identity. My father started a business when I was 6 years old … so it was just inculcated in that you worked and that you got on with it. And so it was work ahead of hobbies … So when you're not working … it's a very different life and it's a big part of your identity. You are like, what the hell do I do now? (Nicole, female, age 55)

Several participants took the challenging step of retirement after SCAD based on medical advice:

> I have stopped working, so that was quite a challenge for me … So [the cardiologist] said, 'look, you know, really, you can't be under any stress. We prefer you not to be working. You're going to be very tired. You are not to be pushing yourself'. So I guess as a woman and having lots of changes in my life, it's like, okay, where do we go from here? (Chelsea, female, age 60)

Other participants did not wish to leave work or could not afford to do so. Some participants changed jobs completely to adapt to their changed needs after SCAD. Adjustments were made to accommodate their advised lifestyle changes, such as avoiding lifting and stress. Several participants reported they had markedly reduced their stress levels by taking a new role with fewer responsibilities. For example, Betty changed jobs to leave a bullying manager and viewed her SCAD event as a catalyst for change:

> Looking back on it, it was about the career change … this is what forced me into actually making that career change, changing my work … if I never had SCAD, I'd still be where I was, exactly … so SCAD, that would be probably the take-home message, SCAD has actually taught me … forced me into making that decision. (Betty, female, age 52)

Several study participants spoke of retraining or changing jobs altogether with a view to accommodating not lifting and providing more flexibility. Joanne described her anger at being restricted and her feelings that she was being dismissed and minimised:

> The cardiologist has also said that I probably should go ahead and get the disability pension. And I just was like, are you mad? I'm not doing that. There has to be a job out there that I can still do as a qualified nurse. That does not involve me going on the disability pension. I'm not doing it. So I think also then I had a mission. I was just like I am not being a stay-at-home-feel-sorry-for-myself person because I don't know how to do that. So I'm going to do what I know how to do and that's move forward and find something that I can do. So I signed up within less than a week … to do an immunisation course online … because I thought well, that can't hurt me to do so. I then threw myself into … full-time study. (Joanne, female, age 40)

Some study participants were in a position to negotiate sick leave or light duties as part of a graduated return to work. Interestingly, the male SCAD participants reported returning to work with little disruption aside from taking some extra care with heavy lifting:

> [I'm] back to work. Still not pushing, [not] carrying anything really, really heavy. I still backed a bit off that at work. I probably could do it … There is some heavy things to lift … not a lot. Occasionally they come up, but either someone else throws them in the car for me, because I deliver stuff … around the local area … So there can be some heavy lifting, but I try to avoid it as much as I can. Maybe that's the only … thing. (David, male, age 56)

However, restrictions on lifting had major implications for the lifestyle needs of study participants who were mothers of young children. Young children must be lifted up by their

caregivers very often in the course of the day. Equipment such as prams and car seats also need to be lifted. Joanne, the mother of a 12-month-old, spoke of her anger at being told she had to be restricted from lifting anything over 10 kilograms; her son was 11 kilograms at that point. For her, the lifting restrictions also affected her career as a nurse, but as a contract worker, she had little bargaining power to request a light-duties roster. The lifting restriction was perceived as having been placed on her without consideration of her psychosocial needs. Study participants reported that, given time to process the information, they understood that the team were advising this management from a position of care and a wish to avoid further complications.

5.6 Theme Summary

Study participants described their recovery from SCAD on a trajectory that was perceived to be facilitated by a number of factors. Evidence of healing and the personal characteristics of both the study participant and their treating cardiologist were described by study participants to be key to recovery. Attendance at therapy sessions and CR was perceived as beneficial. A SCAD event was viewed as a life-changing experience that led to a changed identity for many participants.

Chapter 6 The Role of Online Support Groups After SCAD

6.1 Overview

In the previous chapter, the details of how the study participants negotiated life after SCAD and the ways in which they adapted to their changed circumstances were described. This chapter presents findings in relation to the third theme: 'Seeking the SCAD community'. The purpose of this chapter is to report on the ways in which participants negotiated their membership of an online SCAD support group to answer the third research question: 'In what ways does engagement with an Australian online support group affect the experience of SCAD?' Membership of an online SCAD support group was perceived as a double-edged sword. Along with benefits, some negative aspects surrounding online group membership were described.

6.2 Benefits of Joining an Online SCAD Support Group

6.2.1 Group Membership Reduced Loneliness

Participants reported that online group membership was beneficial in terms of alleviating a sense of loneliness and isolation. Stories of SCAD experiences and SCAD recovery were shared within online support groups, and this provided participants with reassurance about potential recurrence and a sense of shared experience, which reduced feelings of isolation. Meeting other people with a rare condition that most people have never heard of was comforting. Some participants were told at diagnosis that they were unlikely ever to meet another person who had experienced SCAD. This claim left the participants with

the impression that they were, and would be, alone in this journey. Joining an online support group and reading other people's stories reduced the sense of isolation and showed the participants that there were, in fact, other people who had survived SCAD:

> Since I spoke to other SCAD people and on the forum … that seems to be the biggest complaint is that total aloneness that you feel. And even though my husband was really supportive, and my mum flew over from [overseas], it didn't fix it. It didn't fix that feeling that … you were the only one that this has happened to, and no one knew how to help you, and no one knew what you're going through. And when I found that Facebook forum, it was like the biggest sigh of relief to know that I wasn't the only one. (Joanne, female, age 42)

6.2.2 Online Groups Provide Reassuring Information

In addition to providing the opportunity to meet others in a similar situation, online groups serve an important purpose of sharing information about SCAD. Information presented to the groups included medical information about SCAD, practical advice, for example, on managing fatigue and stories about the experience of living with SCAD. Obtaining information about SCAD through online support groups provided comfort to those who were managing their responses (both physical and psychosocial) after SCAD. As Daphne said, 'The stuff on the internet is mostly just through talking to other people who have had a SCAD. That's the most useful source. It's reassuring about the ongoing issues' (Daphne, female, age 52).

Betty, whose SCAD diagnosis was met with scepticism from her family, described a sense of validation regarding her diagnosis, in particular, of the psychosocial distress she was grappling with. She remarked, 'The Facebook pages have been my saviour, because that gives you the evidence … you know, you see people going through … [SCAD] … and being relevant and valid' (Betty, female, age 52).

Meeting other people with the same diagnosis experiencing similar responses and impacts provided evidence that Betty's reactions to having SCAD were acceptable or 'normal'. The opportunity to read the stories of other people who have survived and thrived after SCAD provided reassurance for participants, particularly to those who had had their SCAD event more recently. As Rebecca recalled, 'I'm really grateful to have found that survivor's group that was on Facebook … just knowing that there are so many other people out there that have experienced similar or worse and others have bounced back really quickly' (Rebecca, female, age 42).

6.2.3 Hope and Gratitude

Reading such stories served as an example and gave the participants hope that they too could recover and return to normal. In addition, reading stories from other people after SCAD enabled helpful comparisons, which allowed recovery from SCAD to be benchmarked against other SCAD survivors' trajectories, both physically and mentally. Reading these stories also engendered a sense of gratitude. Franklin reported that these stories reminded him that he was lucky in his presentation, treatment and recovery:

> I think I'm a lot better off than most the folks that are in those groups. Like, pretty sad … yeah, some of them are like, you know, they're people are pretty disabled. And they're also living with a lot of anxiety … because it's not at all clear that that's it's a one-and-done kind of a problem that they're going to have to deal with. Looking at some of these folks on some of the support group is that they're not faring very, very well. Compared to me, that feeds into my sense of gratitude and relief and just, you know, good fortune. (Franklin, male, age 55)

Group membership also facilitated connection with others who could understand what they were going through, both online and in person. Sometimes, membership in the online community translated into meeting other people who had experienced SCAD at community

events, such as the annual ‘SCADaddle’ fundraising walk. Online group membership facilitated face-to-face social connectedness:

> Because you feel so alone, they keep on telling you it’s rare so you feel so alone and you have no one else to talk to about it. Honestly on that SCADaddle walk we did, we all just walked together and we just talked each other’s head off! Five kilometers was over just like that! Like anything I guess, that’s what support groups are. (Annelise, female, age 60)

6.3 Negative Aspects of the Online Community

6.3.1 Alarming Stories Online

The benefits of group participation and connection to others came at the cost of increased fear and uncertainty through being exposed to stories about other patients’ poor health outcomes. Participants were concerned by stories from other people who had had complications during their SCAD event. This included cardiac arrest and resuscitation efforts. Other stories described experiencing health challenges after SCAD, such as heart failure symptoms or debilitating fatigue. Reading stories such as these engendered a sense of being overwhelmed and stressed about their own health conditions:

> lots of people saying … ‘I’ve got this problem. What do you reckon?’ ‘This happened to me’. ‘I’ve just had my second SCAD and they had to revive me. I nearly died.’ All that sort of stuff is a bit overwhelming when you’ve just had one yourself. (Daphne, female, age 52)

Becoming aware of complications after SCAD and becoming aware that there could be SCAD recurrence contributed to a sense of unease for participants, who were grappling with their own physical and emotional responses after SCAD.

6.3.2 Guilt vs Gratitude

Contrary to feelings of gratitude described previously, a sense of unease occurred for some when reading stories of complications in recovery when the participant themselves had a comparatively good outcome after SCAD. David described being overwhelmed when reading stories of difficult outcomes after SCAD:

> It gets a bit overwhelming at times. Just reading some of the people's [stories], what they're going through. It's like, it's affected some people so much worse. I find it hard saying 'I'm fine. I started playing soccer six weeks after' and they're struggling a lot worse. So, reading all that, it gets a bit much for me. (David, male, age 56)

While David was grappling with the fact that, as a man, he was in the minority in the group, he also felt that he could not share that he was doing well after his SCAD event, given that others were struggling with very real ongoing health problems after SCAD.

6.4 Managing Memberships

People changed their membership status accordingly: where membership was perceived as depressing or anxiety inducing, they left the group or reduced participation and consumption of online material. Nicole described dropping out of the group when she realised that reading stories about people having a recurrence of SCAD was 'depressing' and not helpful to her recovery. Gail reduced her viewing of material due to feeling 'unnerved'.

However, Kelly thought that it was good to read about people surviving SCAD:

> [It] helped reading on that SCAD Facebook page … reading about it, you know … people are surviving this, which is good … I was talking to the one of the nurses [who] said to me [about another SCAD patient] 'Oh, she had a complete dissection. And she didn't make it to hospital'. And that quite upset me. So seeing so many people, you know, getting through it and surviving, it is good. (Kelly, female, age 47)

Participants also reported being concerned about the material people post on the online groups. Some participants were not comfortable with incorrect or inappropriate information being shared with group members. Terri recalled reading a thread discussing whether SCAD was a heart attack. She had to balance providing more factual information against leaving a discussion that was stressful to her:

> This lady posted that she went to her GP and said she had a SCAD and he said that a SCAD isn't a heart attack … then there were a couple of survivors who got on and went, 'Well, technically it's not a heart attack'. And of course me goes, 'Well, hang on, let's just check the sources. Yes, it is a heart attack because it's the coronary artery has been affected … the causes of heart attack are not all the same, so SCAD is a type of [heart attack]'. Now, some people are coming in and they're going, 'No, it's not a heart attack. It can turn into a heart attack or it could turn into a cardiac arrest, but it's not a heart attack'. And I'm sitting there going, 'Okay, back away, do not get into this because this is just stress inducing for me'. (Terri, female, age 57)

Gail felt that group members should consider the appropriateness of posting medical questions online to be potentially answered by laypeople. She recognised the members of the groups' 'expertise' in SCAD but advocated for certain questions to be directed to medical professionals and for the online group to provide 'general good sense'. Chelsea echoed this with the observation that she also felt that posting certain things was not appropriate:

> then there are other people saying, you know, 'I've got palpitations, should I go and see my doctor?', you know, 'is that something I should worry about?' or 'I'm on this medication?' or 'I have to choose a cardiologist, who do you think?' … some I keep well clear of. (Chelsea, female, age 60)

However, on balance, Chelsea thought that online group participants were 'sensible women' who could make the appropriate judgement about what was good advice or not. She reported the following:

> It's sensible information … no one's saying 'I'm giving up all my medication and trying some homeopathic thing', or, you know, 'I've given up all my medication, I'm trying this qilong tea'. No. No weirdos like that, you know, everyone's very conscious that the medication that cardiologists are recommending is actually, you know, helping them along the line. A lot of, you know, some people are taking up, you know, meditation, mindfulness, yoga, all of those things. I don't have any objections to that sort of thing. But if it was a group where people go, you know, I prefer to go the really alternate route, I think I'd probably be turning them off. (Chelsea, female, age 60)

6.4.1 Group Advice—Individual Needs

Membership of an online group provided a sense of community and reduced the sense of loneliness, but study participants recognised that information given by group members regarding various facets of SCAD recovery (e.g., return to work) varied according to different people's experiences after SCAD. Therefore, group members should be aware that each person as an individual would recover differently and would have individual needs:

> The SCAD group … I was into it to start with … It's only been 6 weeks. Now I'm drawing away from it because I don't know how I'm supposed to feel … Is this how I'm supposed to be feeling? I don't know. Is this the same for everyone else? I don't know, because everyone's experience is different … some of them I know have had stents and … bypasses or whatever. So their medical history is completely different to mine, so that makes it hard too because it's not same for same. It's not like-for-like … so that makes it hard to try and work out how you should be feeling, what you should be experiencing I guess, or what your experience is because there's no base. (Melissa, female, age 55)

Understanding that group members were indeed individuals and might require a more nuanced or tailored response might lead to other members suppressing their participation. Susan said that:

> I don't comment a lot on when people ask things, because like I said, everybody's different. The biggest thing is—and follow your doctor's advice, because so many people on those forums give advice. They're not doctors, and each case is individual. I go by what my cardiologist says because she's the expert. (Susan, female, age 56)

6.4.2 Frustration with a Negative Culture

Conversely, a few participants had more negative remarks to make about the online groups. On occasion, the discourse within the group was described as negative. Comments in the groups that study participants viewed as pessimistic or defeatist were at odds with the ways they wanted to recover and manage their own psychosocial responses. Susan described that she felt that:

> a lot of the group, I just felt like some—how do I—just really like a pity party of 'I can't do this' and 'my husband doesn't understand' and 'I can't work and I can't …' I don't think that way. I was more like when can I get back to [exercise]? … because that's the way my mind works. But it was helpful to see what other people experienced too. (Susan, female, age 55)

Hayley described frustration with the negative culture that she perceived arising from time to time within the online support group. While recognising that individual members have their personal responses, negativity was understood as contrary to recovering from SCAD through being positive and proactive. Frustration could also arise when group members seemed unable to see that they were lucky to have survived a life-threatening condition such as SCAD. Hayley described the following:

> I do get frustrated with … this is gonna sound terrible too, [I'm] quite accepting and quite open to, you know, people's own journeys, but … it pisses me off when people are victims … completely, just whinging the whole time. 'Why me?' … 'this isn't fair', 'this is bullshit'. Blah, blah, blah, you know, and they're having that impact … That makes me angry. So … I do tap out of our SCAD survivor group a little bit as well, because that often happens … I have chatted to a few other people who feel the same as me around that. And … that's not fair, because everyone has their own journey. And everyone responds to this in different ways. But I guess for me, it just … it pisses me off. (Hayley, female, age 41)

In addition, the focus on the provision of information about SCAD within the group could be understood as detracting from the support the group could potentially provide. The group was perceived as welcoming, but the emphasis on information provision was perceived as too narrow and lacking depth. Rather, placing stories about SCAD experiences within the context of people living their lives and evolving due to surviving a SCAD event could add dimension and perspective. Terri had been a member of a support group for a different health condition and described her experience there:

> I don't think a lot of them are taking or putting much into the group. If there's something that they feel they can answer, they will answer. But it's not like other support groups where the support is about your day-to-day coping, rather than a focus or a search for information … with the [other illness support group] it's in the background of the interactions that you're having, because you've met people who become your tribe, your group. Yes, you have the thing that brought you all together, but you know about your families and your friends and all of those sorts of things. So when I think support group, that's what I was hoping it was going to be … but this is wholly and solely focused about SCAD. (Terri, female, age 57)

6.4.3 Evolving Online Engagement

Some study participants reported that if they had left the group due to frustration or being overwhelmed, as they recovered, they returned to the group to act as mentors. A time

lapse after SCAD allowed space for them to feel they could provide helpful answers and support to the newer members and be a role model to prove that it is possible to recover well after SCAD. Annelise described that 'now I've reached that point where I can go back on and I can encourage others and giving positive outcomes like … be kind to yourself, make sure you rest when you need to' (Annelise, female, age 60).

Study participants wanted to take the opportunity to provide advice for people who may experience SCAD in the future. They were generally positive about the future after SCAD, and they were positive about the role of online support groups despite negative aspects, such as feeling overwhelmed by the content. Daphne wanted to reassure others:

> I would say, take it easy. What … you've got is an injury. You need to rest. But it will get better. Read what's on the internet, join the Facebook group if … you're so inclined. It can be a little overwhelming. Especially at first. (Daphne, female, age 53)

The participants also wanted to provide practical advice for both people who have experienced SCAD and healthcare professionals. Participants recognised the substantial psychosocial effects of SCAD but were reassuring in their advice:

> Relax, don't let your head run away and play mind games on you. Because it will consume you for the next couple of years until you feel like you're out of it. And you can finally relax. The mind games are next level. (Kelly, female, age 47)

Participants also suggested that more support for people after SCAD was needed, particularly psychosocial support:

> The overarching thing for me is that we can do better than sending people off out of the hospital after such an event with a script and make an appointment for some exercise. Not good enough. You know, it's too frightening. There should be follow-up phone calls at home in the next day. That afternoon. That night is terrifying, that first night home, the sleep deprivation that we all suffer because we're scared to go to sleep. (Laura, female, age 60)

6.5 Theme Summary

In summary, participants in this study endorsed the role of online support groups as a valuable tool for recovery after SCAD. Online support groups provided much-needed information, and, by placing the information in a context of shared experience, the SCAD information was practical and genuine. By meeting others who were also going through SCAD recovery, study participants did not feel so alone, and this brought comfort. Participants reported they believed that SCAD information should be consistent with the information provided by specialist healthcare professionals and were concerned about information that could be perceived as contradicting important medical advice. Participants in this study spoke of their resilience and their efforts to recover well, and some voiced concerns that negativity in online support groups could be unhelpful or detrimental to group members. Despite those concerns, study participants wanted to give back to the community through making positive contributions to the online support groups that had supported them.

Chapter 7 Discussion

The aim of the SCAD-Insights study was to gain an in-depth understanding of the experience and the effect of SCAD from the patient's perspective to inform the design of support services and resources. It also sought to answer the following research questions:

1. In what ways do people experience and make meaning of a SCAD event?
2. In what ways do people negotiate life after SCAD?
3. In what ways does engagement with an Australian online SCAD survivor support group affect the experience of SCAD?

7.2 Literature Review

The integrative literature review presented in Chapter 2 identified limited qualitative research pertaining to patients' perspectives regarding the effect of SCAD on their lifestyle and their well-being, the challenges they faced in recovery after SCAD and their opinions on service delivery (Turner et al., 2023).

The prominent theme of the literature review was a perceived lack of information about SCAD; many participants reported that the information they received was insufficient or inadequate. Dissatisfaction with the given information ranged across different aspects of the SCAD experience, including aetiology, management and prognosis. A perceived lack of knowledge about SCAD among healthcare professionals and frustration with being provided inappropriate information was prevalent (Turner et al., 2023).

Other themes in the review included living with emotional responses after SCAD and the recovery needs after SCAD. Closely linked to the perceived lack of information after SCAD were reports of profound emotional responses. The participants of studies in the literature reported intense emotional reactions after SCAD, including feeling shocked and

overwhelmed, and they likened their responses to being a roller-coaster. The review found that perspectives from male SCAD survivors and those of families or unpaid caregivers of SCAD survivors were missing from the literature (Turner et al., 2023).

7.2 The SCAD-Insights Study

Chapters 4, 5 and 6 presented the qualitative findings from the SCAD-Insights study that reported on the data from semi-structured interviews conducted with 17 participants recovering from a SCAD event. Seeking to understand the multifaceted patient experience after SCAD, these chapters presented data exploring three themes:

- SCAD is a mystery: emotional shock and loneliness compounded by an information void.
- SCAD is life-changing: adapting and finding one's place in the world.
- Seeking the SCAD community: online groups can be a double-edged sword.

Participants in the SCAD-Insights study reported a range of emotional responses after SCAD. The unexpected and dramatic diagnosis of AMI led to profound feelings of shock and overwhelm. Some participants went into denial about their condition, while other participants became fearful, given the life-threatening nature of a heart attack. Participants reported further emotional shock when told about the SCAD diagnosis. In addition, participants described a sense of loneliness in their experience because they were told that SCAD is rare, and that it is a mystery. Not understanding what was happening or why intensified their emotional responses and affected the way the participants took control of, and progressed in, their recovery.

Despite facing these challenges, the SCAD-Insights study participants reported recovery over time facilitated by various factors, including information-seeking, their own personal characteristics and using supports such as attending a CR program. Membership of

online support groups was particularly important and was generally reported in positive terms, although some negative aspects reportedly affected the usefulness of these groups. The SCAD-Insights study participants provided their perspectives on the supports needed by people after SCAD, including the need for tailored information and for psychological support. Adaptation to a post-SCAD identity was reported by many participants, particularly those whose SCAD event had occurred several years prior to participation in this study.

There are few examples of primary research undertaken that investigate the patient experience after SCAD (Turner et al., 2023), so the SCAD-Insights study makes a valuable contribution to this limited body of research. The findings from the SCAD-Insights study revealed further evidence of the profound psychosocial burden of SCAD, particularly in the context of the previously healthy population in which it typically occurs. The SCAD-Insights study showed that the psychosocial burden after SCAD is affected by the uncertainty and lack of information surrounding this under-studied and mysterious condition.

The SCAD-Insights study extends the themes discovered in the literature review and includes SCAD survivors' perceptions of the processes they undertook on their recovery trajectory. Additionally, the study provides information on patients' perceptions of its effect on their families and social networks. The SCAD-Insights study demonstrates the gendered aspects of SCAD as a predominately female heart condition and provided some information on the experience of men after SCAD, who are a rare sub-section of the SCAD population.

This chapter presents the discussion of this research project, including its strengths and limitations. This chapter will discuss the study findings in the context of the current SCAD and broader cardiac research literature to address the aim of this thesis: to understand the multifaceted patient experience after a SCAD event. The SCAD-Insights study makes recommendations for future PCC after SCAD and holistic SCAD research.

7.3 SCAD is a Mystery: Uncertainty After SCAD

7.3.1 Delays in Seeking Help

The SCAD-Insights study participants did not view themselves as typical heart-attack patients, which led to delays in their seeking medical attention in many instances. This mirrors the literature on women's perceptions of their risk of AMI (Chandrasekhar et al., 2018; Lichtman et al., 2015; Madsen & Birkelund, 2016). Self-imposed delays in seeking treatment were reported as being based on a cultural view of heart attacks as a male condition, guilt at using health resources and a fear of being labelled a hypochondriac (Madsen & Birkelund, 2016). Women after AMI had not recognised their risk of heart disease, had attributed their symptoms to non-cardiac issues and described a process of managing competing demands prior to seeking help (Lichtman et al., 2015). Contrastingly, a recent systematic review (n = 45) found no relationship between pre-hospital delay and symptom knowledge, embarrassment or worry about troubling others (Arrebola-Moreno et al., 2020). However, this review did note that gender differences in pre-hospital delay were not considered, and that women do consistently report longer pre-hospital delays (Arrebola-Moreno et al., 2020).

7.3.2 Emotional Responses After SCAD

The participant experience after SCAD was highly emotional. The participants described a range of emotions in response to having a heart attack in the first instance and when subsequently being diagnosed with SCAD. Their emotional responses included feelings of shock, anger, betrayal and denial. In particular, study participants reported a feeling a sense of loneliness in the context of uncertainty and the perceived lack of information. SCAD, and by extension, the participants themselves, were considered a mystery.

The wide-ranging emotional responses reported in the SCAD-Insights study are reflected in the current qualitative literature regarding the SCAD patient experience (Turner et al., 2023). People after SCAD described a 'roller-coaster of emotions', including shock and disbelief, confusion, fear and anxiety in the aftermath of their SCAD event (Murphy et al., 2022, p. 5) or 'being caught off guard' by the onset of an unexpected illness condition (Clark et al., 2021, p. 8).

The emotional responses described in the SCAD-Insights study also reflect patient responses reported in the wider cardiac literature. Research demonstrates that people frequently experience psychological distress after ACS (A. Jackson et al., 2018; Lichtman et al., 2014; McPhillips et al., 2019; Petriček et al., 2015). People after a cardiac event present a wide range of negative emotional responses, including depression, anxiety, guilt and anger. Further, they ascribe these emotional responses to the presence of physical symptoms, limitations placed on them by their condition and uncertainty about the condition (McPhillips et al., 2019).

The concept of cardiac distress was developed in recognition of, and to encompass, the multifaceted nature of people's psychosocial responses after being diagnosed with a cardiac condition. Cardiac distress has been defined as a 'persistent negative emotional state' spanning across 'multiple psychosocial domains that challenges a person's capacity to cope with living with their heart condition; the treatment of the condition; and the resultant changes to daily living' (A. Jackson et al., 2018, p. 290). Cardiac distress can also undermine a person's 'sense of self and future orientation' (A. Jackson et al., 2018, p. 290).

Emotional responses to acute cardiac events are characterised by features of trauma, including an abrupt and unexpected onset, the risk of mortality and a loss of control and sense of helplessness (Vilchinsky, 2017). SCAD is no exception. The particular nature of SCAD, which unexpectedly affects younger people often with minimal cardiac risk factor profiles,

makes it a particularly confronting experience, as evidenced by both the SCAD-Insights study and the broader SCAD research (Clark et al., 2021; Murphy et al., 2022; Wagers et al., 2018).

Profound emotional responses after illness events are not confined to the cardiac arena. For example, the literature surrounding rare diseases reports that these patients also experience a range of emotions due to their conditions (Ashtari & Taylor, 2022; Cohen & Biesecker, 2010; von der Lippe et al., 2017). They commonly experience feelings of loneliness, emotional distress, disempowerment, guilt, frustration, fear, anger and loss (von der Lippe et al., 2017). This psychosocial distress is reflected in lower scores on indicators of quality-of-life (Cohen & Biesecker, 2010).

7.3.3 Factors in Uncertainty After SCAD

As the data analysis unfolded, it became increasingly evident that the emotional responses and the mysterious nature of SCAD suggested the applicability of the Uncertainty in Illness model (Mishel, 1988). Participants in the SCAD-Insights study began their experience with a set of pre-conceived ideas about health, their own health and their social roles. They viewed themselves as healthy, and because they were younger to middle age, they were carrying out the typical responsibilities of that age group, including family care and career. The symptoms of SCAD (e.g., the onset of chest pain) were unexpected, unfamiliar and of an unknown cause.

According to Mishel's theory, uncertainty in illness is characterised by the inability of a person to make meaning of an illness event (Mishel, 1988). Uncertainty affects people across many different illnesses and is a factor that causes stress to those suffering from a life-threatening illness (Giammanco et al., 2015). Uncertainty can be linked to negative psychosocial outcomes, such as anxiety and depression, and it can negatively affect quality of life (Giammanco et al., 2015). For example, for people after a cardiac event, uncertainty has

been related to lower quality of life for both them and their carers (Giammanco et al., 2015). Mishel's theory of Uncertainty in Illness accounts for the factors that affect a person's ability to comprehend, respond to and make judgements regarding their illness event. The ways in which an illness event unfolds influence whether uncertainty develops. If symptoms do not present in a recognisably consistent manner, and if the event situation is unfamiliar and the events do not fit within expected norms, then uncertainty can develop (Mishel, 1988).

These factors include the person's educational level, the availability of social supports and the cognitive ability of the person to process information about their diagnosis (Mishel, 1988). Profound emotional responses, including shock, pain, discomfort and fear, as described by the SCAD-Insights study participants, are well known to reduce the person's cognitive ability to process cues, thus, increasing the risk of uncertainty (Mishel, 1988). Negative psychological reactions, including shock and fear, can limit the ability of the person to absorb and process information in the acute stages of a cardiac event (Greco et al., 2016). Many of the SCAD-Insights study participants recalled a sense of feeling shocked upon hearing they had been diagnosed with SCAD, and a few spoke of their inability to take in information or make decisions in the acute stages of their SCAD experience.

Within the rare disease literature, research shows that the psychological effects of illness are related to a lack of knowledge of and uncertainties about many aspects of the experience. This includes uncertainty about the future and specific uncertainty about the treatments, prognosis and management of the condition. Additionally, there is uncertainty regarding healthcare professionals' knowledge and, therefore, their ability to treat and manage the condition (von der Lippe et al., 2017).

The study participants, and those in other SCAD research (Clark et al., 2021; Murphy et al., 2022), recalled healthcare professionals telling them that SCAD is not well understood,

has no real treatment options and that there is the possibility of recurrence and even death. The outcomes after SCAD were perceived by participants as unknown and unspecific.

In addition, SCAD is an overwhelmingly female heart condition and is understood as being gendered by people after SCAD. This was particularly felt by both male participants in the present study, who expressed consternation at suffering from what is perceived to be a female condition. For both men, gender was an extra dimension that added to their uncertainty after their SCAD event.

7.3.4 Perceived Lack of Information Affects Emotional Responses

Information about SCAD provided to the SCAD-Insights study participants was perceived to be limited and inadequate. Not only did the study participants want to understand what SCAD is, they also reported that they needed to know why it happened. They reasoned that if they knew why it had happened, then they could better manage their health in the future and prevent any recurrence.

Many participants in the SCAD-Insights study indicated that they were given some information about the pathophysiological processes involved in SCAD. However, the information provided to the participants did not address the mystery surrounding SCAD. They perceived the information concerning why SCAD had happened, what the psychosocial effect(s) could be and how the diagnosis could affect their future recovery and life to be poor in quality and quantity. Some participants reported that the effect of profound shock and fear from the diagnosis was not taken into consideration by healthcare professionals. Other study participants recalled being sent home with perceived minimal support, while many were given lifestyle limitations (e.g., lifting nothing heavier than 10kg) that did not reflect their individual lifestyle needs, such as work or child care. People after SCAD reported feelings of frustration and exasperation due to the lack of knowledge about SCAD among healthcare professionals.

The perceived lack of information reported by participants in this study, and in the literature (Bouchard et al., 2021; Clark et al., 2021; Murphy et al., 2022), is in part accounted for by the actual paucity of knowledge about SCAD. SCAD was first described in 1931, but only since the wider use of coronary angiography and the recent advent of intra-vascular imaging technology has SCAD diagnosis been possible (Franke et al., 2019). Moreover, knowledge about SCAD is potentially hampered in the context of gender bias in cardiovascular research. Women have not traditionally been included in cardiovascular research (Jin et al., 2020). In addition, without accurate diagnosis, its inclusion in research will necessarily be lower. Diagnosis of AMI in younger women is known to be subject to gender bias; testing of cardiac biomarkers and coronary angiography in younger women is performed less frequently than in men (Amrani-Midoun et al., 2021). Further, much of the current understanding about the outcomes after SCAD has been based on single-centre case series and limited to biomedical data such as mortality and morbidity rates, which do not fully capture people's experiences after AMI (Murugiah et al., 2022). Outcomes after SCAD, such as quality of life, are important to people but have been less well reported in the literature (Murugiah et al., 2022).

Recommendations based on recent research into SCAD provide advice for clinicians regarding medical treatment, such as revascularisation, in addition to exercise and follow-up (Garcia-Guimarães et al., 2020). While it has been suggested to refer people after SCAD to support groups (Kim, 2020), little additional advice regarding education provision has been made available to clinicians.

Study participants who had had their SCAD event more recently reported that their healthcare professionals at the time of diagnosis had some knowledge about SCAD, and that they had received some education. Importantly, two study participants reported they had received SCAD-specific patient information brochures. These brochures were produced by a

SCAD patient advocacy group. Nevertheless, all study participants reported that they perceived the information they were provided to be inadequate for their needs. Frustration was sometimes expressed in response to inappropriate or generic information material provided.

All study participants reported searching on the internet for additional information about SCAD in an attempt to remedy the lack of information they received. This is consistent with the research that shows people after SCAD report a lack of information. Clark et al. (2021) described that people were 'swirling in an information vacuum' after SCAD.

7.3.5 Search for Information

The participants' dissatisfaction with a perceived lack of information and uncertainty about SCAD mirrors the current research regarding peoples' information needs in recovery from AMI generally. Despite the evidence that the delivery of appropriate health information is associated with reduced levels of psychological distress, improved patient satisfaction and perception of control, people continue to report that they are dissatisfied with the information they received and reported unmet information needs (Greco et al., 2016). In addition, clinicians do not consistently appreciate cardiac patients' need for information, nor how these needs change over time (Greco et al., 2016). Learning needs after AMI change over time with disease progression and are influenced by the person's individual 'cultural and spiritual traditions' (Huriani, 2019, p. 295).

Rather than being provided standardised patient information pamphlets, people after AMI want information tailored to their needs (Decker et al., 2007). People after a cardiac event prefer educational materials that contain 'actionable, concrete and detailed' health messages, but material is of a 'one size fits all' nature (Vosbergen et al., 2014, p. 640). In health conditions where the onus of day-to-day management lies with the person, and the ramifications 'pervade' everyday life, a 'one size fits all' approach cannot be sufficient

(O'Kane et al., 2016, p. 495). This was echoed by the SCAD-Insights study participants, in particular, those who had received SCAD-specific material but considered the provision of this information to be a 'tick-box' exercise rather than a true patient-centred collaboration.

Taking the Search for Information Online

Initial information about SCAD was provided to study participants in the acute phase after SCAD, where they were under stress, in shock or in pain. Study participants wanted to understand more clearly how SCAD had happened and wanted additional detailed information about how they could recover. For this information, they turned to the internet.

The collection of information from clinicians about a medical condition can be time-consuming and require effort, and it usually only occurs within the confines of an appointment (O'Kane et al., 2016). Under these circumstances, people will search for information outside the clinician–patient relationship and will do so in a way that is more accessible. However, the accessibility of self-acquired information may come at the cost of reliability (O'Kane et al., 2016). Clinicians are aware of people's information-seeking on the internet and actively manage their patient's internet searches by warning them of misinformation and guiding them towards more useful content (Timmermans, 2020). The use of online material can be used to complement rather than replace clinician expertise (Timmermans, 2020).

7.4 Recovery: Negotiating Life After SCAD

Participants in the SCAD-Insights study described the ways in which they responded to this life-changing event and adapted to life after SCAD. How recent the SCAD event was varied from 6 weeks to 8 years. Thus, the SCAD-Insights study presents findings on their perceptions and reflections at different points on the SCAD recovery trajectory. Study participants with more recent SCAD, while still coming to terms with the emotional effects,

were hopeful they would recover with the passing of time. Participants with more historical SCAD reflected that they had indeed recovered, and, in many cases, SCAD had acted as a catalyst for making meaningful lifestyle changes.

The participants' relationships with their healthcare professionals, particularly their cardiologist, were reported to be of importance to recovery. Seeing evidence of healing provided by a second angiogram helped those participants who had received this investigation. CR was not offered to all participants, and although it generally benefitted those who did attend, participants made several important criticisms of it, most notably, the lack of tailoring the CR programs to their needs.

Nevertheless, study participants described their recovery trajectories as isolated. A perceived lack of coordinated recovery supports meant they felt they had to manage their recovery pathways alone. Many participants recognised that recovery would occur over time, and they described relying on their perceived personal strengths.

7.4.1 Using Personal Resources and Evidence to Recover

Because uncertainty in illness is inherently characterised by ambiguity and a lack of clarity, there is a potential for many different conclusions to be drawn, which allows people to frame their own responses and their own paths to recovery (Mishel, 1990). Uncertainty can be perceived as a threat or as an opportunity; people can take action using their own toolkit of coping mechanisms (Mishel, 1988).

The participants in the SCAD-Insights study described relying on their self-declared inner abilities, such as stoicism, optimism and, in one case, faith, as ways of coping. Some mentioned a refusal to adopt the victim role, and many spoke of their self-advocacy. Language such as 'survival mode' and 'pushed through' were used by participants. Such personal characteristics were thought by study participants to have made a valuable contribution to a reduction in their sense of uncertainty and an increase in their confidence in

their recovery. Similarly, it was noted by Petriček et al. (2015) that after AMI, a person's personality characteristics, for example, optimism and hopefulness, were important factors in 'facing up to' their health condition (p. 23).

7.4.2 Managing Mystery: Patient–Provider Relationships and Uncertainty After SCAD

Many participants in the SCAD-Insights study spoke of the importance of their cardiologist to their recovery. They spoke of the need for their treating healthcare professional to have specialist knowledge about SCAD. Some participants expressed a lack of trust in cardiologists or healthcare professionals who did not know about SCAD, and they were willing to search for a cardiologist who understood it.

In the acute phase after SCAD, study participants were reliant on their healthcare professionals for medical advice and depended on being informed about SCAD by their clinicians. Such a reliance gradually subsided as they negotiated their recovery, although some study participants who were managing ongoing symptoms continued to require support from their healthcare professionals. Participants in the SCAD-Insights study who required ongoing investigation described that having tangible evidence of healing assisted in their recovery. Similarly, people after AMI in a separate study noted that diagnostic tests helped them come to terms with their health; a person's subjective responses could be placed within objective findings (Petriček et al., 2015).

The experience of AMI generally can be understood as 'nonlinear'; that is, recovery stages overlap until gradually the person comes to a degree of acceptance (Petriček et al., 2015). In the early stages after an AMI, people feel dependent on their treating healthcare professionals and report a sense of security within the hospital and a sense of trust in the healthcare professionals (Petriček et al., 2015).

Power imbalances observed in the healthcare professional – patient relationship have been critiqued, particularly from a feminist research perspective, and there have been calls for

more recognition by the healthcare system of the knowledge people bring to their illness experience and recovery and respect for the person's autonomy (Mead & Bower, 2000). Within the dimensions of the PCC model, people progress from relying on healthcare professionals in the acute phase, particularly on their clinical expertise, to becoming experts in their own condition (Mead & Bower, 2000). However, despite the emergence of the 'expert patient', particularly in rare conditions, a power imbalance remains: patients are not yet fully independent of healthcare professionals because they are still not as knowledgeable as their clinicians (Timmermans, 2020, p. 259).

However, in addition to the need for SCAD knowledge from their healthcare professionals, the current study's participants stated they wanted care and support. They accepted the honesty of healthcare professionals who admitted their lack of knowledge about SCAD and preferred a relationship with their providers based on openness and respect. The need for healthcare professionals to display caring and empathic behaviour has been borne out in literature examining care after cardiac events and PCC more broadly: undoubtedly, this is what people want from their healthcare professionals (Borracci et al., 2015; Rapport et al., 2019; Reid et al., 2022). Greater patient satisfaction resulting from empathy from clinicians is associated with healing (Borracci et al., 2015).

7.4.3 Managing Mystery: Participation in CR After SCAD

Attendance at and participation in CR was an important recovery strategy detailed by the SCAD-Insights study participants. Not all study participants were referred to CR. Some participants recalled being told by healthcare professionals it may not be beneficial. Other study participants reported their belief that referrals to CR came too late. These participants reported that they had to take action themselves to rectify this and obtain the physical and emotional support they felt they needed. When reflecting on their recovery, some study participants made no mention of CR at all.

Those who did attend CR found it helpful to their confidence and recovery after SCAD. However, all study participants reported a perceived lack of tailoring to their individual needs. They reported a sense of not fitting in with the predominately older male CR cohort. Additionally, participants felt themselves distinct by virtue of being the only person with SCAD in attendance.

Research pertaining to people with SCAD attending CR is limited, but it has demonstrated that the provision of tailored CR support within standard CR programs was safe and beneficial, which was shown by a reduction in negative mental health indicators (Krittanawong et al., 2016). Expert opinions on SCAD management options recommend that people participate in a CR program, in particular, to manage their psychological distress and ongoing physical symptoms after their SCAD event (Hayes, 2014). One study of a dedicated CR program for people with SCAD (n = 70) has also been published (Chou et al., 2016). This program was adapted from a standard CR program to provide additional psychosocial support and peer support (Chou et al., 2016). Improvements in mental health indicators and reduced cardiac symptoms following SCAD events were reported (Chou et al., 2016).

Some study participants reported that the healthcare professionals providing their rehabilitation did not know about SCAD. In addition, some female participants chose not to attend the CR education sessions due to other priorities, such as work or childcare requirements. Such factors are well known to negatively affect women's attendance at CR (Supervía et al., 2017). In contrast, the two male participants in the present study reported particularly positive accounts of their experience in CR. This corresponds with research that suggests men prefer gym-based exercise (Hanson et al., 2021), which is the predominant mode of exercise in CR programs (Neubeck et al., 2022). Despite any misgivings, the study participants who attended CR endorsed it as an important recovery option after SCAD to all people who may experience SCAD in the future.

The management of cardiac distress is a recommended focus of CR. Australian CR guidelines recommend that CR should facilitate people returning to or even improving their baseline 'everyday functioning' (Woodruffe et al., 2015, p. 431). Education and support should be tailored to the individual and include a referral for additional support if required (Woodruffe et al., 2015). CR directly following the acute phase of the condition is the 'right moment' for psychosocial intervention (Chauvet-Gelinier & Bonin, 2017).

However, as Rao et al. (2020) reported, while efforts have been made to integrate psychological health management within CR programs, widespread changes in the delivery of such support have not yet been achieved. Psychosocial management strategies such as stress management and relaxation techniques are often included in CR, but attendance and adherence to CR are suboptimal (McPhillips et al., 2019).

People attending a CR program who fulfilled the criteria for anxiety, depression, or both, reported negative psychosocial outcomes (McPhillips et al., 2019). People sought reassurance that they could return to normal (McPhillips et al., 2019). There were also reports that CR staff were less accessible due to workloads or that the introduction to and commencement of CR came 'too late' (McPhillips et al., 2019, p. 11).

7.4.4 Lack of Knowledge in the Public Domain

Concerns were expressed by study participants that there is a lack of knowledge about SCAD in the wider community. SCAD-Insights study participants reported that their primary healthcare practitioners did not know about SCAD, which prompted concerns about their ongoing day-to-day management after SCAD. Further, awareness about SCAD in the general community was reported by study participants to be non-existent. No family members, friends or community contacts knew about SCAD. The participants reported that this lack of knowledge about SCAD, including their general practitioners and the wider community,

contributed to their distress after their SCAD event and their sense of being alone in their recovery.

In the literature, people after SCAD report becoming fearful and anxious when faced with a perceived lack of knowledge to guide treatment or when there is conflicting advice from healthcare professionals (Tweet et al., 2011). People after SCAD report that the lack of awareness about SCAD contributes to the isolation they feel (Bouchard et al., 2021; Murphy et al., 2022). Increasing public awareness about SCAD is identified by people after SCAD as a priority (Dang et al., 2023). The frustration people after SCAD feel is reflected in the wider rare disease literature. People with rare diseases become frustrated when they are unable to find peers who can understand their situation or when their treating healthcare professionals have minimal or no experience with their particular condition (Gaddy & Topf, 2021). Having to frequently explain their condition to new clinicians or community contacts reinforces a sense of frustration and isolation (Gaddy & Topf, 2021).

In response to this lack of knowledge in their communities, the SCAD-Insights study participants described how they became informal educators. They spoke of distributing information they had obtained from their own internet searches to their family members, friends and local healthcare clinics. The study participants circulated information to increase awareness within their local communities to allay misinformation and increase the general knowledge of SCAD to benefit people who may experience SCAD in the future. Patient groups play an important role in increasing awareness of their condition across the general community. For example, SCAD Research Inc Australia collates all media reports about SCAD, some of which they have guided themselves (SCAD Research Australia Inc., 2023).

In the context of limited government support for research generally and specifically for funding rare conditions (Pinto et al., 2016), this increased awareness has the added benefit of increasing the ability of patient organisations to raise money for research. Non-profit

community support groups have become important in initiating and progressing research, in addition to patient support (e.g., cystic fibrosis support groups; see Pinto et al., 2016). Similarly, SCAD patient groups are heavily involved in the funding and production of SCAD research (Tweet et al., 2011) and in the provision of support to people after SCAD (SCAD Research Inc Australia, personal communication, 2023).

7.4.5 Family and Relationships After SCAD

The SCAD-Insights study revealed information regarding the ways in which the participants' SCAD experience affected their relationships and interactions with others, including family members. The emotional upheaval after SCAD resonated through participants' families and social circles. Most study participants reported that their partners, family members and friends experienced similar feelings of shock and overwhelm in the immediate aftermath of their SCAD event in a way similar to the participants themselves.

Lack of Support

A number of study participants, including both men, praised the support they received from their partner or family. However, some participants noted that, over time, the family and friends they usually relied on for social support could be unhelpful. They described feeling that others did not understand what they were going through. Participants talked about having an invisible condition and having to carry on despite challenges, including emotional changes and fatigue. Because they did not look ill, other people did not view them as having been affected by their illness experience over the long term.

Female study participants felt they had to return to the full capacity of their previous roles, particularly as mothers and partners. The literature on women and AMI describes the effect of women's social roles, particularly as family-oriented and caring, on recovery from AMI (Galick et al., 2015; Smith et al., 2017). Women report being disappointed by a lack of

emotional and practical support from family members after their AMI, having a fear of being a burden to others and an inability to find time to care for themselves (Galick et al., 2015). Women after AMI report that they maintained their caring role within their families and continued to focus on supporting others despite their health challenges (Smith et al., 2017).

Intimate Relationships After SCAD

Sexuality is an important aspect of overall quality of life (Boothby et al., 2018). Only one participant spoke directly, albeit briefly, about the effect of SCAD on their sex life, and another hinted at changes in her marital relationship. Another participant spoke of her challenges in the dating scene and having to decide whether to tell someone she had a SCAD event and risk rejection or stigma. The existing SCAD literature gives some information about future pregnancies after SCAD for those affected by it during the peripartum period (Hayes et al., 2020); however, no research regarding the effect of SCAD on sexuality was discovered during a review of the literature (Turner et al., 2023). There is research regarding the effect of heart disease generally on people's sex lives and on people's need to discuss sexuality after a cardiac event as part of their CR program (Abramsohn et al., 2013; D'Eath et al., 2013). This is an area of potential future research into the patient experience after SCAD.

Parenting After SCAD

The majority of SCAD-Insights study participants were parents. Participants who were parents of older children recalled that their children were shocked by the event but had since recovered. Some of these older children supported their parent in maintaining a healthy lifestyle. Some of the mothers of teenage children described that they felt their children had the expectation that they would continue mothering as normal, and this expectation created a physical and emotional burden on these mothers.

Two study participants with younger children spoke of the ways they felt the SCAD event had affected their children and themselves as mothers. They described the physical and emotional challenges they faced in caring for young children after their SCAD event; one participant in particular described the distress she felt that her role as a mother had changed. Research conducted into chronic illness and the experiences of motherhood reports that emotional distress arises when symptoms of illness affect their ability to carry out mothering tasks (Parton et al., 2017; Vallido et al., 2010). 'Disrupted mothering' occurs when mothers perceive that their life as a mother is 'disordered', and they experience guilt and distress (Vallido et al., 2010, p. 1436). Resources such as social support can help manage the disruptions that illness brings (Parton et al., 2017). The SCAD-Insights study participants described a reliance on family support to help manage the disruption to their mothering role but also reported feeling alone and distressed by being unable to perform their mothering role. Contrastingly, the male participants in the SCAD-Insights study, who both were fathers, reported no such disruption to their parenting role.

7.4.6 Seeking Normality: Returning to Work After SCAD

The study participants also spoke of their return to work and of managing changes to their work conditions. Return to work pathways varied: many participants took leave to recover, some took retirement, and others used their SCAD event as a catalyst for changing jobs or retraining for new roles. Having limitations on lifting after SCAD was a consideration for some participants returning to work. Some participants described reducing work stress as an important factor for them when considering their return to work. Both male study participants described that they were able to return to their work and social roles relatively seamlessly.

The experience of the study participants returning to work reflects that of other SCAD research that reports a reduction in employment hours or leaving employment altogether

(Bouchard et al., 2021). Bouchard et al. (2021, p 474) also note that people after SCAD seek a reduction in caregiving responsibilities to further reduce lifestyle stress. Contrastingly, this was not reported by any of the participants in the SCAD-Insights study.

Women are less likely than men to return to work after AMI in the context of high stress burden, lower quality of life and caregiving demands (Dreyer et al., 2016). However, strategies such as reducing employment hours or caregiving responsibilities may not be options open to all people after SCAD. Participation in work is an important aspect of well-being, and people living with CVD generally report a lack of advice regarding their return to work and a lack of access to 'work-related' health care, which together create barriers to a successful return to work (Hagendijk et al., 2023, p. 2). People with CVD report their need for a tailored approach to work-specific education and management (Hagendijk et al., 2023).

7.4.7 A New Identity After SCAD

Several SCAD-Insights study participants, particularly those with more historical SCAD, spoke about how their lives had changed for the better after SCAD. They described forming a new identity. This identity might be symbolised publicly by having a tattoo or by adopting a social media profile including the descriptor 'SCAD survivor'. Others adopted the new role as informal educator and mentor.

The concept of illness perception pertains to how people view their health condition and its associated treatments and indicators, such as quality of life (Van Bulck et al., 2018). Illness identity builds on illness perception to consider how the health condition has affected the person, how they think of themselves and the extent to which that health condition is integrated into their identity (Van Bulck et al., 2018). Illness challenges a person's understanding of their identity and their ability to reclaim their sense of self (Oris et al., 2018).

In processing this challenge, four identity states have been described (Oris et al., 2018). The first is the illness identity state of engulfment, where the person's life is dominated by the event (Oris et al., 2018). This was commonly reported by participants who had a recent SCAD event. These participants described their feelings of shock and overwhelm and a desire for more information to try to make sense of what happened. Second is the illness identity state of rejection, which refers to the rejection of the illness as part of the person's identity (Oris et al., 2018). While a few participants questioned their diagnosis, all study participants focused on increasing their understanding of SCAD and described their search for management options to avoid recurrence; these are not signs of rejection. The concept of rejection encompasses the neglect of the illness to the point of treatment non-adherence (Oris et al., 2018).

The third state, acceptance, refers to the extent to which a patient can accept the illness as part of their identity without being overwhelmed (Van Bulck et al., 2018). The final state, enrichment, pertains to the ways in which people feel that their illness has changed their outlook and that they have grown through their experience (Van Bulck et al., 2018). Both acceptance and enrichment were observed in the SCAD-Insights study participants who had their SCAD event more than a year prior to their interview. These participants described coming to terms with their SCAD event and, in doing so, forged new identities. SCAD acted as a catalyst for some participants to change their life, for example seek a new job, or make decisions to act in new ways, thus enriching their life.

7.5 Engagement with Online SCAD Support Groups

7.5.1 PCC and Online Groups

When the development of patient and healthcare movements began in the 1970s, laypeople had limited access to medical knowledge (Lupton, 2013). The PCC model

developed from ideas borne of these patient movements (Langberg et al., 2019; Mead & Bower, 2000). Around the year 2000, various PCC models, including the US Institute of Medicine model, were formalised (Langberg et al., 2019), as was the Mead and Bower PCC framework adopted in the SCAD-Insights study (Mead & Bower, 2000).

With a major focus on how healthcare professionals should practise, the PCC model considers the dimensions of patient-centredness as occurring within the formal healthcare system. Over recent decades, there has been a widespread adoption of the concept of PCC within healthcare systems, particularly as an indicator of quality. Simultaneously, there has been a revolution in society at large with the development of the internet. With the introduction of social media platforms such as Facebook in 2004, there has been a proliferation of patient groups across illness conditions (Gaddy & Topf, 2021).

Of the five dimensions of the PCC model, those of biopsychosocial, patient-as-person and doctor-as-person are easily applied (Mead & Bower, 2000). For example, SCAD-Insights study participants described that while biological explanations were provided, there was a need for the recognition of the psychosocial effect of SCAD, which reflects the biopsychosocial dimension of the model. They also spoke of their personal contexts and responses to their SCAD event, which reflects the patient-as-person dimension. Additionally, the doctor-as-person dimension was shown by the ways in which healthcare professionals played a role in the participants' recovery after SCAD, with its emphasis on the importance of the individual characteristics of the healthcare professionals involved in patient care.

The remaining dimensions of the PCC model, the therapeutic alliance and sharing power and responsibility, are less easily applied to the SCAD-Insights study. The dimension of the therapeutic alliance is envisaged as that of an egalitarian healthcare professional – patient relationship characterised by respect, active involvement in decision-making and patient empowerment (Langberg et al., 2019, p. 1231). Given the preponderance of online

support groups, this professional–patient relationship is no longer the only alliance that can form, nor is it even the most important one. The SCAD-Insights study participants were generally content with the relationships they had with their healthcare professionals, but despite this, the support they obtained from within the SCAD online support groups was reported to be of major importance to their recovery.

The SCAD-Insights study participants described their recovery trajectories as lonely. They described a reliance on perceived personal characteristics and interactions with peer support groups after SCAD. The PCC dimension of sharing power and responsibility depends on the provision of information to the patient that can enable active decision making (Langberg et al., 2019). In addition to the 'competence gap' between patients and their healthcare professionals (Langberg et al., 2019, p. 1229), the SCAD-Insights study participants all reported their dissatisfaction with the amount of knowledge they received, and that the information they did receive was inadequate for their needs, in particular, for planning their recovery. This too was addressed by recourse to online support groups. In light of these developments, the PCC model needs to take the patients' online experience into account when delivering care.

7.5.2 SCAD-Insights Participants Online

All participants in the SCAD-Insights study were members of online SCAD support groups and had joined these groups in the immediate aftermath of their diagnosis. In particular, study participants felt a lack of support after their SCAD event. This led to them relying on online support groups for information and emotional support. Study participants' involvement in online peer support groups was described as one of the most valued supports for SCAD recovery. Study participants described that membership of online support groups was very important in alleviating the sense of loneliness that had overcome them in the immediate aftermath of SCAD. There was a sense of validation that came from reading other

people's stories, and it was beneficial for participants to meet others who knew what they were going through.

Both membership of and participation in online communities and groups have been shown to empower people across a variety of illnesses. Research regarding the membership of online support groups demonstrates that there is a reduction in feelings of loneliness (Ashtari & Taylor, 2022; van Uden-Kraan et al., 2009). In cancer support groups, emotional support, a decreased sense of isolation and an increased sense of hope are reported by group members (Delisle et al., 2017). Members of cardiac patient support groups report benefits from speaking to others with similar experiences (Junehag et al., 2014). Group members can learn how to cope with the various challenges that illness presents from their peers (Delisle et al., 2017; O'Kane et al., 2016).

Information about illness conditions obtained from clinicians alone is perceived as inadequate by people in their quest to validate normality (O'Kane et al., 2016). Research demonstrates that people seek to compare their experiences with others and use this comparison to understand what is normal (O'Kane et al., 2016). Patient-generated information can assist others to compare their symptoms and triggers to that of their peers (O'Kane et al., 2016). People are then able to combine their own health data, information about the condition and peer experiences to make meaning of their own experience and answer questions such as 'is my experience normal?' (O'Kane et al., 2016, p. 494).

In response to the uncertainties surrounding an illness and the challenge of being able to make meaning of the circumstances, people are drawn to making comparisons with others in the process of social comparison (Tennen et al., 2000). Comparison with others is a method by which people can self-evaluate (Corcoran et al., 2011). Making upward comparisons—comparing oneself with others perceived to be 'better'—can provide motivation, while downward comparisons—comparing oneself with others with lower

performance—can enhance a person's self-view (Corcoran et al., 2011). Making upward comparisons in illness support groups can provide hope and role-modelling but can also have a negative effect on self-esteem if they are not progressing as well in recovery (Malloch et al., 2023). Downward comparisons, by contrast, can assist in coping with illness by way of seeing others as 'worse off' (Corcoran et al., 2011). The SCAD-Insights study participants described both experiences during their involvement in online support groups. They reported feeling a sense of hope that they could recover and a sense of gratitude that they were doing well in comparison to others.

The support environment evolves as a community member's needs change; people might leave the environment due to a bad experience or if their needs for support change (Frohlich, 2014). The SCAD-Insights study participants also revealed some negative aspects related to their memberships of online groups. In some cases, being exposed to stories about others' negative health outcomes increased their fears and anxieties about their own SCAD recovery. Several participants raised concerns about the accuracy of information being presented by group members, while others noted that they were unhappy with the negative attitudes of other group members. Such negativity was understood as inimical to a positive mindset for recovery after SCAD. Several participants reported they had reduced their participation in the group due to these perceived disadvantages. Some reported that they had subsequently returned to the group feeling they had recovered and could act as mentors to the newer members.

Research regarding the disadvantages of online support groups describes concerns around the excessive volume of information, the veracity of information and privacy concerns (Ashtari & Taylor, 2022; Moorhead et al., 2013; van Uden-Kraan et al., 2008). Privacy concerns were not raised by the SCAD-Insights study participants; however, members of social media groups may be unaware of the risks involved in sharing personal

information (Moorhead et al., 2013). Only a few participants raised concerns about the quality of information provided in the group, but they were confident they could critically assess information and manage their participation accordingly.

7.6 Strengths, Limitations and Future Research

This study has contributed to our understanding of the multifaceted patient perspectives of their experiences after a SCAD event. It is the author's understanding that this is only the second qualitative study researching the patient experience after SCAD conducted in Australia, and the first was published while the SCAD-Insights study was underway.

As reported in Chapter 2, there remains a limited number of qualitative papers reporting on the patient experience after SCAD. The current research describes a profound emotional response after SCAD and widespread dissatisfaction due to a perceived lack of information that contributes to ongoing uncertainty. Online communities are described, but a detailed examination of membership of these support groups is in its early stages. The perspectives of family members, caregivers and men with SCAD are lacking.

While the SCAD research community recognises the need for such research, most existing studies are case reports and investigations of the physiological aspects of SCAD (Saw et al., 2019). In the current study, the research design of semi-structured interviews in the context of such a paucity of information and from the inclusive position of a social constructionist feminist perspective (Wigginton & Lafrance, 2019) allowed participants to share their experiences freely. Themes generated from the data contribute to a deeper understanding of the SCAD patient experience, which, in turn, provides valuable information to the SCAD community and the healthcare professionals caring for people after SCAD.

The inclusion of participants at various time points since their initial SCAD event enabled an appreciation of the effect of time on their perspectives and the changes that have

been made to SCAD management over time. For example, healthcare professionals do now understand more about SCAD and can provide some education to their patients, and online supports have proliferated over the last decade. Importantly, we learnt how people report negotiating their recovery over time.

Study participants were recruited solely from the SCAD Research Inc Australia public Facebook group and its associated private Facebook group for SCAD survivors. If participants are active in an online forum, they might be more responsive to contributing to research. In addition, several study participants were from healthcare and research professional backgrounds, so they may be more responsive to participating in research. Murugiah et al. (2022) note that their SCAD sample had a higher education and higher family income than the general population and were more likely to be working full-time and, as such, may be more likely to participate in research.

While two participants had one-year-old babies at the time of their SCAD event, the PASCAD definition is limited to the period between the third trimester to 200 days postpartum (Havakuk et al., 2017). The SCAD-Insights study, therefore, did not include any participants with PASCAD. While SCAD may account for 1–4% of all AMIs, up to 43% of all pregnancy-related AMI are attributable to SCAD (Franke et al., 2019), which represents 5–17% of SCAD cases overall (Hayes et al., 2020). Given these numbers, it was hoped that PASCAD survivors might have volunteered to participate. However, women with cardiac disease post-partum are typically psychologically distressed and may participate in their own specific support groups that can fulfil their needs for connection (Hutchens et al., 2022).

In addition, the study included two male perspectives of the SCAD patient experience. In keeping with the inclusivity inherent in feminist research, all survivors were welcomed. As men with SCAD present with different precipitating factors than women (Fahmy et al., 2016) and may have different post-SCAD experiences, the inclusion of men in

SCAD research is recommended. It is notable that the inclusion of two male participants of a total of 17 study participants is roughly commensurate with the general sex proportions in SCAD (Franke et al., 2019).

An additional intent of the study was to capture the voices of the families and carers of SCAD survivors. The literature review demonstrated that in addition to the paucity of qualitative research on the patient experience of SCAD, the voice of family members and carers was absent. Study participants were asked at interview if they had a family member or carer who would be interested in participating, but none followed-up with the researcher. Although participants discussed their perspectives on the effect of SCAD on their relationships, the voices of family members and carers were not captured. Qualitative research focused on the experience of family members and carers, from their own perspectives, would help to clarify their needs and elucidate their perspectives on the effect of SCAD on families.

7.7 Conclusions and Recommendations

The SCAD-Insights study provided a view into the multifaceted patient experience after a SCAD event. Study participants generously shared stories about their experiences from the onset of symptoms and diagnosis with SCAD along their recovery trajectory. Participants were eager to communicate their advice to benefit people who may experience SCAD in the future. Based on this advice, recommendations arising from the SCAD-Insights study are as follows.

7.7.1 Support to Mitigate Uncertainty

At an individual level, more information must be provided to people with SCAD throughout the illness process. Importantly, the information must be tailored to the individual's needs. The SCAD-Insights study participants spoke strongly about the need for

increased education, not only about SCAD as a pathophysiological problem, but also more education about what to expect on their journey through the hospital system, what the psychosocial effects might be and what supports are available. Given the influence of online support groups, education regarding assessment of the quality of online information is vital.

In the spirit of PCC, an individual patient should be understood as a unique person with a unique background and needs. Careful assessment of the individual patient's needs must follow, and careful attention must be paid to communication (Borracci et al., 2015). Acute-care cardiology departments must increase their activism to ensure adequate levels of staff with the appropriate skill sets to provide best-practice care and education. Achieving this will allow healthcare professionals the time they require to provide appropriate individualised patient care.

7.7.2 Development of CR Programs to Cater to People After SCAD

CR services must adapt to provide appropriate services to people after SCAD. CR is a cost-effective service, and poor participation may result in avoidable harm (Driscoll et al., 2020). The relatively low numbers of people with SCAD may not make SCAD-specific CR services feasible (Bouchard et al., 2020), especially in light of research that suggests that women generally need different types of services in CR programs than men (Neubeck et al., 2022). One option to increase the feasibility of SCAD-specific CR programs could be the introduction of telehealth CR programs specifically targeted to people after SCAD. Telehealth CR programs were successfully instituted during the COVID-19 pandemic (Neubeck et al., 2020).

The SCAD-Insights study participants observed the need for a tailored approach within CR programs, including the need to provide psychological and peer support and support for their family members; this is echoed in the current SCAD literature (Binnie et al., 2023; Bouchard et al., 2021; Murphy et al., 2022). A tailored approach to management is

important given the low feasibility of providing a SCAD-specific service to a small group (Bouchard et al., 2020), particularly for those who do not have access to a major SCAD referral centre. A tailored approach could also incorporate resilience training; people with SCAD with higher resilience had lower rates of anxiety and depression (Johnson et al., 2020). A Cognitive Behavioural Therapy-based program was also beneficial for people after SCAD (Vaca et al., 2021).

7.7.3 Support for Families and Caregivers After SCAD

Research into the family member and caregiver perspectives after SCAD is needed. Family members and caregivers require additional support in managing their own responses after a life-threatening event and in the longer term to provide the support that people after SCAD indicate is needed.

7.7.4 Education and Training of Health Professionals

The SCAD-Insights study participants advocated for increased education for existing and future healthcare professionals, especially those working in the field of cardiology and primary care settings. Healthcare professionals must be equipped with knowledge about SCAD and the psychosocial support needs of vulnerable patients experiencing unexpected life-threatening events. In addition, testimony from the SCAD-Insights study participants, stressed that healthcare professionals require education and training to address shortcomings in delivery of PCC after SCAD.

7.7.5 Health Provider Engagement in Online Support Groups

Healthcare professionals working with people after SCAD have indicated that online social support groups would ideally be an additional source of support to formal, professionally-delivered supports to allay problems with misinformation (Bouchard et al.,

2020). Healthcare professionals, particularly those in CR, could increase their interaction with online patient support groups to ensure the information and support provided by these forums are appropriate and safe for participants. This has been noted in the current SCAD literature (Neubeck et al., 2020). The involvement of healthcare professionals in support groups should be done with a sensitivity towards the group members who may prefer greater privacy or a more patient-led perspective.

7.7.6 Public Awareness About SCAD

Public health campaigns to raise awareness of SCAD in the general public can be integrated into existing campaigns to educate women about CVD generally. Given the life-threatening nature of SCAD, health campaigns regarding minimising delays in seeking medical attention would be particularly valuable. In addition, SCAD awareness campaigns are relevant to post-natal services.

7.7.7 Conclusion

Taken together, these recommendations would increase supports for people after SCAD, and place a greater focus on patient-centred care. In addition, the development of education for people after SCAD and healthcare professionals would be strengthened and tailored to the specific needs of people after SCAD and awareness about SCAD would be increased across the general community.

In the context of limited research conducted into the patient experience after SCAD, the SCAD-Insights study has added to our understanding of this experience. The patient experience of SCAD is characterised by uncertainty, frustration and distress in the aftermath of a SCAD event, exacerbated by the perceived lack of information and supports. Reliance on the internet for information and for support through membership of online support groups

plays a central role in negotiating life after SCAD. The delivery of patient centred care to people after SCAD should be tailored with regard to this experience.

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Appendix 1: Facebook Advertisement



Appendix 2: UTS Ethics Approval

HREC Approval Granted - ETH21-6703

Research Ethics <research.ethics@uts.edu.au>
Tue 15/03/2022 11:29

To: Research Ethics <research.ethics@uts.edu.au>;Michelle DiGiacomo <Michelle.DiGiacomo@uts.edu.au>;Elizabeth Turner <Elizabeth.Turner@uts.edu.au>

1 attachments (319 KB)
Ethics Application.pdf;

Dear Applicant

Re: ETH21-6703 - "Understanding the experience after a spontaneous coronary artery dissection (SCAD) event"

Thank you for your response to the Committee's comments for your project. The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy.

Your approval number is UTS HREC REF NO. ETH21-6703.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.
- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat.
- The Principal Investigator will notify the Committee of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions on how to submit an amendment application can be found here.
- The Principal Investigator will promptly report adverse events to the Ethics Secretariat. An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.
- The Principal Investigator will report to the UTS HREC or UTS MREC annually and notify the Committee when the project is completed at all sites. The Principal Investigator will notify the Committee of any plan to extend the duration of the project past the approval period listed above.
- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).

- The Principal Investigator will notify the Committee of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

This research must be
undertaken in compliance with the Australian Code for the Responsible Conduct of Research
and National Statement on Ethical Conduct in Human Research.

You should consider this your official letter of approval. If you require a hardcopy please contact the Ethics Secretariat.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please don't hesitate to contact the Ethics Secretariat and quote the ethics application number (e.g. ETH20-xxxx) in all correspondence.

Yours sincerely,
The Research Ethics Secretariat

On behalf of the UTS Human Research Ethics Committees
C/- Research Office
University of Technology Sydney
E: Research.Ethics@uts.edu.au

Ref: E38

Appendix 3: SCAD-Insights Study Participant Information and Consent Form

PARTICIPANT INFORMATION SHEET

UTS-ETH21-6703 – Understanding the experience after a spontaneous coronary artery dissection (SCAD) event

WHO IS CONDUCTING THIS RESEARCH?

My name is Elizabeth Turner, and I am a Master of Nursing (Research) student at UTS. My supervisors are Associate Professor Michelle DiGiacomo and Dr Serra Ivynian.

WHAT IS THE RESEARCH ABOUT?

The purpose of this research is to develop a deeper understanding of the experiences of people after they have had a spontaneous coronary artery dissection (SCAD) event. This will provide important insight for the health care system in designing care and programs for people with SCAD.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you have had a medically diagnosed SCAD event and therefore have direct patient experience of SCAD and recovery from SCAD.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate, I will invite you to participate in a one-off individual one-hour semi-structured interview that will be audio recorded with your permission. This interview will be conducted via a scheduled phone call or Zoom video conference call, at a time and place selected by you. The interview will ask open-ended questions about your health, your SCAD experience and what helped or hindered your recovery. About 2 months later, you will be mailed or emailed a summary of your input to check and verify. This checking is estimated to take 20 minutes. A reply-paid envelope will be supplied if required. This checking will also be optional.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there are some risks or inconvenience. Participation in an interview may be inconvenient, however, you will be able to select your time and location for the interview for your own comfort. You may become upset remembering and talking about a past traumatic event. You may feel embarrassed discussing your behaviour or your feelings. You may experience fatigue participating in an hour-long interview.

However, you will be supported during and after the interview. You will be provided with contact details of support services. You will have the opportunity to have phone follow up after the interview to check in. Your participation is valued and provides the opportunity for you to make a contribution to future SCAD patients and their families.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. If you decide not to participate, or to withdraw from the study, it will not affect your relationship with the researchers or the University of Technology Sydney.

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WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

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, by contacting Elizabeth Turner. If you withdraw from the study, your study tapes will be erased, and the transcripts will be destroyed. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. Once identifying features such as your name have been removed, all files will be securely held in Elizabeth Turner's UTS OneDrive account. She is the only person to have access to these files. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. All identifying features such as name will be removed from your transcript and a pseudonym applied.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

The results of this research may also be shared through open access (public) scientific databases, including internet databases. This will enable other researchers to use the data to investigate other important research questions. Results shared in this way will always be de-identified by removing all personal information (e.g. name, address, date of birth etc.).

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think I or my supervisors can help you with, please feel free to contact me at elizabeth.a.turner-1@student.uts.edu.au. You can also speak to a local independent contact, the UTS Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au.

WHAT IF I NEED SUPPORT?

If you feel you require support following the interview or participation has raised issues for you, please feel free to contact me at elizabeth.a.turner-1@student.uts.edu.au. You can also contact

Head to Health
National Heart Foundation on 13 11 12 or
https://www.heartfoundation.org.au

Australian Centre for Heart Health on 03 9445 9296 or
https://www.australianhearthealth.org.au/contact-us

Lifeline on 13 11 14
https://www.lifeline.org.au

Beyond Blue on 1300 22 46 36
https://www.beyondblue.org.au/about-us/contact-us

Your general practitioner

You will be given a copy of this form to keep.

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

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CONSENT FORM

UTS-ETH21-2708 – Understanding the experience after a spontaneous coronary artery dissection (SCAD) event

I _____ *[participant's name]* agree to participate in the research project being conducted by Elizabeth Turner.
Email: elizabeth.a.turner-1@student.uts.edu.au.

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney

I understand that I will be given a signed copy of this document to keep.

I am aware that I can contact Elizabeth Turner, or the UTS Ethics Secretariat if I have any concerns about the research.

_____ ____/____/____
Name and Signature [participant] Date

_____ ____/____/____
Name and Signature [researcher or delegate] Date

Appendix 4: SCAD Patient Interview Guide

Understanding the experience after SCAD

Semi-structured Interview Guidelines for person after SCAD

Greeting:

Researcher: Hello (Participant Name). Thank you for taking the time to participate in this interview today.

Introduction

You've been invited to take part in this interview because you have had a medically diagnosed SCAD event, and as such have direct experience of what this was like and how it impacted your life.

The purpose of this study is to gain a deeper understanding of how people experience SCAD, to write about this experience for the health care community and for this to be used to develop better health care after SCAD.

This interview will run for roughly 60 mins, (or however long we need to explore your experience).

Would it be ok if I audio record the session so I can type out what you said please?

I will also take written notes to record my experience during the interview to assist me with analysing the information later on. Is that ok?

Anonymity:

I want to re-assure you everything you say today will be kept confidential and private. The transcript of the interview will be kept safe with the me on UTS's secure servers in a password protected folder.

Your personal information will be removed from the transcript and replaced with a fake name. Would you like to select your own fake name starting with the letter …?

You can feel free to talk freely about your experiences, feelings and thoughts. You can withdraw at any time, or if there are any questions you feel uncomfortable about, you can choose not to answer.

There are no right or wrong answers, as long as it reflects your personal experience truthfully then it is valuable.

Do you have any questions? If not, we can begin.

Topics:

- SCAD experience

So, to start, Can you tell me about the experience with your heart?

This might include: did you know what was happening, did anyone explain to you, what were you thinking/feeling/doing at the time etc.

- Post-event experience

In what way has SCAD had an impact on your life?

This might include impact on your physical health, emotional wellbeing, psychosocial wellbeing, financial wellbeing, career, etc since the SCAD event.

What impact has SCAD had on how you see your self (identity, self-image etc)?

Do you think your family/carer has been affected by this (SCAD)?

If so, in what way?

- Health services engagement

What treatment/management did you have at diagnosis and following SCAD?

What was that experience like? For you? For your family?

- Recovery experience

What has helped your recovery from SCAD?

What has hindered your recovery from SCAD?

Can you think of any unmet needs in your SCAD recovery?

OR: Thinking about your SCAD recovery, is there anything you would want to be done differently?

What advice, if any, would you give to someone recovering from SCAD?

Wrapping Up:

Is there anything else you'd like to add?

Indicate the next steps: I will transcribe the interview and send you by email (or snail mail with stamped self addressed envelope) a summary of the interview. Please check this summary so that you believe it reflects accurately what we spoke about

Thank you!

Appendix 5: Interview Safety Distress Protocol

Distress and safety protocol for SCAD interviews

Prior to the commencement of the interview:

- The researcher will check with participants that the current time is an appropriate one to proceed based on how they are currently feeling and the availability of a family member, friend or other support person immediately after the interview should they feel the need to do so.
- The researcher will ensure that participants have understood sufficient information regarding the risks and benefits of the research to enable them to make an informed choice about whether they should freely accept or decline participation. This will include details of the kinds of questions that will be asked, the participants' right to choose not to answer any questions they prefer not to and to pause or stop the interview at any time.
- Participants' attention will be drawn to the sources of support identified in the participant information sheet (PIS) should these be required.

Strategies to assist participants who become distressed during an interview.

Should a participant become distressed during the interview, the following actions will be taken by the interviewer:

1. Pause the interview and give the participant time to recover.

2. Remind the participant that (s)he doesn't have to answer any question that causes distress and give the options of leaving the interview to another time or stopping it altogether.

3. Utilise the Subjective Units of Discomfort (SUD) scale to assess participant distress and note the time.

4. Where the participant does not want to continue, spend time with the participant to discuss their concerns and support them.

5. Utilise the Subjective Units of Discomfort (SUD) scale to assess participant distress 10- 15 minutes after the first rating to compare scores.

5. Before ending the encounter, remind the participant of options for seeking support and request permission to call them back the next day to 'check in with them' and (if they have chosen to continue their participation at another time) make arrangements to continue the interview.

6. If permission is granted, call back the next day to check on the participant's wellbeing. Only mention continuing the interview if the participant chose to continue the day before and, even in this instance, check again that the participant wants to continue, explicitly giving the option of discontinuing participation.

After the interview

An additional notification of this information will also be given to those participants should they become distressed during the actual study.

Conclusion

It is the researcher's duty of care to ensure that there is a balance consideration of the benefits against the risks. The research will ensure these strategies are put in place prior to commencing the interviews or discussions.

Participant Distress and Safety Protocol:

Recognise Participant Distress	A participant indicates they are experiencing a high level of stress or emotional distress OR A participant may exhibit behaviours suggestive that the interview is highly stressful such as crying, inability to speak, or shaking.
Step 1	Pause the interview The researcher (who is a health professional) will offer immediate support Assess mental status: Tell me what thoughts you are having? Tell me what you are feeling right now? Do you feel you are able to go on? Do you feel safe? Assess participant score on SUD and record time. Note that 3/10 is rated as 'mild distress'. Assess if participant distress reflects that expected of interview on a sensitive topic, or if participant is in danger
Evaluate effectiveness	Resume interview if participant is willing. Re-assess SUD 10-15 minutes after first assessment. Note that expectation for score to drop by 2-3 points in time frame. Go to Step 2 if participant cannot continue. Go to Step 3 if participant SUD score remains high
Step 2	Discontinue the interview Provide advice on options for support as listed in the PIS Discuss the participants' concerns and provide further support within researchers' capabilities. Notify Principal Investigator of incident.
Follow up	Follow participant up with courtesy call (with participant consent) OR

	Encourage the participant to call either if s/he experiences increased distress in the hours/days following the interview
Step 3	Continue to discuss participants' concerns and provide ongoing support within researchers' capabilities. Remain with participant. Call 000 for immediate care. Notify Principal Investigator. Researcher to attend debriefing with supervision team as required.

Researcher Distress and Safety Protocol

Safety and Distress Considerations	Balance a "safe" working environment with maintaining research "quality" Consider potential physical and psychological impact on the researcher of the participants description of life experiences Consider how many interviews could safely be undertaken in a week Consider potential for emotional exhaustion
Operation	Appropriately scheduled interviews during a week Ability to contact supervisors where needed in case of emergency or risk Regular scheduled debriefing sessions with supervisors Keep reflexive journal of thoughts, reflections and feelings which may then become part of fieldwork notes
Evaluation	Assess for chain of communication in case of emergency or risk Assess for alerted emotional states prior, during or after data collection Assess for feelings of potentially "challenging" or "difficult" interviews Attendance at regular scheduled debriefing sessions with supervisors
Follow Up	The researcher has access to a counselling service (eg UTS) or a research mentor if she experiences increased distress Communicate with supervisors during and after the interview as needed

Adapted from Draucker C B, Martsolf D S and Poole C (2009) Developing distress protocols for research on sensitive topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350

Appendix 6: Abstract Accepted at ACRA National Annual Scientific Conference 2022

The patient experience of Spontaneous Coronary Artery Dissection (SCAD): an integrative review

E. Turner, S. Ivynian, L. Hickman and M. DiGiacomo.

Background
There is considerable burden of anxiety, depression and post-traumatic stress disorder in SCAD patients, yet research is limited on the experience and impact of SCAD from the patient perspective. Understanding the patient experience of SCAD is critical in provision of quality patient centred care.

Methods
An integrative literature review was conducted to understand the experience of SCAD and post-event implications. Five data bases were searched. Search terms included "spontaneous coronary artery dissection", "SCAD", "patient", "experience", "perspective" and "opinion". English language, peer reviewed primary research in people with a diagnosis of SCAD that reflected the patient experience were included. Data indicating the SCAD experience including distress prevalence were extracted into an Excel spreadsheet and narrative synthesis of included studies followed.

Findings
From 350 identified studies, nine were included for review. On average, SCAD cohorts presented mild to moderate levels of depression and anxiety, with one study reporting severe symptoms in 86%. Younger and post-partum SCAD patients, and those with lower resiliency had higher scores for anxiety. Post-traumatic stress disorder was observed in up to 43% of SCAD cohorts. Stress levels of 50 - 93% were reported. Ongoing chest pain (68%) and fatigue (56%) impacts on quality of life. SCAD patients reported challenges in recovery including anxiety associated with fear of recurrence and uncertainty, and a need for greater support.

Conclusion
SCAD patients are psychologically distressed, with higher rates of post-traumatic stress disorder than after atherosclerotic myocardial infarction. SCAD patients have unique recovery needs. Psycho-education and peer support may benefit survivors.

(250 words)

Appendix 7: Poster Presented at ACRA National Annual Scientific Conference 2022

Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

The patient experience of Spontaneous Coronary Artery Dissection (SCAD): an integrative review

E. Turner[1], S. Ivynian[1], L. Hickman[1,2] and M. DiGiacomo[1].
[1]IMPACCT, University of Technology Sydney, [2]University of Wollongong.

Introduction

SCAD accounts for up to 4% of overall AMI cases and occurs mainly in women with mean age 51.1 years [1]. SCAD seen in 31% of AMI in women < age 60 years and 43% of pregnancy related AMI [1].

Known anxiety, depression, and post-traumatic stress disorder in SCAD patients [1] but limited research on the experience and impact of SCAD from the *patient perspective.*

Aim

To describe the current state of the literature on the experience of SCAD and consequences for patients following a SCAD event.

Methods

An integrative literature review [2] was conducted following PRISMA guidelines [3]. Five data bases CINAHL, Scopus, Embase, Medline, CENTRAL were searched using search terms: "spontaneous coronary artery dissection", "SCAD", "patient", "experience", "perspective" and "opinion".

English language, peer reviewed primary research in people with SCAD that reflected patient experience was included. Data were extracted into Excel and narrative synthesis followed. JBI quality assessment tools [4] were used and all papers were included.

Results

Retrieved	350 papers
Included	9 papers
Total participants	1600
Sample size	ranged from 7 to 442 participants
Age	ranged 30 to 71 years
Female	60 – 100% of participants
Time since SCAD event	2 weeks to 27 years
Settings	US, Canada and The Netherlands
Study designs	3 case series, 5 cross sectional and 1 qualitative design

Largest study (n= 442) [5] and one CR study (n=354) [10] used data from an international SCAD database based in US.

Results

Self-report psychosocial outcomes

- On average *at least* mild anxiety and depression [6]
- Higher levels of distress observed in other samples [7,12]
- PTSD observed in 28% [5] - 43% [7] of samples
- Stress levels ranged from 50% [8] - 93% [7]

- Higher anxiety scores in younger SCAD survivors, post partum SCAD [8] and in lower resilience [7]
- Reported no resolution of stress levels 6-12 months later [7]

Psychosocial outcomes in longer-term management

- 3 reports:
  - SCAD specific CR (n=70) [9]
  - SCAD database – standard CR (n=354) [10]
  - Psycho-education pilot study (n=7) [11]

- CR is safe [9,10]
- Reduction in mental health indicators post CR [9,10,11]
- Lack of referral for 67% of SCAD survivors [10]
- Psycho-education effective [11]

Perceptions of SCAD survivors

- Online survey (n= 367) [12]
  - SCAD event highly stressful
  - 25% received no information
  - 82% received inadequate information

- Qualitative interviews (n=15) [13]
  - Living with anxiety, uncertainty and social isolation
  - Impact on identity
  - Need for tailored support and information

Discussion

SCAD patients are psychologically distressed with higher rates of PTSD after SCAD (up to 42%) than after atherosclerotic AMI (12%) [14].

CR is effective in supporting SCAD patient mental health [9,10] but lack of referral to CR is common (67%) [10].

Literature from North America and Europe: unknown experience elsewhere.

SCAD patients reported anxiety, fear of recurrence and uncertainty, and a need for greater support from both professionals and peers [13].

Conclusions

SCAD patients are a unique group with unique recovery needs.

Standard CR programs can be tailored to include psycho-education and peer support for SCAD survivors.

SCAD patients must have opportunity to provide detailed information about their experience.

Understanding the patient experience of SCAD is critical in the provision of quality patient centred care.

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