WOMEN’S DESCRIPTIONS OF THEIR EXPERINCES REGARDING LIFESTYLE MANAGEMENT AFTER SPONTANEOUS CORONARY ARTERY DISSECTION

by

Connie Clark

BSN, The University of British Columbia, 2004

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The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, the dissertation entitled:

Women’s descriptions of their experiences regarding lifestyle management after spontaneous coronary artery dissection

Submitted by Connie Clark in partial fulfillment of the requirements for the degree Master of Science in Nursing

Examining Committee:

Dr. Sally Thorne- Co-supervisor

Dr. Sandra Lauck- Co-supervisor

Dr. Martha Mackay- Supervisory Committee Member
Abstract

Spontaneous coronary artery dissection (SCAD) is a form of acute coronary syndrome (ACS) most commonly experienced by younger women and occurs when an arterial dissection or hematoma causes a blockage in one or more coronary arteries. A review of the literature reveals that women may experience ACS differently than men; most of the lifestyle management strategies used by health care providers are based on the needs of men. Additionally, there is minimal literature about SCAD and its impact on health status. The purpose of this qualitative research study is to learn more about younger women’s experiences of SCAD, more specifically their experiences with lifestyle management following the event. Guided by interpretive description methodology, seven women were interviewed 3-18 months after their SCAD event. An iterative data analysis process revealed the overarching theme of being lost in an unfamiliar diagnosis and four subthemes; being diagnosed with an unfamiliar disease, swirling in an information vacuum, finding something to hold on to, and reconstructing life. Because SCAD is a rare diagnosis, is early in its research, and has a different disease pattern with treatment and management than is the case for typical ACS, the study participants felt as if their lives were on hold after SCAD. They lacked the informational support they needed and had to wait several months for an appointment with an HCP who had expert knowledge and understanding of this particular disease. The implications of these findings include the observation that the experience of these women is similar to that of other patients with rare disease in that they are coping with an information vacuum. It seems women with SCAD would benefit from more information about their diagnosis immediately after their diagnosis. The findings suggest that there may be a role for an advanced practice nurse, or a team-based approach, to ensure that the knowledge needs of this population are better served. A diagnosis of SCAD creates multiple challenges in
managing the condition and adjusting to a new lifestyle; therefore, it is important to find better strategies to support these women in this difficult process.
Lay Summary

The goal of this study was to better understand the experiences with lifestyle management for women after spontaneous coronary artery dissection (SCAD). Seven women shared their experiences and the findings revealed that women had challenges accessing accurate information about SCAD at the time of diagnosis, at the time of discharge from hospital, and while they were managing at home. This made the women in this study feel lost in their diagnosis and that they felt like their lives were on hold until they were eventually able to see the health care professional specialist who had some knowledge of their specific condition. Once the women saw the SCAD specialist, they reported feeling better informed about their cardiac event and therefore better able to resume some of the activities they had engaged in prior to their SCAD. This suggests there is a need for better initial and ongoing access to information and reliable sources to better help women manage their SCAD.
Preface

Under the guidance of my co-supervisors: Dr. Sally Thorne and Dr. Sandra Lauck, and committee member Dr. Martha Mackay, I completed all aspects of this research. This study received approval from the UBC Research Ethics Board. Certificate number H18-00065. To date, no part of this thesis has been published.
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<tr>
<td>AACS</td>
<td>Atherosclerotic Acute Coronary Syndrome</td>
</tr>
<tr>
<td>ACS</td>
<td>Acute Coronary Syndrome</td>
</tr>
<tr>
<td>BREB</td>
<td>Behavioural Research Ethics Board</td>
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<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
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<td>CR</td>
<td>Cardiac Rehabilitation</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular Disease</td>
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<td>FMD</td>
<td>Fibromuscular Dysplasia</td>
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<tr>
<td>HCP</td>
<td>Health Care Professional</td>
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<tr>
<td>ID</td>
<td>Interpretive Description</td>
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<tr>
<td>MI</td>
<td>Myocardial Infarction</td>
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<tr>
<td>SCAD</td>
<td>Spontaneous Coronary Artery Dissection</td>
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<tr>
<td>UBC</td>
<td>University of British Columbia</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Chapter 1: Introducing the Topic

Heart Disease as a Major problem

Cardiovascular disease (CVD) has been identified as the number one cause of death globally (World Health Organization, May 2017). The World Health Organization (WHO) (2017) reported that approximately 17.7 million people died of CVD in 2015, which is equivalent to 31% of all deaths around the world. Furthermore, the WHO estimated that 7.4 million of all 2015 deaths related to CVD were caused by acute coronary syndrome (ACS).

Acute Coronary Syndrome in Women

ACS occurs when there is a disruption of blood flow through the coronary arteries that supply blood to the heart muscle (myocardium) (Woods, 2010). A common cause of ACS is a buildup of plaque in the coronary arteries, also known as atherosclerosis, and subsequent rupture of the plaque, leading to arterial occlusion (Woods, 2010). Common symptoms associated with ACS include severe chest pain or discomfort, pain radiating to other areas of the upper body (shoulder, neck, and jaw), fatigue, shortness of breath, diaphoresis and/or indigestion (Woods, 2010). Treatment goals include restoring coronary blood flow through various interventions (Woods, 2010). CVD and ACS are serious conditions that affect both men and women. However, ACS is still widely considered to be primarily a syndrome affecting men (Hildingh et al., 2007; Rosenfeld & Gilkeson, 2000). The Center for Disease Control and Prevention (2017) has identified that one of four deaths related to heart disease occurs in a woman and that heart disease is the leading cause of death for women.

There is research that suggests men and women could experience ACS differently (Almond, Salisbury, & Ziebland, 2012). The majority of the research on ACS has involved male
subjects and only in the last 20 to 25 years has some research been focused on women. In general, women tend to be less educated about ACS, under-diagnosed, delay seeking treatment longer than men, and are not as well managed by their health care providers (Almond et al., 2012; Galick, D’Arrigo-Patrick, & Knudson-Martin, 2015; Leifheit-Limson et al., 2015). Furthermore, younger women with ACS could experience the disease differently than older women (Bęckowski, 2015). One study on ACS demonstrated that 8% of the study subjects were women under the age of 55 years (Davis, M. et al., 2015). Given this information, younger women appear to be a very unique population who experience ACS differently than men and older women.

**SCAD as an Alternative Form of ACS in Women**

Spontaneous coronary artery dissection (SCAD) is a form of ACS that occurs most commonly in younger women (Saw, Mancini, & Humphries, 2016). “SCAD causes myocardial ischemia and myocardial infarction due to obstruction of coronary blood flow from intimal dissection and/or intramural hematoma formation” (Tweet, Gulati, & Hayes, 2015). SCAD was initially thought to be a rare diagnosis, although as of now its true prevalence is unknown because it is under-diagnosed by health care professionals (HCP) (Saw et al., 2016). Nevertheless, recent studies have shown that its prevalence is between 8-35% among women under the age of 50 diagnosed with ACS (Nakashima et al., 2016; Otten et al., 2014; Saw, Aymong, Sedlak et al., 2014; Vanzetto et al., 2009). Studies have consistently demonstrated that SCAD predominantly affects women over men, with 74-95% of SCAD occurring in women between the ages of 33-62 (Nakashima et al., 2016; Otten et al., 2014; Rashid et al., 2016; Saw et

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1 SCAD occurs when there is separation between any of the 3 layers of the coronary artery wall and is usually classified as non-atherosclerotic in nature (Saw et al., 2016).
al., 2014; Tweet et al., 2012; Vanzetto et al., 2009). According to Saw et al (2016), women who have fibromuscular dysplasia (FMD), are pregnant or have experienced multiple pregnancies, are receiving hormonal therapy, or have been diagnosed with a systemic inflammatory disease are at greater risk of developing SCAD. Additionally, Saw et al. discovered that there is an association between SCAD and precipitating factors such as an intense emotional event or physical activity. Similar to some women experiencing ACS due to atherosclerosis, women with SCAD describe chest discomfort as a common symptom (Chen, Woods, Wilkie, & Puntillo, 2005; Saw et al., 2016). In terms of management of SCAD, cardiovascular HCPs are still learning about SCAD and there is limited research in this area. There are no evidence-based management goals and, due to lack of research, nurses and other HCP rely solely on expert opinion when deciding on how to support these younger women diagnosed with SCAD.

**SCAD’s Impact on Younger Women’s Health Status**

Currently, there is minimal literature that describes the experiences of younger women with SCAD and its impact on health status. However, there is literature that describes women’s experiences after ACS in general, including negative feelings in the recovery stage (Smith, Frazer, Hall, Hyde, & O’Connor, 2017; Stevens & Thomas, 2012), changes in the role within the family and in relationships (Almond et al., 2012; Galick et al., 2015; Lacharity, 1999; Svedlund, Axelsson, Institutionen för hälsovetenskap, Fakulteten för humanvetenskap, & Mittuniversitetet, 2000), and negative interactions with HCP (Galick et al., 2015; Hildingh et al., 2007; Smith et al., 2017). Additionally, depression and anxiety are commonly seen in patients with ACS and can affect quality of life and survival (Hayes, 2009). Younger women have the highest incidence of depression immediately after myocardial infarction (MI) (Mallik et al., 2006). Patients experiencing depression after MI are less likely to follow recommendations to manage their diet,
exercise, stress, and social support (Ziegelstein et al., 2000). Little is known about the association between depression and anxiety and SCAD. More research is needed to inform cardiovascular nursing care and to support the creation of management guidelines for nurses and other HCPs.

Research has shown that attendance at a cardiac rehabilitation (CR) program can significantly decrease anxiety and depression among women following a major coronary event (Lavie & Milani, 1995). CR is an organized program for patients diagnosed with most forms of heart disease that supports them with risk reduction and secondary prevention strategies. It has been shown to reduce patients’ morbidity and mortality and to improve patient’s quality of life (Taylor et al., 2004). Medical management recommendations for patients with SCAD are different from those of patients with atherosclerotic ACS (AACS); therefore the current CR models may not fully meet the needs of patients diagnosed with SCAD.

Purpose of Research

The purpose of this research is to learn more about younger women’s experience with SCAD, more specifically with their experiences with lifestyle management after the event. As outlined above, younger women’s experiences with ACS can be different from men and older women (Bęckowski, 2015). Since SCAD primarily affects younger women, this specific patient population needs to be studied in order to produce more information about this form of ACS. Currently, there is minimal research on SCAD, with most of the studies on the topic being published in the last six years. As a result, current SCAD management guidelines are primarily based on expert opinion rather than evidence, and there are minimal recommendations regarding psychosocial interventions. This raises the question of whether or not current management strategies are meeting the psychosocial needs of younger women with SCAD.
Although the exact prevalence of SCAD is unknown, current research suggests it is as high as 8-35% of women under the age of 50 diagnosed with ACS (Nakashima et al., 2016; Rashid et al., 2016; Saw et al., 2014; Tweet et al., 2012). Since SCAD is more common than previously thought, it would be beneficial for nurses and HCPs to have more knowledge about how to manage patients after SCAD. The current research on women’s experiences with ACS reveals several differences in risk perception, symptom management, treatment-seeking behaviour, and treatment options between men and women. Younger women often underestimate their risk of ACS (Leifheit-Limson et al., 2015), delay seeking treatment (Leifheit-Limson et al., 2015), and are less likely to be prescribed goal-directed therapy (Davis, M. et al., 2015), when compared to men. This information demonstrates a lack of knowledge about ACS among both women and HCPs. One can assume that this would also be the case for younger women with SCAD and their HCPs. Additionally, as discussed above, women have reported that they experience challenges with lifestyle management after ACS, more specifically with negative feelings, changes in role, and negative interactions with their HCP. In order to help close our knowledge gap, research that considers the perspective of younger women after SCAD is needed so knowledge can be translated to women and HCPs. More information about women’s experiences after SCAD will also provide a foundation for developing lifestyle management guidelines that are specific to this patient population.

One lifestyle management strategy for patients after ACS includes attending CR. Current expert opinion suggests that patients with SCAD should also attend CR (Saw et al., 2016). Given the difference in management strategies between AACS and SCAD, there is a question as to whether current CR meets the needs of younger women with SCAD. A cardiovascular center in North America has developed CR that is designed specifically for patients with SCAD (Chou...
et al., 2016). Patients with SCAD who do not have access to a SCAD specific CR are referred to CR programs that are designed for patients with all kinds of CVD. Information on younger women with SCAD’s experiences with lifestyle management could help nurses and HCPs decide if the current SCAD specific CR models and/or traditional CR models meet the needs of patients or if modifications to the programs are needed.

Patients who are diagnosed with SCAD will have many encounters with HCPs and more specifically nurses. This includes when they present at the hospital, before, during and after their angiogram, and throughout the recovery phase of the event. Therefore, it is essential for nurses to have a clear understanding as to the nature and management of SCAD. Gaining knowledge around the patient’s experiences with lifestyle changes and challenges after the event will assist nurses in developing in-hospital care plans and lifestyle management strategies that will assist the patient with their diagnosis. With more knowledge about SCAD, nurses could cater their discharge teaching content to the needs of this younger female population and hopefully address more of the psychosocial challenges of these patients. As described above, CR can be a big part of a patient with SCAD’s recovery plan. Nurses are a part of the CR health care team and can greatly influence how the program is delivered to patients. Knowledge from this research will hopefully allow nurses to adjust CR to better meet the physical, emotional, and psychosocial needs of the patients. To gain more insight into younger women’s lifestyle management experiences after SCAD, the proposed study will seek to explore what can be learned from younger women’s descriptions of their lifestyle experiences after being diagnosed with SCAD that may be useful in application to nursing and health care practice.
Overview of Thesis Proposal

The purpose of this thesis is to learn more about younger women’s experiences with lifestyle management after SCAD. Chapter 1 provides background information on ACS and SCAD. It also outlines why younger women with SCAD are a unique patient population and that currently, there is minimal research available looking at their unique experiences. Chapter 2 summarizes the literature available on women’s experiences with ACS. Due to the fact that there has been very little research published on women’s experiences with SCAD specifically, the review will broaden to include women’s experience with AACS. Trends from the literature will be presented and, where applicable, will be applied to younger women with SCAD. Chapter 3 presents the methods that will be used to conduct the research, including an outline as to why interpretive description is best suited for answering the research questions. Sampling, data collection, data analysis, and ethical considerations will also be discussed. Chapter 4 discusses the finding from the analysis while chapter 5 includes an in-depth discussion of these findings. Finally, chapter 6 concludes the thesis and highlights the implications of the study findings on practice.
Chapter 2: Literature Review

Spontaneous coronary artery dissection (SCAD) is a less common form of acute coronary syndrome (ACS) when compared to ACS resulting from atherosclerotic processes (AACS). Due to the relatively recent increase in understanding of this condition, there is limited research exploring women’s experiences before, during, and after the coronary event. Therefore, this literature review will focus on women’s experiences with ACS in general, which mostly relates to AACS. Within the discussions on risk factors, symptoms, care, treatment, and recovery, linkages to SCAD will be made. Since most of the linkages are based on assumptions, it is obvious that more research focusing on women’s experiences with SCAD is required in order better understand this unique diagnosis and its implications for nursing practice.

Being at Risk

Risk Awareness

A meta-analysis conducted by Jensen and Moser (2008) showed that the majority of women did not know that heart disease was the leading cause of death among women worldwide. Furthermore, several other studies have shown that women under-estimate their risk of AACS, despite the presence of risk factors (Hart, 2005; Jensen & Moser, 2008; MacInnes, 2006). Younger women, specifically, also underestimate their risk (Lacharity, 1999; Leifheit-Limson et al., 2015; Lichtman et al., 2015). The VIRGO study (2015) found that even though younger women were at similar risk as men for AASC, prior to their myocardial infarction, they were 11% less likely than younger men to report discussions where their primary health care professionals (HCP) identified their risk and 16% less likely to have a discussion with their HCP about risk modification.
Not only women, but also physicians appear to under-estimate women’s risk. A small survey study of 529 internists and obstetricians and gynecologists in New York State discovered that these physicians had limited knowledge of practice guidelines related to cardiac risk factors for AACS among younger women (Barnhart, Lewis, Houghton, & Charney, 2007). This indicates that HCPs may not be properly educated about women’s risk factors for AACS. A meta-analysis by Hart (2005) revealed that lack of communication between women at risk for AACS and their HCP continues to be a large problem. She hypothesized that this lack of communication could impact women’s knowledge about their risk factors and the importance of risk behaviour reduction. She also called for increased education for women and the general public. The lack of knowledge about AACS is of concern given the prevalence of heart disease in women. The exact prevalence of SCAD is unknown due to under-diagnosis; however, it is estimated that it is 1.7-4% of patients presenting with ACS (Saw et al., 2016). If women and HCPs are unaware of the women’s risk of AACS, it can be assumed that they would be even less aware of the risk of SCAD.

Risk Factors

Some of the typical risk factors for AACS include age, sex (male), positive family history, smoking, hypertension, dyslipidemia, diabetes mellitus, obesity, sedentary life style and stress (The Heart and Stroke Foundation, 2017c). While many of the modifiable risk factors are present in both men and women, there is literature that suggests there are sex/gender differences related to risk of AACS (Kostapanos, Florentin, & Elisaf, 2013). Some of the most commonly documented risk factors for AACS for women include positive family history, hypertension, diet, and sedentary life style (Hart, 2005; McSweeney et al., 2003); whereas men have a higher risk association with current or previous smoking (Anand et al., 2008). There is also evidence to
support the notion that young women experience the risk factors of AACS differently than do younger men and older women. One recent study found that more younger women (under 55 years old) had diabetes and hypertension than did younger men and that younger women were more likely to be smokers and obese when compared to older women (Davis, M. et al., 2015). It is notable that all three of these risk factors are modifiable. The risk factors associated with SCAD are different from the risk factors associated with AACS: most of the risk factors associated with SCAD are non-modifiable, such as fibromuscular dysplasia (FMD), systemic inflammatory diseases, and pregnancy (Saw et al., 2016). However, a slightly higher prevalence of hypertension and dyslipidemia in patients with SCAD has been observed (Saw et al., 2014), indicating that there may be some benefit of exploring AACS risk factor modification with SCAD patients. The American Heart Association has guidelines for prevention of cardiac disease in women which includes strategies for managing hypertension and dyslipidemia (Mosca et al., 2011). The recommendations for blood pressure and cholesterol level control may be beneficial for prevention of SCAD. However, there is currently no evidence that suggests appropriately managing FMD and systemic inflammatory diseases reduces patients’ risk for SCAD.

Hart (2005) describes the barriers women face related to changing behaviours to promote cardiac health. She lists family/caretaking role, athletic incompetence or inexperience, financial constraints, lack of time and fears related to safety as the primary barriers identified by women. No research was located on the experiences of women with SCAD related to risk modification (e.g., controlling blood pressure and cholesterol or increasing physical activity) or whether their interactions with their HCPs prior to the event would impact their risk for SCAD. Women with SCAD may come across the same barriers to cardiac risk factor modification as women with
AACS, given their age and stage of life. As FMD is the most common risk factor associated with SCAD (Saw, Ricci, Starovoytov, Fox, & Buller, 2013), it would be interesting to learn if women known to have FMD were educated by their HCP about their risk of SCAD.

**Feeling the Symptoms**

The symptoms of AACS include chest pain or discomfort (including aching, pressure, tightness or burning), radiating pain, nausea or vomiting, indigestion, dyspnea, diaphoresis, light-headedness, fatigue, or feeling restless (The Heart and Stroke Foundation, 2017a). In a study examining women’s early and acute (at the time of the MI) symptoms related to AACS, the most common acute symptoms discovered for women were shortness of breath or dyspnea, weakness, unusual fatigue, cold sweats, and dizziness (McSweeney et al., 2003). From the sample of women in that study, 43% did not experience any sort of chest discomfort during the acute phase of their coronary event. Other studies have also found that chest pain was more likely to be absent for women when compared to men (Almond et al., 2012) and that younger women did not always experience classic symptoms such as chest pain (Stevens & Thomas, 2012). However, other studies have found that women and men had similar clinical symptoms of AACS (Mackay, Ratner, Johnson, Humphries, & Buller, 2011) and that women had a slightly higher prevalence of chest pain when compared to men (Moser, McKinley, Dracup, & Chung, 2005). These contradictory findings in the literature contribute to the challenges of educating women about the symptoms of AACS. The most common symptoms of SCAD are chest pain/discomfort that radiates to the arm and/or neck, nausea and vomiting, diaphoresis, and dyspnea (Saw et al., 2016). Women with SCAD appear to present with more defined chest pain but they also experience other symptoms, such as nausea and vomiting, diaphoresis, and dyspnea, which are not as easily attributed to a cardiac cause. This raises the question of whether women with
SCAD have the same variability in symptoms when compared to women with AACS. To date, there is no qualitative research available outlining women’s experiences with the symptoms of SCAD. Additionally, the current literature discussing the symptoms of SCAD is simply a list with minimal descriptions. More descriptive information would be beneficial to enable comparisons between SCAD and AACS.

After women begin experiencing the symptoms of AACS, there are factors that influence their perception of the symptoms. As stated above, women often have described their symptoms of AACS as highly variable and at times unrecognizable (Davis, Leslie L. et al., 2013). In a qualitative study by Davis et al. (2013) of women’s experiences with the symptoms of AACS, women either immediately recognized their symptoms as being cardiac in origin or their symptoms were uncertain and ever-changing. Madsen and Birkelund (2016) found that women’s responses during a myocardial infarction (MI) were influenced by whether or not they perceived the symptoms as threatening. According to the researchers, if women perceive their symptoms as non-threatening, they will often wait for the symptoms to go away or will self-medicate. The women in this study indicated that they often did not perceive their symptoms of a MI to be severe or threatening. More research is needed to help understand how women with SCAD experience their symptoms, in part to assess whether or not they perceive their initial symptoms as non-threatening.

The literature on SCAD suggests that there are precipitating factors that may trigger the SCAD (Saw et al., 2014; Tweet et al., 2012). These factors include intense exercise, intense emotional stress, labour and delivery, valsava-like maneuvers, recreational drug use, and hormonal therapies. One cardiologist in a quaternary hospital manages patients with SCAD and questions them about precipitating factors up to two weeks prior to their event. In her study
(2014), she discovered that, prior to the event, 40.5% of 168 patients with SCAD experienced an intense emotional trigger and 24.4% of the patients reported engaging in intense exercise. There is no evidence to confirm whether women with AACS have precipitating factors; however, based on the physiological differences between AACS and SCAD, it would not be surprising if there were variances in this regard. Interestingly, the literature does indicate that women with AACS experience prodromal symptoms up to a month prior to their MI (McSweeney et al., 2003). McSweeney et al. found that 95% of the women in their study experienced prodromal symptoms which included fatigue, sleep disturbance, dyspnea, indigestion and/or anxiety. Currently, there is no literature exploring prodromal symptoms prior to SCAD. It would be interesting to see if women with SCAD experience these symptoms or any other symptoms in the weeks prior to their event.

Finally, there is literature that describes HCP’s knowledge and response to symptoms of women with AACS. Women have described how they felt their physician was not aware of the signs and symptoms of ACS for women (Murray, O'Farrell, & Huston, 2000). Additionally, HCPs influenced some women to disregard their symptoms and often misdiagnosed them (Murray et al., 2000). Younger women described encounters with HCP in which they did not receive prompt or full work-up of their symptoms (Lichtman et al., 2015) and they felt they were not taken seriously during their initial visit to their HCP (Stevens & Thomas, 2012). Due to the lack of evidence regarding the experiences of women with SCAD interacting with HCP, only assumptions can be made about whether women with SCAD have similar experiences with their HCP. A better understanding as to why HCP respond in this way to women with AACS is necessary to allow for comparisons with women with SCAD. Additionally, independent research examining women with SCAD’s experiences with HCP would be beneficial.
Seeking Care

Delays in seeking hospital treatment upon onset of AACS are associated with worse outcomes, including recurrent ischemia, re-infarction, arrhythmias and cardiac death (Wu, Moser, Riegel, McKinley, & Doering, 2011). For the best patient outcomes, treatment for AACS or MI should begin within 90 minutes of arrival at the emergency department (O'Gara et al., 2013). It has been discovered that the majority of women delay seeking hospital treatment for ACS longer than men (McGinn et al., 2005). In one study, women reported seeking hospital care an average of 14 hours after onset of initial symptoms compared to an average of 2.8 hours for men (O'Donnell, Condell, Begley, & Fitzgerald, 2006). There is currently no literature on whether women with SCAD delay seeking health care and what the impact of delaying would be. Given that women with AASC delay seeking treatment for several reasons, information on whether women with SCAD delay seeking hospital treatment is needed. Additionally, given that women with SCAD appear to experience more defined chest pain/discomfort than women with AACS, it would be interesting to see if the more distinct symptom influences how quickly women with ACS seek treatment.

Researchers have reported on the reasons women state they delay seeking treatment for AACS. First, the literature suggests that there is a strong connection between the severity and location of symptoms and seeking treatment. Patients with AACS are more likely to delay seeking treatment if their symptoms are not easily attributed to an issue with their heart or if they do not perceive the symptoms as serious (Moser et al., 2005). As discussed above, women’s symptoms of AACS can be highly variable (Davis, Leslie L. et al., 2013) and not always associated with chest pain/discomfort (Almond et al., 2012; McSweeney et al., 2003; Stevens & Thomas, 2012). Women described that their decision to seek care was heavily influenced by the
severity and suddenness of onset of their symptoms and whether they could carry on with their normal activities (Gyberg, Björck, Nielsen, Määttä, & Falk, 2016; MacInnes, 2006). The variability of women’s symptoms and frequent presence of non-cardiac symptoms could help explain why women delay seeking hospital care longer than men. Given that the most common symptom for women experiencing SCAD is chest pain, delays in seeking hospital treatment (if they exist) may not be as easily attributed to variable symptoms. However, as stated above, diaphoresis and dyspnea are also identified as symptoms of SCAD but it is unclear whether these symptoms are present in conjunction with chest pain or not. The current literature on SCAD suggests that symptoms are not highly variable; however, there is minimal research done in the area. Second, one reason women delay seeking hospital care at the time of AACS is because they are concerned about how their change in health would impact other people in their life. In Moser et al.’s (2005) study that compared reasons why men and women delay seeking hospital treatment, it was discovered that women were more likely than men to delay because of a fear of troubling others. Younger women specifically appear to be more concerned about their family and work responsibilities in addition to how their family would react to their change in health status (Lichtman et al., 2015). There is evidence to suggest that women attempt self-care or self-remedy in an effort to stay at home and avoid going to the hospital (Gyberg et al., 2016; Lacharity, 1999; Lichtman et al., 2015). It is not known if women with SCAD delay seeking hospital care or what their reasons may be if they do delay. Therefore, it is difficult to make connections between the literature on AACS and SCAD. More research is needed in this area to increase HCP and nurses understanding of SCAD in relation to symptoms and hospitalization.
Needing Immediate Treatment

Once a patient with ACS presents to the hospital, the information gathered around the presenting symptoms should lead to diagnostic tests including an electrocardiogram (ECG) and serum troponin levels (O'Gara et al., 2013). Given that women’s symptoms are highly variable (Davis, M. et al., 2015) and do not always include chest pain (Almond et al., 2012; McSweeney et al., 2003; Stevens & Thomas, 2012), there could potentially be immediate diagnostic challenges for women with ACS. It appears that women with SCAD experience less variability and more severe chest pain as symptoms, so the same issues with diagnosis may not be present. However, SCAD is less common than AACS and the literature suggests that awareness of women’s risk for AACS is an issue; therefore, there is potential for diagnostic issues for women with SCAD. Coronary angiogram is the primary way of diagnosing SCAD and accurate and early diagnosis is essential, as management goals are different from AACS (Saw et al., 2016). Of great concern for women with SCAD is that research has shown that younger women are less likely to have a coronary angiogram when compared to younger men (Davis, M. et al., 2015). Additionally, there may also be challenges in that SCAD is not always easy to detect on angiogram (Saw et al., 2014). It is essential for interventional cardiologists to identify SCAD so that the appropriate management strategies can be implemented.

Pharmacological interventions are a big part of treatment of both AACS (O'Donnell et al., 2006; O'Gara et al., 2013) and SCAD (Saw et al., 2016). Recent studies have found that younger women with AACS are less likely to receive goal-directed medical therapy when compared to older women and to men (Davis, M. et al., 2015; Smolina, Ball, Humphries, Khan, & Morgan, 2016).

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2 Coronary angiogram is a widely used diagnostic procedure where a catheter is inserted into the coronary arteries and images are created in order to view abnormalities of the cardiac vessels (Woods, 2010).
2015). It was hypothesized that this was due to younger women’s presentations, insufficient recognition of AACS by HCP, and concern with the safety of medications due to their young age (Davis, Melinda et al., 2015). Some of these concerns could also be barriers for women with SCAD. SCAD is less common than AACS and therefore could potentially be more easily misdiagnosed and mismanaged. Current expert opinion, based on observational studies, regarding treatment of SCAD suggests conservative treatment with pharmacological therapy (Saw et al., 2016). More specifically, prescription of beta blockers is essential to reduce arterial shear stress and thus reduce the likelihood of subsequent events (Saw et al., 2016). More research is needed examining whether women with SCAD are consistently prescribed beta blockers and if these women are adherent to the therapy.

Other information emerging from the literature includes examination of gender differences in involvement in care of AACS at the time of diagnosis. It was reported that younger women felt it was important to be involved in the decision-making process about treatment options, but they were less likely to be involved in care in the hospital when compared to men (Arnetz & Arnetz, 2009). Additionally, younger women were less likely to report having discussions about lifestyle changes with the cardiology staff (Arnetz & Arnetz, 2009). It seems that involvement in care decisions would be important for women with SCAD, as there is a need for them to adhere to their medication regimen and make modifications to their lifestyle to avoid further complications (Saw et al., 2016). It can be assumed that there would be benefits to women being a part of the decision-making process, as this would increase their knowledge about their health status and empower them to make changes. Also, women with SCAD may have the same desire as women with AACS to be more involved with their care after diagnosis of their illness. There is currently no literature indicating if this is an issue for women with
SCAD; however, it is a topic worthy of more research so that adjustment to nurses and other HCP’s approach to treatment can be made if necessary.

**Recovering and Physically Managing ACS**

There is literature reporting on the mortality and the long term outcomes for women with AACS. In a 2001 study examining the sex/gender and age differences in mortality after hospital discharge for MI, it was found that younger women had higher mortality rates than men of similar age but that the women’s mortality decreased as they aged (Vaccarino, Krumholz, Yarzebski, Gore, & Goldberg, 2001). In the researchers’ subsequent study, there were improvements in younger women’s mortality rates; however, younger women still had higher rates when compared to similarly aged men (Vaccarino et al., 2009). It was also discovered that younger women had significantly higher hospital readmission rates after their event when compared with younger men (Davis, M. et al., 2015). Current morbidity and mortality information on SCAD includes only basic statistics with no comparisons between sociodemographic factors. One study showed that from 0-47 months after the event, 17% of patients experienced a reoccurrence of SCAD and there was a 10-year reoccurrence rate of 29.4% (Tweet et al., 2012). Additionally, 1 and 10-year mortality rates were found to be 1.1% and 7.7% respectively. These statistics support the need for long-term follow up with patients with SCAD, including risk reductions strategies. This is similar to the needs of women with AACS.

In AACS, once reperfusion of the coronary arteries has been achieved, recovery strategies can be implemented. One of the goals of secondary prevention following AACS is modifying the risk factors for heart disease to lower a person’s chances of another AACS (O’Gara et al., 2013). These strategies include smoking cessation, exercising, eating healthily,
lowering cholesterol and blood pressure, and managing stress (The Heart and Stroke Foundation, 2017d). However, recommendations for long term management of patients with SCAD is not well documented in the literature. Expert opinion guidelines suggest patients should be conservatively managed with strict adherence to their medication regimen and adjustment of their lifestyle to prevent another event (Saw et al., 2016). Both forms of ACS require patients to make permanent lifestyle changes once they are discharged from the hospital, and that in itself may pose many challenges for women, especially younger women who play a key role in their families.

**Experiencing Social and Emotional Health Challenges**

Having reviewed the literature in relation to women’s experiences with recovering from ACS, I have identified four main themes representing relevant trends across the literature. These are: feelings/emotions identified by the women; changes in family role and/or relationships; presence of anxiety, depression and stress; and interactions with HCP. While all the reviewed studies focused on women recovering from AACS, AACS and SCAD are both serious cardiac events that require patients to make significant lifestyle modifications. Furthermore, the majority of patients diagnosed with SCAD are female and it can be assumed that their psychosocial needs may be similar to women with AACS. Therefore, some or all of these themes may have some relevance for consideration of the issues for women with SCAD.

**Negative Feelings**

The first trend emerging from the literature is that women often feel fear, denial and anger during their recovery stage of illness. In one study, women described feeling fearful immediately after discharge because they were scared of living with their new diagnosis and worried about recurrent heart attacks (Smith et al., 2017). This fear resulted in them feeling
vulnerable. Steven (2012) made similar connections between fear and vulnerability and explained that one of the causes of fear identified by women was related to a lack of knowledge/information about recovery on behalf of HCPs. Furthermore, women in her study reported that feelings of fear had negative effects on their participation in family activities. Women also denied their diagnosis because they did not want to be seen as someone who was sick (Svedlund et al., 2000), which led to avoidance of lifestyle changes (Smith et al., 2017). Other studies suggested that women experienced extreme fatigue and the sense that their bodies were not the same, which contributed to negative feelings associated with recovery (Lacharity, 1999; Stevens & Thomas, 2012). Two studies discussed how women felt angry about their diagnoses, with participants in both studies questioning “why me?” (Lacharity, 1999; Stevens & Thomas, 2012). A study comparing older and younger women’s experiences during recovery found that younger women tend to be more focused on anger when compared to older women (Murray et al., 2000). The younger women saw the diagnosis as a major disruption in their lives and used more emotionally-focused coping strategies such as seeking support. It is possible that women with SCAD also feel fear, denial, and/or anger in the recovery phase of their illness, but there is currently insufficient evidence around this to provide guidance for nursing interventions.

**Interpersonal Relationships**

The literature on women’s experiences with their family life and relationships after AACS indicates that they struggle with negative feelings associated with changes in their relationships, lack of appropriate support, and difficulties resuming their role(s) within the family. Several studies described women’s feelings of guilt about changing their family role (Galick et al., 2015) and how they felt they were a burden on their family (Galick et al., 2015; Lacharity, 1999; Stevens & Thomas, 2012; Svedlund et al., 2000). Women in one study believed
that heart disease had a negative impact on their relationships with family and friends (Svedlund et al., 2000). Other women described their relationships as a source of stress (due to their loss of their role in the family) and, as a result, the women felt inclined to hide their diagnosis and health issues from others to improve their relationships (Galick et al., 2015). After AACS, younger women were more likely than younger men to have intra-family conflict (Xu et al., 2015). One older study that considered sexual health reported that AACS negatively impacted intimate partner relationships for some women (Lacharity, 1999). On the other hand, some studies have also found that women’s relationships could be a source of support (Lacharity, 1999; Smith et al., 2017). However, one study noted that, although women stated they felt supported by their families, it appeared that they were spending more time supporting others (White, Hunter, & Holttum, 2007). Women also reported that family members could be overprotective (Murray et al., 2000) and would downgrade their health status (Hildingh et al., 2007).

In several studies, women have described the need to retain their family/caregiver role and the challenges associated with that (Hildingh et al., 2007; Lacharity, 1999; Smith et al., 2017; Stevens & Thomas, 2012; Svedlund et al., 2000). Many women had a need to care for their family members and they often had trouble letting go and allowing others to help them (Hildingh et al., 2007; Lacharity, 1999). For example, if they allowed someone else to complete household tasks, women felt they had lost control. Many women retained their caregiver role and focused on supporting others, rather than themselves (Smith et al., 2017). This impacted their prioritization of managing their health and changing their lifestyle, a key component to recovering from AACS. Additionally, as reported in one older study, women with young children had the difficulties of meeting the needs of their children (Lacharity, 1999). Women also reported that for them to successfully transition back into the caregiver role, they needed to
adapt and adjust to the situation (Hildingh et al., 2007) by giving and receiving support, acknowledging the need for health-promoting behaviour, and focusing on empowerment to ensure they have a successful recovery from their AACS (Galick et al., 2015).

Unfortunately, there is currently no literature describing the experiences of women with SCAD in terms of their family role and relationships after their coronary event. Considering the younger age of women who have SCAD, the trends from the literature of negative feelings associated with changes in their relationships, lack of appropriate support, and difficulties resuming their family role may be applicable to women with SCAD. Research investigating the recovery experiences of women with SCAD is needed to understand whether their needs in this area are the same as women with AACS.

Psychological Distress

Anxiety, depression, and stress were also common themes in the literature regarding the experiences of women recovering from ACS. Increased in-hospital and post-discharge complications have been linked to anxiety (AbuRuz & Masa’Deh, 2017) and depression (Lichtman et al., 2014). Research has shown that women experience more anxiety after an acute MI when compared to men (Kim et al., 2000). Some women described feeling anxious about physical aspects of their recovery, such as over-exertion or recurring MI (White et al., 2007). Other women identified anxiety related to being “a sick person” and therefore they withheld their feelings of worry and stress (Svedlund et al., 2000). Younger women have a greater prevalence of depressive symptoms prior to and during an acute MI compared to younger men (Smolderen et al., 2015). Some women questioned “why me?” and were unable to understand how this could have happened to them, while others felt depressed because of the major changes they were experiencing (Lacharity, 1999; Stevens & Thomas, 2012). Research specifically examining
sex/gender differences in stress during recovery from AACS has found that higher baseline stress caused worse recovery outcomes for young to middle-aged patients in both men and women after an acute coronary event (Xu et al., 2015). Women in this study perceived themselves to have greater psychological stress at baseline when compared to men. This work done by Xu et al. also described the differences in the attributed cause of stress between men and women, outlining that women reported feeling more burdened by family role responsibilities. This suggests that women’s needs related to stress are different from men’s and, therefore, management strategies must take this into account.

Currently there is minimal evidence about depression and anxiety among SCAD patients and none related to stress levels. In one study, the degree of self-reported depression among SCAD patients was similar to that of women after AACS (Liang, Tweet, Hayes, Gulati, & Hayes, 2014). However, self-reported anxiety levels were slightly lower among women with SCAD than among women with AACS (Liang et al., 2014). Regardless, both depression and anxiety appear to be present in women after SCAD (Wagers, Stevens, Ross, Leon, & Masters, 2018); therefore, they should be considered throughout the recovery phase. Some of the current research suggesting strategies for management of anxiety and depression for women with AACS could be applied to women with SCAD, given that women with SCAD experience anxiety and depression as well. However, more research into the cause of anxiety, depression, and stress for SCAD patients in particular might help HCP better understand any distinctive aspects of the experiences of these women.

**Interactions with HCP**

The final trend emerging from the literature in relation to women’s experiences with recovery after ACS is negative interactions and lack of support from HCP. Women reported
often feeling dismissed or discounted by their HCP and felt that they were not taken seriously (Galick et al., 2015; Hildingh et al., 2007). HCP neglected to answer women’s questions (Galick et al., 2015) or provide enough information, which created feelings of uncertainty for the women (Hildingh et al., 2007). Most women felt that HCP could have done a better job informing them of the expectations during recovery (Stevens & Thomas, 2012). This lack of knowledge contributed to feelings of fear and worry for the female patients. Women also described a perception of a lack of knowledge about women and ACS on the part of their HCP (Murray et al., 2000). It seemed that women wanted more information from their HCP but instead had to turn to other sources to receive it (Galick et al., 2015). Additionally, women described barriers to receiving information from their HCP because they believed their HCP assumed that ACS mainly affected men and that there seemed to be a gender bias (Galick et al., 2015; Murray et al., 2000). When asked about what they felt they needed from their HCP to improve their experiences with recovery, the women stated they wanted two-way connections with their HCP, to have multiple ways of approaching health promotion, and to collaboratively develop health goals (Galick et al., 2015). Furthermore, women needed their health care to be gender-specific with targeted interventions to promote change (Smith et al., 2017). Given that it is primarily women who are impacted by SCAD and that it is a relatively uncommon condition, it can be assumed that patients with SCAD may have challenges with interactions with and information from their HCP. During my observations in a specialized clinic in a quaternary hospital, the lead cardiologist described a lack of knowledge on the part of many cardiologists in terms of long-term management of these patients. This indicates that research examining the experiences of women with SCAD with their HCP in the recovery phase would be useful to HCP and more specifically nurses. This knowledge could help the nursing profession identify ways to achieve
positive partnerships between patients with SCAD and HCP. It could also strengthen relationships in settings such as clinics and CR programs environments in which nurses play an active role as members of the patient’s health care team.

**Attending Cardiac Rehabilitation Programs**

Cardiac rehabilitation (CR) is often recommended to patients as part of the recovery process after AACS. CR is a structured program offered by a multidisciplinary team that includes exercise training, emotional support, and education on lifestyle modification (The Heart and Stroke Foundation, 2017b). CR has been shown to reduce hospital readmission (Dunlay, Pack, Thomas, Killian, & Roger, 2014) and mortality rates (Dunlay et al., 2014; Taylor et al., 2004), and improve quality of life after AACS (Shepherd & While, 2012). Men and women receive similar physical benefits from CR (Dunlay et al., 2014; Hazelton et al., 2014); however, women are less likely than men to be referred and to attend (Sanderson, Shewchuk, & Bittner, 2010). In one meta-synthesis, women reported that they had not received enough information about CR and were not given the opportunity to attend (Hildingh et al., 2007). Other studies described that younger women had difficulties attending the program because of child care or work commitments (Batten & Day, 2006; Lacharity, 1999). Based on this, minimal information, lack of referral, and timing of the CR program seem to be barriers to compliance with CR for women. This could be true for women with SCAD as well, but there is currently no research examining referral rates and adherence to CR in women with SCAD.

Many women who did enrol in CR following AACS reported that the program did not meet their emotional needs. In one study, younger women discussed how, despite being enrolled in CR, they still had the need for a formal program to aid in their recovery, indicating that a different kind of support was needed (Murray et al., 2000). In another study, women felt that CR
programs were designed for men (Hildingh et al., 2007). As described above, several women reported challenges with relationships (Svedlund et al., 2000) and experienced anger after AACS (Murray et al., 2000). Unfortunately, women who attended CR after AACS did not appear to have an increase in relationship satisfaction nor did CR decrease their feelings of anger (Hazelton et al., 2014). This may be due to CR not addressing patients’ needs related to maintaining health relationships or managing anger. As previously noted, women experience higher rates of anxiety and depression after ACS in comparison to men (Kim et al., 2000; Smolderen et al., 2015). There is evidence to suggest that participation in CR can reduce anxiety (Lavie & Milani, 1995) and depression (Milani, 2007) among female patients. However, women have also reported that they do not always feel comfortable asking questions during CR (Batten & Day, 2006), making it challenging for them to fully address their specific recovery needs.

Overall, CR appears to be meeting only some of women’s social and emotional needs. There is evidence to suggest that women need higher levels of social support and the opportunity to speak to others who are sharing similar experiences (Galick et al., 2015; Murray et al., 2000). Additionally, they need gender-specific strategies that will help them manage their stress (Xu et al., 2015). Finally, women may require gender specific, appropriately timed, and targeted interventions to support them with the necessary lifestyle change. Therefore, it may be necessary to adjust CR programs to meet the needs of female post-AACS participants. It can be assumed that women with SCAD will have social and emotional needs that should be addressed by HCP and nurses during their recovery. However, it is unknown what these requirements are and whether the current recovery strategies are meeting them.

The benefits of CR for female patients with SCAD have not been extensively studied. Early research indicates that it seems to be safe for women after SCAD to participate in an
adapted CR program to improve aerobic capacity, body composition, and depression and stress (Silber, Tweet, Bowman, Hayes, & Squires, 2015). Many women have reported that they felt there was some physical and emotional benefit to attending the program (Krittanawong et al., 2016). Similar to women recovering from MI, it appears that physicians under-refer women to CR after SCAD (Krittanawong et al., 2016). This suggests that there may be some overlap in barriers to attendance for patients with SCAD and those with AACS. As there is currently no research examining women with SCAD’s experiences with recovery, therefore it is difficult to determine if the available CR is meeting their psychosocial needs. Given that women with SCAD are younger, recognizing the implications of age on social health status and the need to resume socioeconomic roles, it could be speculated that their CR needs may be different from those with AACS. Thus further research addressing this topic is needed.

Conclusion

Given that there is limited information on women’s experiences before, during, and after their SCAD, this literature review focused on discussions about the experiences of women with AACS while highlighting the limited evidence available to describe the unique features of SCAD. Some similarities and differences between the two populations were identified; however, several assumptions about needs during recovery are being made due to inadequate understandings of the implications of gender, age, and social and emotional needs. Further research is needed to examine the experiences of women with SCAD to enhance our understanding of this phenomenon. This includes having a better understanding of the challenges they may have managing their change in health and lifestyle, including the issues that may present themselves in relation to attending CR. Such knowledge could be of particular relevance to nurses as they adapt current health care strategies for AACS so that women with
SCAD receive ideal care, are supported in their experiences, and realise optimal long term health outcomes.
Chapter 3: Methodological Approach

Based on the literature discussed in chapter 2, it is evident that younger women have unique experiences before, during, and after acute coronary syndrome (ACS). Although spontaneous coronary artery dissection (SCAD) is a form of ACS, most of the current research involves women with atherosclerotic ACS (AACS), which is associated with several differences in patient demographics, pathophysiological responses, and impact on mental health, compared to SCAD. Therefore, more research examining the experiences of younger women before, during, and after SCAD is needed. The proposed study is designed to develop knowledge toward answering the research question:

What can be learned from younger women’s descriptions of their experiences regarding lifestyle management after being diagnosed with SCAD?

Methodology

Interpretive description (ID) was used as the methodology of this research. “Interpretive description is a qualitative research approach that draws upon the philosophical structure of applied disciplinary knowledge for its interior logic and design decisions” (Thorne, 2013 p 295). ID was originally developed in 1997 by Thorne, Reimer-Kirkham, and MacDonald-Emes in order to help applied science researchers navigate the challenges associated with the more regimented social science methodologies in a manner that produces knowledge applicable to the practice disciplines. Applied science researchers often have challenges because many human experiences cannot be comprehensively understood through the other methodologies (Thorne, 2016). ID allows the researcher to make modifications to the traditional social science methodologies so that the applied science researcher is better able to answer their research question (Thorne, 2016). Modifications are necessary because nursing practice is context based
and registered nurses rarely expect to follow fully standardized approaches to care; therefore, variation in experience is an important component of the knowledge required to account for practice context. By employing ID, I followed a logic model that can be similar to the nursing process itself, including assessing, interpreting, planning, acting, and evaluating. Within the nursing process, modifications are made to account for context. By utilizing ID, I examined the experiences of younger women with SCAD from the participant’s subjective and experiential point of view in order to seek commonalities and variations in individual situations that are not constrained by time or context (Thorne, 2016).

ID was the appropriate methodology for my research because I am an applied science researcher examining the experiences of younger women regarding lifestyle management after being diagnosed with SCAD. My background is nursing and, as stated above, ID caters to the needs of an applied science researcher in that it allows for the use of the nursing process to guide aspects of design decision making. For example, ID allowed me to make modifications as needed through the course of my study based on the evolving research process, such as the responses and needs of the participants. Additionally, it allowed me to pose research questions that have clinical relevance and answer them by utilizing techniques that fit well with the context of the information (Thorne, 2016). Finally, ID permitted me to draw on current nursing knowledge of women’s experiences with ACS but also to create new insights into the experiences of specifically women with SCAD (Thorne, 2016). It is my hope that this new information will, in turn, help shape how health care professionals (HCP) support younger women with SCAD.
Methods

Study setting

A cardiologist who specializes in SCAD operates an outpatient SCAD clinic at a tertiary care center in Vancouver, British Columbia. At this clinic, new and previously diagnosed patients with SCAD are seen by members of the health care team for health management after their diagnosis. Potential participants for this study were identified through the SCAD clinic. After participants were enrolled, interviews were conducted in a neutral place, either at the hospital, in the participant’s home, or other public areas that was acceptable to both the participant and the interviewer.

Gaining entry

In order to begin the process of gaining entry to the outpatient SCAD clinic, I arranged to meet with the cardiologist and was able to spend two days observing in her outpatient clinic. These observations provided me with some insight into the patient population at the clinic and helped me determine the suitability for recruiting in this setting. When gaining entry to this study setting, it was important for me to consider the fact that I am a registered nurse currently working in the cardiac sciences department at the tertiary hospital. Luckily, I have never worked directly with this cardiologist so, after I informed her of my cardiac nursing background, I made sure to keep our conversations focused on SCAD and my proposed research. By approaching the relationship in this manner, I was setting the stage for balance between being an insider and outsider within the study ³ (Thorne, 2016). Moving forward, once my committee had approved my thesis proposal and ethics approval was obtained from the University of British Columbia.

³ With ID, applied science researchers who conduct research in settings they are familiar with have an insider’s perspective while researchers who are not familiar with the study setting are considered outsiders (Thorne, 2016).
(UBC) Behavioural Research Ethics Board (BREB), I started the process of recruiting participants from the SCAD clinic using the process approved by the cardiologist. The cardiologist was aware of the details of my study, including the research question and purpose of the research.

There are some special concerns outlined by Thorne (2016) that I considered in order to gain entry into the research role. Firstly, I spent some time before, during, and after entering the field critically reflecting on my current knowledge of ACS and SCAD. This helped me acknowledge any potential biases or related implications my nursing and/or cardiac knowledge may have on the research. I kept track of these reflections in a reflective journal so that I could revisit them regularly throughout the study and ensure they are not influencing the research in any way. Secondly, it is also important that I understood that my role in this context is that of a researcher seeking to understand the experiences of younger women with SCAD, and not cardiac nurse. There needed to be serious attention paid to when it was or was not appropriate to intervene as a HCP (Thorne, 2016). As a result, I required a clear plan as to available referral options should the need for intervention arise within the study context. Thirdly, I needed to be aware of the information I choose to disclose to the participants and how this information could impact the results of the study. For example, I found a balance between making my motivations and intentions with the research clear and not disclosing too much personal information. Finally, I needed to avoid validating the participants by nodding my head or by making statements such as “I agree” which may cause the participant to feel they are answering the questions correctly. Rather than conveying the message that there are right or wrong answers, I wanted to support study participants to focus on explaining their experiences from their own point of view (Thorne, 2016).
Participants

Based on cohort studies found in the literature, patients diagnosed with SCAD are mostly younger females of European decent (Saw et al., 2014; Tweet et al., 2012). In order to address heterogeneity, efforts were taken to ensure the sample was reflective of the patient population who experience SCAD. Inclusion criteria included: (1) female sex, (2) less than or equal to 55 years of age at the time of the SCAD, (3) proficient in speaking and reading the English language, (4) a documented diagnosis of SCAD in the 3-18 months prior to the time of their interview. The time line of the last 3-18 months since the event better allowed for the participant to recall their experiences with lifestyle management after being diagnosed with SCAD. It also provided the participants opportunity to gain experience with recovering from SCAD. Exclusion criteria for this study included: (1) women who have co-morbidities that do not allow them to fully participant in the current recommended lifestyle management strategies for SCAD, for example, women who were unable to mobilize or who had pre-existing mental health issues. (2) Women who had experienced complications during their SCAD, such as stroke or recurrent arrhythmias that required additional modifications to the current lifestyle management strategies. (3) Women who had a recurrence of SCAD or a previous diagnosis of ACS. These participants were excluded because their experiences of making significant cardiac health lifestyle modifications may be influenced by a previous event.

Sampling Strategy

When considering which type of sampling strategy to use, it was important to consider who would provide the richest data and who would increase my understanding of people’s experiences with lifestyle management after SCAD (Polit & Beck, 2012). ID encourages the researcher to choose a sampling strategy that will be reflective of the group of people who have
experienced or are experiencing the phenomenon being studied (Thorne, 2016). Given that it is known that most of the younger women diagnosed with SCAD are of European decent, I purposively sampled to try to ensure the appropriate variation is met with respect to heritage and ethnicity, as well as various social contexts. Additionally, since my research question involved learning about younger women’s experiences with lifestyle management after SCAD, purposive sampling allowed for me to recruit participants who have actually experienced SCAD and who can speak about what it was like to manage their life after the event.

**Sample Size**

ID does not indicate a specific sample size for studies but instead challenges the researcher to ask: “how many instances of a thing would we need to include in our observations and analysis in order for the findings to have any merit to those for whom we are conducting the research?” (Thorne, 2016 p. 103). SCAD is a relatively newly discovered phenomenon and there are currently no qualitative studies published in the literature analysing patient’s experiences with lifestyle management. Therefore, it may be possible to create new insights into this type of ACS with a small sample size. Additionally, since I utilized purposive sampling, trends in the data quickly became apparent. In following the recommendations of ID, I did not suggest a specific sample size, but rather continued conducting interviews until there was sufficient evidence from the data and analysis to answer the research question (Thorne, 2016). However, I estimated that sufficient evidence from the data may arise after 8-10 participants were interviewed. Other factors that I considered when thinking about sample size were the feasibility of the research (given that I am a novice researcher completing a master’s thesis), the possibility of some participants being poor informants, not providing rich data, and the possibility that the women’s experiences with SCAD may be more or less complicated than I have assumed.
Recruitment

Recruitment for this study took place at the outpatient SCAD clinic located in the tertiary hospital in Vancouver. Prospective patients were provided with a recruitment package to take home with them after their medical appointment or the packages were mailed directly to potential participants. All packages were numbered and distributed to patients by a member of the SCAD health care team (in person or by mail). The package contained the recruitment flyer (Appendix A), the informed consent (Appendix B), a letter from the SCAD cardiologist summarizing the study (Appendix D), and my contact information (phone number and email address). When they receive the package, participants were asked to review the package at home and contact me if they were interested in participating in the study. Once a participant contacted me to discuss participation in the study, the informed consent document was reviewed with the patient over the phone (but not signed) and the interview date, time, and location was determined. Prior to the start of the interview, the participant was provided with their gift card and another detailed explanation of the informed consent. After the explanation, the participant was asked if they would like to give consent to participate in the study and sign the informed consent document. If the participant chose to sign the consent the interview proceeded. If not, the participant kept their gift card and was thanked for their consideration.

Ethical Considerations

When conducting research in any capacity, ethical considerations must be taken into account to maintain participant welfare, to demonstrate fairness, and to be respectful. The ethical considerations discussed here include informed consent, confidentiality, data storage, and financial incentives. Once all the ethical requirements of the UBC BREB and formal operational
research approval was granted by the tertiary care, the study moved forward and data collection began around the experiences of younger women with lifestyle management after SCAD.

**Informed Consent**

Written informed consent of every participant was required and each participant was provided with the information necessary to understand the research. (Polit & Beck, 2012; Thorne, 2016). The informed consent document (Appendix C) was given to prospective informants and it included information on the study’s goals, types of data that will be collected, all required procedures (interviews), sponsorship, how participants will be selected, potential risks and benefits, compensation, confidentiality pledge, voluntary consent, their rights to withdraw or withhold information, and contact information of the researchers. Participants who chose to enrol in the study were regularly reminded of their rights with regards to consent to ensure they remained informed especially in interviews where sensitive topics were discussed.

**Confidentiality**

Unfortunately, due to the nature of the research methodology and the small sample size, anonymity, or the inability of the researcher to link the participant to the data, (Polit & Beck, 2012) was impossible. Therefore, I needed to consider confidentiality in the absence of anonymity in this research. This included assuring the participants that all identifying information was be removed from the data and that the data would not be accessible to others who are not involved in the study. Additionally, participants were assigned a unique identifying number so that the data could be efficiently organized and analyzed while maintaining participant confidentiality.
**Data Storage and Financial Incentives**

The standards outlined for data storage by the UBC BREB were followed. All hard copies of documents associated with the research were locked in a cabinet in a secure location. All electronic documentation was stored on a password protected hard drive and was not uploaded on any shared storage devices or websites. Five years after the research is completed, all documentation associated with the study will be destroyed.

As an appreciation of their time, a financial incentive of a $25 gift card was provided to each participant at the start of their interview. This incentive was not conditional on the participant completing the interview and, should they have chosen to withdraw from the study at any time, they would have kept their gift card.

**Data Collection**

ID allows the researcher to select the most appropriate data collection methods in order for the researcher to ensure they are able to gain high-quality qualitative knowledge about the phenomenon being studied (Thorne, 2016). While the researcher is given the freedom to develop data collection strategies as they see fit, they must, however, follow an operational logic and use specific techniques and strategies that align with other components of the study (Thorne, 2016). For example, the researcher must select a data collection strategy that will best answer the research question. For this study, interviewing the participants and allowing them to tell their story provided the most useful data to help explain their experiences.

I gathered data through one-on-one interviews with each participant enrolled in the study in a private setting. According to Thorne (2016), interviews are a useful core for developing knowledge about clinical issues and allow the researcher to gather subjective data on the chosen
topic. Interviews were semi-structured and questions were open-ended to ensure specific components of the topic were covered but to also allow the participants to speak freely and tell their personal story about their experience (Polit & Beck, 2012). An interview guide was used to help me to consistently cover all aspects of the topic (Appendix D). Each interview lasted 35-50 minutes so that the participant was given the time to get comfortable in the interview and to fully describe their experiences with lifestyle management after SCAD (Polit & Beck, 2012). All interviews were audio recorded and then were transcribed verbatim by a transcriptionist experienced with confidential research interview preparation. After transcription was complete, I double checked the documents for accuracy against the original recordings prior to starting data analysis.

Within ID, data collection and data analysis occur concurrently; therefore, data collection stopped when enough patterns and consistent themes emerged from the data to draw conclusions (Thorne, 2013; Thorne, 2016). As described above, a smaller sample size allowed for this. It is my hope that with these data collection strategies, the information gathered will inform the nursing practice and other HCP about the lifestyle management experiences of women after being diagnosed with SCAD.

Data Analysis

One of the key underlying principles of data analysis with ID is that it’s an iterative process involving concurrent data collection and analysis, with constant reflection, asking of questions, and considering all options (Thorne, 2013). This means that I fully immersed myself by reading and re-reading the data and allowing time for reflection and to consider all aspects of the information. Data was examined at a variety of levels, including from an overview of general participant experiences, to the small details of the information shared. I challenged my
thinking by asking myself to “ponder, challenge, chew on, wrestle with and massage pieces of data until they can be formed into parts that seem individually and collectively to tell us something we did not know previously about the phenomenon” (Thorne, 2013 p 301). After repeating this process over and over, it was possible to consider different aspects of content in relation to each other and patterns started to emerge (Thorne, 2013). The themes were then grouped together. At this point, I began a second phase of analysis, where relationships were examined closely in order to obtain insights about the logic of the findings (Thorne, 2013). By following this iterative process, conclusions can be drawn from the data that I hope will create the opportunity for the development of nursing knowledge about women’s experiences with lifestyle management after being diagnosed with SCAD.

Similar to other qualitative research methodologies, there are some potential hazards that could present themselves in the data analysis phase of ID (Thorne, 2016). Firstly, premature closure occurs when researchers stop at a finding that they deem to be meaningful, without considering other aspects of the theme (Thorne, 2016). In order to avoid this, I critically reflected on emerging themes in my reflective journal and considered different ways of organizing the content prior to choosing one. Secondly, misinterpreting frequency could occur in ID data analysis, which is when the researcher wrongly assumes that one theme is more or less relevant than others because it occurs more or less frequently in the data (Thorne, 2016). With this in mind, I reflected on the other variables that could influence misinterpreting frequency such as the wording of the interview questions and considered all aspects of the theme before deciding on its relevance. Again, my thoughts and ideas were documented in my reflective journal. Finally, there is the possibility of overinscription of self in which the researcher’s position in the study could influence the data analysis process (Thorne, 2016). Therefore, it was
important to periodically step back from the data to allow myself time to reflect and consider other details that might be missed. It was also a time to recognize my own biases and challenge my thought process. Additionally, reading and re-reading my reflective journal reminded me of where I am positioned in the study. Data analysis using ID included a constant review of the research questions to ensure that I was on track to produce rich information that will help nurses and other HCP develop more knowledge about lifestyle management of patients with SCAD.

**Credibility**

When conducting qualitative research, it is important to consider strategies to enhance the quality of the research (Polit & Beck, 2012). Furthermore, because the results of qualitative health science research often play a major role in shaping nursing practice and how we manage patients’ health, it is essential that every health-science-related study is credible. To enhance credibility and trustworthiness of my study examining the experiences of younger women regarding lifestyle management after being diagnosed with SCAD, I considered ID’s evaluation criteria.

Firstly, research using ID as its methodology must hold epistemological integrity (Thorne, 2016). In other words, the chosen methods of the research must be developed around the nature of the research question. Throughout the methods section of this chapter, I have provided a clear rationalization as to why I have chosen the specific method. For example, I justified my decision to gather data in the form of interviews by explaining that this particular strategy would provide the best information to answer the research question.

Secondly, representative credibility should be considered with an ID study to ensure the sampling strategy aligns with the phenomenon being studied (Thorne, 2016). This can be
achieved by data triangulation, which is when several data sources are used to ensure the results are accurate (Polit & Beck, 2012). For this study, I used purposive sampling with the intention of enrolling participants that would be able to share their experiences with SCAD in detail and clearly answer the research question. Additionally, I interviewed more than one participant to gain knowledge of younger women’s experiences with lifestyle management after SCAD from a number of different perspectives.

Thirdly, in order to enhance a qualitative study’s credibility, the researcher must be able to clearly articulate how decisions were made throughout the study (Thorne, 2016). ID describes this as demonstrating analytical logic (Thorne, 2016). To achieve this, I kept an analytical log which included detailed descriptions of each decision and the factors that were considered that may have influenced the decision. Additionally, I practiced reflexivity, which is the process of critically reflecting on my biases or personal intentions that may influence the results of the study (Polit & Beck, 2012). I kept a reflective journal where I documented all my reflections throughout the study. Finally, I wrote a detailed summary after each interview of key points made and any remarkable context that I needed to consider. These three strategies allowed for transparency in my data collection and analysis process.

The final evaluative criteria examining the credibility of a study using ID is interpretive authority (Thorne, 2016). Increasing interpretive authority involves verifying that the interpretations of the researcher about the phenomenon being studied are based on the participant’s subjective truth and not on the researcher’s biases or assumptions (Thorne, 2016). In considering interpretive authority in my study, I addressed reactivity which is when participants react in a certain way because they know they are being observed or studied (Polit & Beck, 2012). I planned for each interview to be 35-50 minutes to allow participants to get more
comfortable in their environment. Furthermore, as described above with gaining entry, I took steps to encourage the participants to share their experiences based on their own personal account and avoided influencing their answer in any way.

**Conclusion**

To date, there is no qualitative research published about younger women’s experiences regarding lifestyle management after being diagnosed with SCAD; therefore, to gain more insight into this phenomenon, this study needed to be completed. Given that the research examined women’s experiences in the context of health care, ID was the ideal research methodology. ID allows qualitative researchers the flexibility to adapt their research methods to obtain the best possible data to answer the research question. By collecting and analysing data concurrently and following an iterative process of analysis, I was able to seek a better understanding of patterns and themes that emerge in the data. Ethical considerations were addressed and approved by the UBC BREB. Next, the tertiary care centre’s operational research approval was obtained. With approval from both ethics organizations, the thesis project moved forward into the data collection and data analysis phases. In order to ensure my study was credible, I needed to rationalize my methods approach, confirm that my sample aligns with the research question, clearly articulate my decision-making process (through my analytical log and reflective journal), and demonstrate my interpretations of the phenomenon are trustworthy. Ultimately, it is my hope that the findings that emerged from this study will help nurses and other HCP gain a better understanding of the experiences of younger women regarding lifestyle management after being diagnosed with SCAD.
Chapter 4: Being Lost in an Unfamiliar Diagnosis

In this chapter, the findings from the interviews of seven women’s experiences with lifestyle management after spontaneous coronary artery dissection (SCAD) will be presented. By analysing the data following an iterative process, the overarching theme of being lost in an unfamiliar diagnosis emerged for these SCAD survivors. The participants described their experiences with being diagnosed with a rare disease. The information they shared also indicated that they were swirling in an information vacuum, where they were not provided with enough knowledge about SCAD. While they searched for a better understanding, the women were able to find something to hold on to and gain some perspective on their diagnosis. This allowed them to begin to reconstruct their life after their event so that they could make lifestyle changes.

Introduction to the SCAD Patient Journey

Following the Iterative Process

As described in chapter 3, data analysis strategies used the principles of interpretive description (ID) in that an iterative process was followed with use of an analytical log and reflective journals (Thorne, 2016). To further ensure I was consistently following an iterative process, I typed a step-by-step plan to follow for data analysis. The plan included a list of questions to ask myself to enhance credibility, reminders to step away from the data, and connection to Morse’s (1994) four cognitive processes to ensure that a higher level of analysis occurred.

I spent a lot of time immersed in the data by reading and re-reading the interview transcriptions. According to Thorne (2016), knowing the data helps the researcher easily navigate the information and facilitates a deeper analysis. After I was familiar with the data, I
spent time highlighting key content and identifying potential topics. I categorized possible topic names in bold and provided a description of my thought process and my reflections using the Microsoft Word comments feature. At this time, I also highlighted quotes from the data that aligned with the topics and seemed to capture what the participant was experiencing.

Afterwards, I challenged my initial thinking around the groupings by re-reading, re-analysing, and reflecting again. This strategy allowed me to spend more time with my notes with the intention of enhancing my analytical structure. Next, I created a list of key ideas that summarized the points the participants made in the interview. Some of the key ideas that emerged included “symptoms”, “information”, “discharge/discharge instructions”, “why me?”, “cardiac rehabilitation”, and “social media”. The interviews were structured in a way that allowed/triggered the women to share their story chronologically, which allowed me to compare for variation and commonalities in the key ideas across the seven cases. However, it was also important for me to recognize and reflect on how the use of a chronological structure may have influenced what the data set did and did not contain throughout the analysis.

The second stage of analysis began when each concept was analyzed individually across all seven participants, followed by comparing the key ideas to each other. Throughout this process, I asked myself questions such as “what am I seeing here?”, “what is the participant telling me?”, and “what are the similarities/differences between the participants?”. With this strategy, I was able to recognize patterns between each participant and between my groupings of the data. I made sure to allow my mind to move back and forth between ideas in the data (Thorne, 2016). This was an important step, as some ideas, such as lack of information, occurred at diagnosis of SCAD, during hospitalization, and at home after discharge. Therefore, with this strategy, I was able to deeply analyse the lack of information across the entire participant’s
SCAD timeline. What emerged from the comparisons allowed me to establish a conceptual framework in which to present the descriptions of the women’s experiences with lifestyle management after SCAD.

**SCAD Illness Trajectory**

The participants described a trajectory of their illness from onset of symptoms to being at home living with their diagnosis. The most common initial symptom the women identified was chest pain, which they often attributed to other, non-cardiac causes. All of the women initially took steps to resolve the symptoms, such as taking antacids, or they ignored them. Once the participants realized that they needed to go to the hospital, they still did not recognize the seriousness of the situation and assumed they would return home shortly after being assessed by a health care professional (HCP). One participant stated: “I went to the ER that night, still at this point in denial, my husband and I thinking that I’m going to get let out and it’s no big deal”. The women described feeling shocked and surprised to find out that they were having a heart attack. When they were told they had experienced SCAD, the study participants reported not having enough information on the diagnosis and they did not understand how it was different from atherosclerotic acute coronary syndrome (AACS). They spend several days in hospital after their angiogram but recalled that, at that time, HCPs did not provide them with any further explanation or knowledge about SCAD. Additionally, the participants were having ongoing symptoms that were confusing and caused a lot of anxiety. The participants said HCPs were very nonchalant about their discharge and that they left the hospital with minimal information on SCAD and how to recover at home. One participant discussed her experiences at the time of her discharge: “There was no eureka moment when I left. Like, okay. Like, it was just really nonchalant”.
Once at home, the participants struggled with ongoing physical symptoms and fatigue, which caused them stress and anxiety. The women described not knowing how to resume their daily activities out of fear of reoccurrence, their knowledge deficit, and their physical symptoms. As a result, the women’s lives were “on hold” until they had a better understanding of the cause of their SCAD, their risk of recurrence, the expectations of how they would feel after the event, what their daily restrictions were, how to start exercising again, and when and how to return to work. The study participants described not having proper sources of information as their general practitioners (GP) and general cardiologists weren’t able to provide them with consistent direction on how to manage their lifestyle. The women were told to wait to see the SCAD cardiology specialist to have their questions answered. Unfortunately, the women had to wait between four and eight months for their appointment with the specialist. In the meantime, cardiac rehabilitation (CR) and social media offered some additional support to some of the participants, but the participants perceived that the best source to help them adjust their lifestyle was the SCAD specialist. The participants in this study also shared that while they waited to see the specialist, they were able to identify what information they needed about SCAD and implement coping strategies to assist them with their physical and mental health. The participants were highly motivated to make modifications in their lifestyle, but there were barriers in their trajectory that delayed their ability to make changes. Additionally, at the time of the interview, the participants continued to describe ongoing needs with physical and mental health that were not being properly addressed by the health care system.

**Organizational Structure**

The participants of this study were lost in an unfamiliar diagnosis of SCAD, which is the overarching theme that emerged from the data. In order to fully capture how the women felt lost
in their diagnosis, the organizational structure of this chapter will include four sub-themes that describe the participants’ experiences with SCAD. These four sub-themes include: being diagnosed with a rare disease, swirling in an information vacuum, finding something to hold on to, and reconstructing life. Given that SCAD is a relatively rare disease, the participants in this study felt lost within the health care system because they did not fit the mold of a patient with an AMI. They were young, previously healthy females who were experiencing new, unusual symptoms that left them feeling confused by this unexpected and spontaneous event. From the time they arrived at the hospital, the women were swirling in an information vacuum in that they were not provided with much information about their diagnosis while in hospital, at discharge, and while they were recovering at home. At different points in their recovery, the women found something to hold on to when they saw the SCAD cardiology specialist, attended CRP, and/or accessed social media. After addressing some of their post-SCAD care needs, the participants were able to begin reconstructing their life, although they still felt somewhat lost in their diagnosis due to ongoing knowledge deficits among HCP and the women themselves.

**Being Diagnosed with an Unfamiliar Disease**

As outlined in the literature review, SCAD is underdiagnosed; therefore, its exact prevalence is unknown. However, based on current data, it is estimated that 1-4% of patients with acute coronary syndrome have experienced SCAD (Saw et al, 2016). The diagnosis, treatment, and management of SCAD are different from AACS; therefore, patients experiencing SCAD do not fit the mold of a patient with AMI. The participants in this study described feeling shocked and surprised when they were diagnosed with SCAD. They also denied the diagnosis. This may be partially because they were young healthy women who did not have many, if any, cardiac risk factors such as diabetes, smoking, or inactive lifestyle. In addition to being
uncommon, SCAD is also a spontaneous, unpredicted cardiac event, which more than likely caught the women off-guard by the diagnosis. One participant shared: “I would probably be less surprised if it was just an actual heart attack”.

The symptoms the women experienced, both initially and ongoing when at home, made them feel lost and were confusing. The participants were surprised that they continued to have chest pain and felt fatigued after discharge, and they were not sure if this was normal. One participant shared: “I would be asking myself, ‘Oh, my god. Am I having another heart attack?’”. While, another woman said: “You know how many other times I wanted to go to the hospital, to just go there because I didn’t know what was really going on?”. There currently is very little information available detailing what symptoms are normal after SCAD and since the event happened out of the blue, the women feared that it would happen to them again.

All the participants in this study questioned why SCAD had happened to them and had a great fear of it happening again. Given how rare SCAD is, the women wondered why it had occurred in them and they searched for reasons that were specific to them. However, since there is not a great understanding of the exact causes of SCAD, they felt lost in their pursuit and therefore struggled with managing their lives after their event. One participant spoke about the hesitation she felt about making lifestyle changes by not having an answer as to why SCAD happened to her: “You know, when you don’t know why, it kind of makes you more resistant to do something”. Some of the factors that the women thought could be the cause of their SCAD included stress, high blood pressure, strenuous exercise, and lifting heavy objects. The women took steps to avoid these potential causes so that they could prevent reoccurrence, which was a major fear of the participants. Since they did not truly know why they had had a SCAD in the first place and SCAD is an uncommon, spontaneous event that happens unexpectedly, the women
were worried that it would happen again. Additionally, as described above, they had ongoing symptoms that made them wonder if they were having another SCAD.

**Swirling in an Information Vacuum**

The participants in this study felt lost in their diagnosis of SCAD because they were not provided with enough information about their disease, leaving them swirling in an information vacuum. The women described in the interviews that during their hospitalisation, at discharge, and as outpatients, they were not given information by HCPs about SCAD. When they arrived at the hospital, they felt in the dark about what was happening. They were told about their diagnosis during the angiogram, which the women described as an uncomfortable procedure and didn’t seem to be a teachable moment. The women shared that after the angiogram they were not provided with any other information about what SCAD was and why it had happened to them. The women said that most HCPs did not address their ongoing symptoms or tell them what was normal.

All of the participants described their discharge instructions as vague and minimal which the women explained left them feeling nervous and fearful. One participant described her experience with being discharged: “There was a lot of confusion. There was a lot of uncertainty. There was a lot of fear. Like, I had no idea. I had no idea of what to do. Like, is—what symptoms I should be looking for, what my limitations should be, what I can and cannot do, what meds I can and cannot have.”. Many of the women shared that they still had questions at discharge about normal symptoms, limitations, medications, activities, and fibromuscular dysplasia (FMD). Any more detailed instructions they received were different for each study participant. For example, one woman was told no lifting, pushing or pulling while another was told no jogging. As a result of their knowledge deficit, women were lost with what activities
they were able to do at home. A lot of the participants were told to rest and take it easy, but they did not know what that meant or how long they should rest for before they would be able to start reintegrating activities into their lives.

For the most part, the participants’ GPs had very little knowledge of SCAD. Additionally, GPs consistently told participants that they were not comfortable answering questions about SCAD, and they would defer to the SCAD specialist. When directing care, it did not seem as if there was consistency between GPs plans of care. For example, one woman was given very strict activity restrictions, while another woman was told to follow minimal restrictions. The few women who saw a cardiologist prior to seeing the SCAD specialist reported similar situations in that their cardiologist did not have a lot of knowledge about SCAD and told the women to wait to discuss their concerns with the SCAD specialist. Because of this lack of knowledge of the GPs and cardiologists, women described feeling even more lost in their recovery, as they were unable to get answers to the specific questions they had in a timely fashion.

Since the participants were not given enough information about SCAD to manage their disease, the women described their lives as being “on hold” while they waited for the answers they needed. Having been discharged with minimal instructions and not having reliable information sources through their GPs or general cardiologist, the women were forced to wait for their appointment with the specialist to find answers. Unfortunately, the waiting time to see the specialist was four to eight months, which the women shared was a long time to wait for answers to their questions. The women described not being able to move forward until they gained more information about SCAD, more specifically why it had occurred to them and how to prevent it from happening again.
The women identified what information they were missing while their life was on hold and shared in the interview that they wanted more information on how SCAD heals, physical restrictions, medications, symptoms, long-term treatment goals, when and how to return to work, and, above all, reoccurrence. One participant shared: “You need to actually sit down and talk to—somebody actually needs to come talk to you, explain exactly what it—because I didn’t fully understand what it was until much later”. As described above, wondering why this happened and fear of reoccurrence were two major issues for the participants of this study. The women were not told by HCPs reasons why this may have happened nor were they given strategies to try and prevent it from happening again. The women were left to search for this information alone and had to make guesses as to why it happened until they received confirmation from the specialist. After the participants found a potential reason that seemed to fit with their story, they could do things to help prevent reoccurrence. One participant explained how knowing why made her feel better about reoccurrence: “Because for me, my reassurance comes from knowing that it’s not going to happen again. I know there’s no guarantee, but to know what to avoid would be—would make me feel much better.”. Another woman described the importance of knowing why and related it to reoccurrence: “I think knowing what has happened or why it happened will give you more tools to try to prevent what—it happening again”. A third participant thought the reason she had experienced SCAD was because she had engaged in highly strenuous exercise that involved a lot of heavy weight lifting just prior to her SCAD. Therefore, she avoided this activity after her event. By avoiding this activity, she felt she had regained some control of her health and was able to start re-introducing other safer types of exercise. Later, when they saw the SCAD specialist, the participants were provided with more
probable causes of their SCAD and they were given information on restrictions and strategies to avoid reoccurrence.

**Finding Something to Hold on To**

The participants in this study identified things that they were able to hold on to in order to gain a better understanding of their SCAD diagnosis. The participants took back some control of their lives by identifying information they needed about SCAD and implementing coping strategies while they waited to see the specialist. On top of this, they also had an appointment to see the specialist, attended CR, and/or accessed social media sites. Overall, the women who were interviewed received much needed support from two or more of these sources, however, not all of them had good experiences with CR.

Identifying what information they were missing and developing coping strategies to use while they waited for answers grounded the participants by giving them a place to start considering how to manage their lives after their event. By identifying what information they needed about SCAD, the women were able to begin searching for answers and start to evaluate which sources would be the most beneficial. While they waited to find answers, the most common coping strategy utilized by the participants was to sit down and take some deep breaths. This was often used when they were participating in physical activities and they started to feel chest pain, palpitations, or shortness of breath. One participant found comfort in knowing that her medication was close by. While these two strategies were beneficial to the women to help them begin to resume daily activities, the participants stated that they also needed support from outside sources, including the health care system.

Perhaps the biggest “stick in the sand” for the participants to hold on to was the SCAD cardiology specialist. All but one of the women interviewed had seen the specialist and all of
them gained a lot more information about SCAD at that appointment. The women reported that they had had a lot of their questions answered by the specialist around why SCAD occurred, rates and causes of reoccurrence, activity restrictions, exercise, available programs, returning to work, and medications. The participants reported that after gaining information from the specialist they felt significantly better and less anxious. One woman talked about how she felt after seeing the specialist: “I just felt better because I had more information, because it was really lack of information on—for me. Like, nobody really seemed to know anything about it.”. Some participants also stated that discussing SCAD and their situation normalized it for them. Another woman reported that she was able to finally return to her job because the specialist was able to answer her questions and provide her with directions on how to resume her work. Unfortunately, not all the women had all their questions and concerns addressed. One woman shared that after she saw the specialist, she still had questions about reoccurrence and the long-term impact of SCAD on her health. Overall, support provided by the specialist was much needed and well received and helped the women come out of the holding period they were experiencing while they waited for more information about SCAD.

Another source of support identified by some of the women was CR, although not all the women reported CR was helpful to them. Some of the women attended community CR and others attended a SCAD-specific program. Some of the women who attended their community CR were preparing to attend the SCAD-specific one. One woman was not referred to CR and another chose not to attend. When they were able to attend, the participants’ experience with CR was generally good. Participants reported feeling more informed about SCAD which made them feel better about moving forward. Because CR was supervised exercise, some participants felt less anxious and/or more confident with exercising independently at home. One woman shared:
“I knew it was important for me because I do like to jump around a bit, and I thought, oh, I was scared to, to be honest.”. Another participant discussed how she felt more confident about exercising: “Yeah. So seeing that it was okay and what numbers to watch for, and any time I had any questions about anything, they were there to answer them. So I just felt much more informed.” Three participants reported modifying the CR programs to meet their physical and emotional needs. This included cutting the length of the program short and asking SCAD-specific questions in the community CRP. One woman reported that she did not have a good experience with her community CRP because she felt out of place with the patient population (according to her, most of the other participants were older and did not have SCAD). She also did not like the team or the cardiologist at the program because they did not spend any time with her and were not able to provide her with any information on SCAD. For the women who attended CR (both in their communities and the SCAD-specific program), they identified some barriers to attending the entire program. They stated that the program was expensive at about $100/month and that getting to and from the center was an issue at times, especially for those attending the SCAD-specific program. Women also identified the timing of the program as a barrier, as it happened during the work day. While CR provided the participants of this study with information about cardiac health and exercising, more SCAD-specific information about how to rehabilitate from their specific cardiac event was needed, along with better access to these services.

The third source of support that participants identified they were able to hold on to was social media. Some of the social media sites that the participants utilized included the Canadian and American SCAD Facebook pages and groups and the SCAD alliance website and group. Overwhelmingly, many of the participants outlined that social media let them connect with other
people who had experienced SCAD and allowed them to see that they were not alone with their diagnosis. The women reported that they were able to read other SCAD survivors’ stories on social media which allowed them to compare their situation to others’. This also was a great forum for the participants to share their own stories and seek support from others. One participant recalled: “So the Facebook page was really, really good in reassuring me that I’m not the only one, because we’re told that it’s rare.”. A drawback of social media identified by the participants was that the information was not always consistent, and that they had to be careful to filter what they read so that they did not become overwhelmed with information that they could not confirm was factual. Several women reflected on the source of information and described that it was important to rely on the SCAD cardiology specialist for medical advice and use the social media as a source of social support. There also was inconsistency as to who was aware of the SCAD resources on social media. Women reported hearing about the resources at different times in their recovery. At the time of our interview, one woman was not aware of the SCAD Facebook groups.

**Reconstructing Life**

Once the participants of this study were able to hang on to something and find information and support with their diagnosis, they were able to reconstruct their lives and make lifestyle changes. The participants reflected on their knowledge deficits and identified what information they needed, while they implemented coping strategies like taking deep breaths. The three most common anchors for participants were 1) the SCAD specialist providing them with direction on how to avoid reoccurrence and resume activities, normalizing their symptoms, and advising on management strategies such as restrictions and medications. 2) CR, which allowed them to safely increase their heart rates and gave them piece of mind about resuming
exercise. 3) Social media sites, which let the participants see that they were not alone in their rare diagnosis and gave them a source of social support. One or more of these three “sticks in the sand” allowed the participants to begin moving forward and resuming their lifestyle.

The participants began introducing an exercise regimen and returned to work. One woman resumed exercising almost immediately after her SCAD but prioritized attending CR so she could learn how to safely increase her heart rate. Another participant wanted to re-build her endurance so she could resume going for long walks. The specialist and CR helped her to feel physically comfortable with returning to this activity. Another woman was able to continue going to her gym and playing volleyball, despite strenuous exercise being a potential cause of her SCAD. Returning to work was another way the participants were able to start reconstructing their lives. Women whose work was not physically demanding returned to work in the weeks after their event while others who had to do a lot of lifting of heavy objects needed to have accommodations or, in some cases, needed to find a new job completely. Knowing their restrictions and limitations helped them come to terms with their new work situations. Many of the participants also discussed the importance of returning to work from a social perspective, as they felt isolated at home, and most of them enjoyed going to work and being around others.

Towards the end of the interview, the participants in this study were asked to provide advice to newly diagnosed SCAD patients. The women emphasised that once you have the knowledge, your life can go back to normal. For example, one woman said: “I personally feel like life can go on pretty much as normal after a SCAD, and I would reassure them of that, and just say that, you know, I feel like knowledge is power, and that they need to find out as much as they can about it, and without, you know, going to the worst place always, right?” Another woman shared: “Try to get back to your regular life as much as you can. Just go on, enjoy.”.
And finally, a third participants simply stated: “your life can go back to normal.”. The participants also wanted newly diagnosed SCAD patients to know that some lifestyle adjustments are necessary but that once they made the modifications, things would stabilize. One participant said: “I guess I would want to know that it’s going to be okay. You just have to follow all the directions [from the specialist] for a while, and adjust your life accordingly.”.

Despite the participants sharing that life can return to normal, they felt that there was still ongoing information and support that they needed so that they could successfully continue to reconstruct their lives. This indicates that the women are still to some extend lost in their SCAD diagnosis despite being able to begin reconstructing their lives. After their initial appointment with the specialist, the women had only annual follow-up appointments scheduled, leaving their day-to-day management strategies in the hands of GPs who they perceived to be uninformed. Additionally, the women also indicated that they began providing their GPs with more information on SCAD, which made them feel frustrated about there ongoing care management. Furthermore, after they completed the CRP they were left to exercise independently. However, social media continued to be a source of support for some of the participants but again, they identified the need to filter the information and recognize that it was not necessarily evidence-based. The participants in this study identified a need for more ongoing support from the health care system, both physical and mental, in order to more effectively reconstruct their lives.

**Summary**

The data collected from the participants in this study about lifestyle management after SCAD revealed that the women were lost in an unfamiliar diagnosis. There were challenges for them with regards to being diagnosed with a rare disease and swirling in an information vacuum. Their SCAD was a spontaneous, unexpected event which created questions around why it
happened in the first place and if it would happen again. Additionally, the women felt that they were not given enough information by HCPs about the disease while in hospital, at discharge, or when they were recovering at home. This contributed to their feelings of being lost and made the participants feel that their lives were on hold while they waited for answers. The participants were able to find something to hold on to when they began identifying what information they needed and developed coping strategies to utilize while they waited to see the specialist. CR and social media sites provide the women with much need support but the biggest “stick in the sand” was the SCAD cardiology specialist. Once the participants found answers to their questions around SCAD, reoccurrence, resuming exercises and other daily activities, and returning to work, they were able to begin reconstructing their lives. However, participants identified an ongoing need for additional physical and emotional support. The implications of all these findings and how we can use them to make positive changes to the healthcare system that would benefit women after SCAD will be discussed more in chapter 5.
Chapter 5: Discussion of Findings

In this study, I report that women who have experienced spontaneous coronary artery dissection (SCAD) have a unique set of needs when managing their lifestyle after their cardiac event. The main theme that emerged for the women was that they were lost in an unfamiliar diagnosis. SCAD is a rare cardiac event; due to lack of knowledge of the condition, the participants were left swirling in an information vacuum. The women found something to hold on to when they saw the SCAD cardiology specialist, attended cardiac rehabilitation (CR), and/or accessed social media as a form of support.

In this chapter, I will discuss the implications of these findings. As anticipated, we found that a need for knowledge about a cardiac event at diagnosis, while in hospital, at discharge, and when recovering at home, and the need to find out why this event occurred in order to prevent it from happening again, were common for the participants. These findings were somewhat expected as they are also commonly reported in the literature among most female patients with acute coronary syndrome (ACS). However, what is unique to SCAD is the fact that it is a rare cardiac event which is different from other forms of ACS, in that it mostly affects previously healthy younger females. Additionally, SCAD is poorly understood within the cardiac sciences, placing these women in a unique situation of being unable to obtain timely and expert advice on the event, why it happened, what to expect, and how they ought to try to live with it for a protracted period of time. In this context, social media took on a level of importance that was surprising and helped fill some gaps with both social and informational support. By discussing the themes that are unique to these study participants, it is my hope that this study can inform current practice in order to contribute to a better recovery environment for women after SCAD.
**SCAD: The Shared Experience with ACS**

The findings of this study reveal that there are some aspects of the participants’ recovery from SCAD that seem to be similar to the recovery of women from ACS. Initial and ongoing symptoms, minimal informational support from HCP while in hospital, missing key recovery and management information, fear of reoccurrence, and learning how to manage a new diagnosis were all common experiences reported among these study participants and also among women with ACS (Galick, D'Arrigo-Patrick, & Knudson-Martin, 2015; Smith, Frazer, Hall, Hyde, & O'Connor, 2017; Stevens & Thomas, 2012). Given these shared experiences, some of the current knowledge on women with ACS could be applied to women with SCAD. Two of the most prominent themes that emerged from the data that were consistent with the ACS literature were the need for more information on their diagnosis and the need to understand why the event happened in order to prevent reoccurrence.

Throughout their experiences, the participants reported that they were not provided with enough information on SCAD during their diagnosis, hospitalization, discharge, and while recovering at home. This is similar to the findings from the literature on women with ACS, in that they, too, reported having had challenges obtaining information from HCP about their diagnosis (Galick et al., 2015; Hildingh et al., 2007; Stevens & Thomas, 2012). One possible explanation as to why women with ACS have more challenges obtaining information when compared to men is that there is a known gender bias within the science and practice of cardiac care. As a result, women are under-researched, under-diagnosed, and under-treated (The Heart and Stroke Foundation of Canada, 2018). It has been reported in the literature that many women perceive that HCPs consider ACS to be a disease mainly affecting men (Galick et al., 2015; Murray, O'Farrell, & Huston, 2000); therefore, the current gender bias may be contributing to the
lack of information provided to women with ACS and to women with SCAD. Furthermore, HCPs do not seem to have sufficient knowledge of the gendered aspects of ACS to properly educate female patients (The Heart and Stroke Foundation of Canada, 2018). The literature suggests that women and men may experience ACS differently for several reasons. First, even though they have similar risk factors, the risk factors affect them differently (Kostapanos, Florentin, & Elisaf, 2013). Next, women have different barriers to making lifestyle changes after ACS (Hart, 2005). Finally, women have different psychosocial needs after ACS when compared to men (Kim et al., 2000). The fact that there are documented differences between men and women and that many HCP seem to be unaware of these differences, may help explain why women with ACS informational needs are not being met. This could also be true for women with SCAD, in that they may be provided with information that is more relevant to patients with ACS, which is atherosclerotic in nature. The Heart and Stroke Foundation of Canada (2018) states that women with ACS should receive individualized care from HCP in order to help address the gender bias. This need appears to also apply to women with SCAD since, not only do they have the challenge of overcoming the existing gender bias, but they are also struggling with a relatively newly identified form of ACS and there is not a lot known about the condition.

The other theme that emerged from the data, that was consistent with the literature on atherosclerotic ACS (AACS), was the need to find out why this event had happened as a means to prevent it from happening again. Smith, Frazer, Hall, Hyde and O’Connor (2017) reported that women felt fearful at discharge after AACS because they were worried about recurrent myocardial infarction (MI). Additionally, two other studies found that women raised questions as to why the MI had occurred in them in the first place (Lacharity, 1999; Stevens & Thomas, 2012). Similarly, the participants of this study verbalized a major fear of recurrent SCAD and
suggested that they needed to know what caused their cardiac event in order to take steps to prevent it from happening again. This fear contributed to their inability to immediately make necessary lifestyle changes, both because they did not understand the condition in general and also because they were unable to make sense of what aspects of their own life and behaviors may have placed them at risk for being affected.

**Distinctive Features of the SCAD Experience**

**SCAD as a Serious Diagnosis in a Young, Previously Healthy Woman**

As previously outlined in chapter 3, approximately 90% of patients with SCAD are female with the mean age being between 44-55 (Saw, Aymong, Mancini et al., 2014; Tweet et al., 2014). The current literature on patients with ACS suggests that women have a different set of physical and emotional needs in their recovery when compared to men. Furthermore, some researchers have compared the needs of younger and older women with ACS and reported that they too are different (Mallik et al., 2006). Since the SCAD patient population is predominantly younger females, we can appreciate that some of their experiences may be very different from that of typical patients who more commonly experience AACS. Because of these age and gender differences, much of what we believe we know, based on the current research that has been conducted predominantly on men and older women with AACS, is not necessarily applicable. It is also the case that women with SCAD cannot be clinically managed in the same way as women and men with AACS, as they present with their own distinctive set of needs. To my knowledge, this is one of the only studies to date that has sought out to uncover the unique needs of younger, female SCAD patients.

One contemporary case series with SCAD patients revealed that 70% of women did not have any cardiac risk factors prior to their event (Saw et al., 2017). Additionally, other research
found that women who experience SCAD are typically physically active and have good general health prior to their event (Hayes, 2014). Therefore, given their current health status, it can be assumed that with the onset of symptoms, many women would not suspect that they would be at risk of having a major cardiac event. The women in this study presented to the hospital with unpleasant and uncomfortable symptoms, but they did not think that these symptoms would amount to anything serious. They were shocked and surprised to learn that they were experiencing a “heart attack” that was life-threatening, of a rare form, and poorly understood. They suddenly went from being in good health to having to cope with and manage a condition that required them to make changes to their lifestyle. The spontaneous nature of SCAD seems to add a layer of complexity with regards to accepting and understanding the disease and greatly contributed to the participants fear of reoccurrence. Additionally, there is not a lot known about the causes of SCAD, so there does not seem to be much patients can do to prevent the event from happening again, leaving these younger, previously health females feeling lost in the early stages of their recovery.

**SCAD as a Rare Cardiac Event**

Current research on SCAD is limited, therefore its true prevalence is unknown. It is estimated by some experts that SCAD is the etiology of 1-4% of all cases of ACS (Saw, Mancini, & Humphries, 2016) but up to 35% of ACS in women under the age of 50 (Tweet et al., 2012). Given its rarity in the cardiovascular disease context, patients’ experiences with a diagnosis of SCAD may bear some similarity to the experiences of other patients diagnosed with a rare disease. A rare disease in Canada is defined as a diagnosis affecting less than 1 in 2000 people (Rare Disease Foundation, n.d.). Much of the literature on rare diseases identifies informational and emotional needs as top priorities for patients. Overwhelmingly, patients
diagnosed with rare diseases report that they have limited knowledge and understanding of their diagnosis and that reliable information is scarce and hard to find (Baumbusch, Mayer, & Sloan-Yip, 2019; Currie & Szabo, 2019; Germeni, Vallini, Bianchetti, & Schulz, 2018). The participants in this study reported similar findings, as they felt they were lost and did not have sufficient information to move forward. Additionally, there was the added stress of being diagnosed with a condition that none of their family or friends had heard of. Similar to the literature on rare diseases, the study participants recognised that they were not provided with information partially because little is known about SCAD and therefore, HCPs did not have the knowledge about the diagnosis to share with patients. This lack of knowledge and confidence in HCPs to guide patients could be attributed both to the fact that there are no clear care guidelines and also that HCPs are often hesitant to provide guidance when they perceive a health condition to be both rare and high risk (Wallenius, Möller, Berglund, Hälsokademin, & Örebro universitet, 2009). However, the participants also reported that their HCPs were not always forthcoming about their potential knowledge deficit and that they did not seem to want to take the time needed to help them find answers. As a result, the participants were left to find alternative sources of information independently. Eventually, the women in the study began providing information about SCAD to other HCPs, especially their general practitioner (GP). The literature on rare diseases reports that patients and actively involved family members often become experts on the disease and frequently know more than those coordinating much of their care (Baumbusch et al., 2019; Currie & Szabo, 2019; Morel & Cano, 2017). Applying this idea to SCAD survivors, there appears to be an opportunity to utilize SCAD survivors as experts in their disease which would allow for more collaboration between HCPs and SCAD patients in identifying gaps in knowledge. Additionally, involving SCAD patients directly in care could
motivate them to actively manage their diagnosis and improve their health. For example, HCP could explore with each SCAD survivor the biggest challenges terms of management and collaboratively set goals that are realistic given the patients perspective and individual lifestyle.

The literature on rare diseases highlights the importance of peer-to-peer support of patients and family members diagnosed with a rare disease. One study drew attention to the importance of peer-to-peer support and identified the benefits of forums like social media because they increase the availability of support to patients and are not limited by geographical boundaries (Baumbusch et al., 2019). The use of peer support could help address some of the support gaps identified by the participants of this study and would allow SCAD survivors to develop and share their expertise on the disease. The participants revealed that they needed social support during their recovery and some of them were able to gain access to available peer support through social media. However, not all of the participants were aware of options for social support, bringing to question the ways in which management strategies are currently being shared with patients. The women who did access peer support online emphasized the benefits of discussing SCAD with other survivors and shared how these discussions normalized their event and made them feel as if they were not alone in this unfamiliar journey. The positive effects of social support reported by the women revealed a need for regular peer support for women after SCAD. The Canadian Organization of Rare Disorders (2015) has identified strategies to better support people living with rare diseases with one of the recommendations being to enhance community support groups. Based on the findings from this study, it seems that a strategy for enhanced, formal community support would also be beneficial to SCAD survivors.

Along with a need for peer support, the study participants shared that they were also missing emotional support from HCP after their SCAD. Similar findings were reported in
studies reviewing HCP support of patients with rare diseases’ emotional needs (Baumbusch et al., 2019; Wallenius et al., 2009). One study on patients with rare diseases connected high levels of stress to a negative impact on mental health and overall quality of life (Anderson, Elliott, & Zurynski, 2013). The women in the current study shared that they found the first few months of their recovery stressful and needed help coping with their new and confusing symptoms. Most of the women reported that they received little to no emotional support from their GPs and other HCPs, which increased their stress levels. Other SCAD research has reported that not only are women with SCAD at risk for developing anxiety and depression (Liang, Tweet, Hayes, Gulati, & Hayes, 2014), but patients actually have increased stress and anxiety after SCAD (Wagers, Stevens, Ross, Leon, & Masters, 2018). This evidence suggests that women with SCAD seem to need support with the emotional aspects of their diagnosis and currently, HCPs are not meeting these needs. More research exploring SCAD survivors’ specific emotional needs and best ways to provide support needs to be conducted.

Clinical Management in the Absence of Evidence-Based Guidelines

ACS is defined as any disruption of blood flow through the coronary arteries and it is most commonly caused by atherosclerosis or a build up of plaque (Woods, 2010). Current research that aims to support recovery management strategies is focused on ACS that is atherosclerotic in nature. This means that current practice standards for ACS prevention and rehabilitation are centered around managing the specific disease process of atherosclerosis, such as controlling diabetes, smoking cessation, modifying diet, and exercising -- all modifiable risk factors (The Heart and Stroke Foundation, 2017c). The SCAD condition process is very different from AACS; therefore, management of SCAD does not fit the mold of management of AACS. Diabetes, smoking, poor diet, and sedentary lifestyle do not seem to be major risk
factors for SCAD (Saw, Aymong, Sedlak et al., 2014). Therefore, when it comes to prevention and risk management, the clinical guidelines that are ultimately established for SCAD patients will be quite different from those for patients with AACS. Instead, the literature suggests that possible risk factors for SCAD may include such conditions as fibromuscular dysplasia (FMD) and systemic inflammatory disease and it points to possible precipitating causes such as stress and high intensity exercise (Saw et al., 2016). While SCAD patients may be able to modify their risk related to precipitating factors, they cannot modify many of the current known contributors to SCAD such as FMD. Thus, exploratory research must continue, as what causes and contributes to SCAD are still not fully understood. It is therefore not surprising that the participants in this study reported a loss of control around not knowing why SCAD had happened to them and not being able to modify their risk factors in order to prevent reoccurrence.

Diagnosis of SCAD poses challenges as this cardiac event is unfamiliar to many HCPs. The women in this study reported feeling uninformed at the time of diagnosis and while in hospital recovering from their cardiac event, because of the uncertainty around their new, unexplained symptoms. A potential cause of this could be that there are no clear guidelines as to the best way to diagnose and treat SCAD. Saw et al. (2016) suggests that the best diagnostic tool for SCAD currently available is angiogram, but it offers only two-dimensional views of the coronary arteries, which may make the dissection difficult to visualize. For example, one woman who was initially interviewed was subsequently excluded because it was determined that she did not have SCAD, but rather coronary spasms. She had been waiting four months for a definitive diagnosis from the expert SCAD cardiologist, because the interventional cardiologist who had performed her angiogram could not determine whether or not her condition was SCAD.
This demonstrates the challenges with diagnosis of SCAD and could also be a major reason why the true prevalence of SCAD is unknown.

When they received their initial diagnosis, most of the participants in the study shared that they were only told that they had experienced SCAD but that they did not know how it was different from AACS. As a result, many women had no idea what was usual for SCAD or whether the usual things that apply to AACS were applicable to their case. The women described feeling out of place in the hospital because they did not present like a typical heart attack patient. They compared themselves to the other patients around them who were often much older and male, which made them feel out of place. Unfortunately, no one was able to explain to them why and how they were different. This gap in care could have potentially increased their stress and anxiety and contributed to challenges with disease management. It seemed that the women faced barriers with knowledge and understanding of their condition at the time of their diagnosis because they did not fit the mold of a typical patient with AACS.

The current recommendation for treatment of SCAD is to manage patients conservatively (no revascularization interventions) unless medically necessary (Saw et al., 2014). Unfortunately, this recommendation is not based on evidence, but only on expert opinion because the only studies available are contemporary case series with a small number of participants. The fact that there are generally no significant medical interventions for patients with SCAD could further contribute to the women’s fear of reoccurrence. Clearly, considerably more research will be required before a body of evidence to support an intervention plan will emerge. Current treatment plans rely primarily on pharmaceutical agents, but little is known about the benefits of medications such as Aspirin, cholesterol-lowering agents, anticoagulants, and angiotensin converting enzyme inhibitors in SCAD patients (Saw et al., 2017). Experts
advise that SCAD patients should take a beta blocker to reduce coronary artery shear stress (Saw et al., 2014); however, the women in the current study reported unpleasant side effects with beta blockers and didn’t have a clear understanding of their importance until after they had seen the specialist. Before gaining this knowledge, some of the participants admitted that they had advocated to have the beta blocker discontinued. It was observed that the SCAD specialist has implemented some strategies for women to alleviate some of the unpleasant side effects of beta blockers including recommending the patients take a lower dose of Bisoprolol\(^4\) just before bed. As a result of the timing and lower dose, the side effects are less prominent and are mostly present when the patient is sleeping. However, the participants’ GPs were not aware of this option, as the women reported only hearing about this through the specialist. Because taking a lower dose of Bisoprolol at night worked to alleviate some of their unpleasant symptoms, the women felt frustrated that their GPs had not made this adjustment earlier in their care. Since treatment options for SCAD are currently under-researched and not well understood, it is easy to see why HCPs may not have had a clear understanding and specific strategies on how to manage treatment strategies for a young, previously healthy, female patient. In the absence of evidence-based guidelines, it is difficult to coordinate efforts between HCPs in the management of SCAD.

It is reported in the literature that some cardiologists who specialize in SCAD recommended that survivors attend cardiac rehabilitation (CR) after their event to support them with resuming exercise, disease management, and mental health (Silber, Tweet, Bowman, Hayes, & Squires, 2015). The participants in this study who attended CR emphasised how the program supported them mainly with resuming activities, as most of them stated they felt a lot better.

\(^4\) Bisoprolol is a type of beta blocker that is usually only taken once a day while other beta blockers are taken more than once (Woods, 2010)
exercising in a controlled environment and under the supervision of an HCP. However, the women did not seem to utilize the other offered aspects of CR such as medication counselling or emotional or social support. Most of the participants ended their program early after they felt confident exercising alone. There could be several reasons why the women did not fully access CR and/or cut the program short. Perhaps the participants in this study did not feel that the medication counselling applied to them with regards to SCAD. As suggested above, pharmaceutical treatments for SCAD are poorly understood, so patients with a SCAD medication regimen can be very different than patients with AACS. It seemed that the women in this study recognized that they were different from other CR participants, and therefore felt they needed to await specific guidance from the specialist about medications. In terms of social support, the literature on women with AACS reports CR did not meet their recovery needs in many aspects including with emotional support (Murray et al., 2000). This could be true for SCAD patients attending CR as well, given that they are younger female patients. Additionally, the women in this study reported that they accessed social support through social media; therefore, this forum could have been sufficient in meeting this need, making the support offered by CR unnecessary. Furthermore, the participants identified the timing of the CR challenging, as it was often scheduled in the middle of the workday. I can speculate that the women prioritized their need to resume exercise followed by their need to return to work. Interestingly, a SCAD-specific CR program has been developed (Chou et al., 2016), which validates that there are major differences in recovery and management strategies between SCAD and AACS. It would be interesting to see if women who attended the SCAD-specific CR also mostly utilized the exercise component of the program and stopped attending when they felt comfortable exercising alone. It would also be interesting to explore which other components of CR are useful to SCAD survivors including
psychological services. This information would provide HCPs with a better understanding of the physical and emotional needs of women after SCAD.

Currently, there does not appear to be sufficient infrastructure in place to support women after SCAD. Once discharged from the hospital, the women shared that their GPs coordinated their care while they waited four to eight months for their initial appointment with the SCAD specialist. Some of the participants were also referred to CR but, other than that, there was no other support from the health care system available to them as outpatients. The women had not been given clear management instructions at discharge, raising the question of how one copes without access to anything by the way of clear guidelines. Searching for answers, the women visited their GPs for support, but reported that their GP did not appear to have the knowledge or resources needed to coordinate their care. Seeing the SCAD cardiology specialist was generally a positive experience for the women in the study, because they were finally provided with more guidance on how to manage their diagnosis. However, the study participants shared that they only had had one appointment with the specialist and that their follow-up appointments were only scheduled on an annual basis. This poses a significant problem with access to ongoing care, as the participants were forced to rely once again on their less-informed GPs to manage their care between the specialist appointments. One study on rare diseases had similar findings and highlighted that health problems for patients with rare diseases do not arise only at the time of the specialist appointments (Baumbusch et al., 2019). Despite the fact that the participants with SCAD were much better equipped with management strategies after seeing the specialist, the issue around ongoing follow-up and support appeared to be a major problem, making it difficult for the participants to reconstruct their lives as they continued to manage their condition.
A Life on Hold

A shared experience among the women in this study was that they felt as though their lives were on hold for an extended period of time because they lacked knowledge about SCAD and had limited sources of information to help them manage their condition. As described in chapter 4, the study participants struggled to obtain information about their diagnosis in the first several months of their illness journey. They were provided with minimal and inconsistent instructions on how to resume their lives back in their communities. Once at home, they experienced ongoing, confusing symptoms and were hesitant to do anything, which they naturally responded by staying away from any sort of physical activity that would increase their heart rate. Given that these women were for the most part previously healthy prior to their event, it may have been a significant challenge for them to spend their days resting on the couch. It was clear that women needed more specific information at the time of discharge from the hospital on how they would physically and emotionally feel at home and directions as to what and how much activity they could engage in. Having more detailed information could have alleviated the participants fear of resuming daily activities and avoided the prolonged feeling of their lives being on hold.

Shortly after discharge, the participants turned to their GPs to provide them with much needed answers to their questions about SCAD. Unfortunately, many of the study participants reported that their GPs lacked the knowledge about SCAD to properly advise them and manage their condition. In fact, several of the women reported that they had to provide their physician with information on their diagnosis, as many of the GPs had not even heard of SCAD. Furthermore, the women described that their GPs often deferred their questions to the SCAD specialist, instead of taking the time to attempt to find the answer themselves. As a result, the
women did not receive much information about SCAD from their GPs. One can imagine how the women felt when they walked into their GP’s office, expecting to gain answers to their questions, only to leave the office with the same uncertainty they had when they arrived. This lack of knowledge on the GPs’ part greatly contributed to the women’s lives being on hold, as they were forced to wait several months for their specialist appointment to obtain information about SCAD. Although the participants did try to access information about SCAD online, the participants shared that they needed to speak with a HCP that understood their condition. This highlights how patients rely on HCP to help them navigate their health issues. Unfortunately for the participants in this study, their GPs were unable to properly support them in this context and thus contributed to a delay in resuming a normal life after SCAD. Research has shown that being provided with information and education about a diagnosis has many benefits, including increased involvement in care and a more positive overall well-being (Decker et al., 2007; Mordiffi, Tan, & Wong, 2002). Therefore, further implications of the participants’ lives being on hold could be that while women waited to see the specialist, they were not as involved in their care as they could have been. Additionally, perhaps they had an increase in stress and anxiety related to not having access to much needed information about their diagnosis.

While the study participants’ lives were on hold as they waited to see the specialist, reintegrating exercise and resuming work were both challenging for some of the women. After receiving little direction on how to start exercising at discharge and from their GPs, the women were left to experiment with different levels of physical activities that they guessed were safe. Generally, the women were cautious, and the process was slow, as anytime symptoms reoccurred or their heart rate would rise, the women reported that they would stop the activity. It is well known that physical activity or exercise has significant benefits for cardiovascular and mental
health (Penedo & Dahn, 2005). Therefore, by delaying returning to physical activities, the women were not reaping the associated health benefits. Better guidelines to provide direction to SCAD patients on how to resume physical activity need to be established.

The participants in this study also described having challenges with returning to work after their SCAD. The women’s anxiety levels were different, depending on the nature of the work they did, but the majority of them were nervous about the day-to-day activities required in their job. Because of the physical process of SCAD and the risk for reoccurrence, it is recommended that women do not lift more than 20-30 pounds at any time after their event (Saw et al., 2016). For many of the study participants, this restriction impacted their ability to do their jobs. It seemed that each profession had a unique set of challenges, indicating that when and how to return to work may need to be handled on a case-by-case basis. When their job was not physically demanding, women were able to return to work fairly quickly after their SCAD, while others had to quit their jobs outright because they were too labour-intensive. Research has shown that adverse changes in employment after ACS result in worse quality of life and higher rates of depression (Warraich, Kaltenbach, Fonarow, Peterson, & Wang, 2018). Therefore, it’s possible that a delay in returning to work or changing jobs completely caused financial stress for some of the women after SCAD, resulting in more stress, anxiety, and depression after the diagnosis.

The women gained the much-needed information on how to manage their SCAD diagnosis during their appointment with the specialist and then were able to start making lifestyle adjustments. This timepoint resulted in their lives no longer being on hold. The specialist provided information on re-introducing exercise, returning to work, symptom management, treatment options, and reoccurrence rates. The women reported having more confidence in their
day-to-day activities and how they felt they had regained some control by being able to implement basic strategies to avoid precipitating another SCAD. Based on the participants’ accounts of their illness trajectory, it seems that there is an opportunity to ensure that women are given access to reliable information immediately after their SCAD. If the women had received similar information from their GPs, potentially they would not have experienced an extended time when their lives were on hold, as they would have had the tools to safely implement management strategies earlier in their recovery. The participants in this study were able to identify what information they received from the specialist that allowed them to return to a more normal way of life. This indicates that, despite the rare diagnosis, information is available about SCAD, but there is a problem with access to the information in a timely manner. Perhaps there need to be better strategies for information sharing among HCP including exploring effective avenues to communicate information between HCPs. Establishing guidelines may also help HCPs better understand how to support a patient after SCAD. However, research has indicated that patients with ACS would like individualized care and this approach improves their overall well-being (Decker et al., 2007); presumably SCAD patients are no different in that regard. Therefore, there does need to be some critical thinking by the HCP who is coordinating care, to ensure that SCAD survivors get individualized care. For example, as discussed above, when and how to return to work should be evaluated on a case-by-case basis. It seems unnecessary and unreasonable for women to experience an extended period of time when their life is on hold after SCAD. Therefore, it is essential to explore ways that HCPs and the health care system can prevent this delay in care from happening to future SCAD survivors.

Of interest, CR appeared to contribute positively to the participants’ recovery by providing the women with the opportunity to resume exercising in a supervised environment.
The women shared that they felt much better initiating their return to exercise in a controlled way and that once they felt more confident exercising independently, they chose to no long attend CR. This indicates that the fear and anxiety the women felt around exercising after their event could have contributed to their inability to reintegrate exercise in their lives. Given this, it seems as if increased access to information about SCAD along with supervised reintegration of exercise may be beneficial to SCAD survivors.

**The Surprising Role of Social Media**

Social support plays a key role in improving mental health and quality of life with patients after ACS (Bucholz et al., 2014). The surprisingly positive role of social media as a means for social support for the women who participated in the study emerged from the data. The participants in the study accessed SCAD-specific sites, such as Facebook groups and the SCAD Alliance. The women explained the emotional benefits they received by being able to read other SCAD survivors’ stories and share their own on these forums. This form of social support allowed them to compare their situation to others and normalized some aspects of their diagnosis. One study that uncovered the importance of social support for people diagnosed with a rare disease also reported that patients benefited from the opportunity to compare their situation to others (Germeni et al., 2018). This information points to the need for increased social support for SCAD survivors and that ongoing peer-to-peer support may greatly benefit women with SCAD. In the case of these study participants, the information they gained about SCAD on social media was the only information they had access to. The women recognized that they needed to be aware of the source of the information on social media, but they were able to gain some insight into what their life may look like after their SCAD through reading about other SCAD survivors’ experiences. Unfortunately, not all participants had access to the Facebook
SCAD group or knew about the SCAD Alliance. There did not seem to be a formal process in place to ensure all women in the province diagnosed with SCAD were provided with suggestions for social support. Given the reported benefit of social media as a form of social support, moving forward, we need to pay attention to helping patients find the appropriate mechanisms for social support and information, which would include accessing online supports.

Although the participants in this study seemed to benefit greatly from social media as a form of social support, there are certainly both advantages and risks associated with accessing this type of forum. Social media is easily accessible and can be used anywhere in the world. Additionally, it gives people the opportunity to connect with others that are not necessarily geographically close to each other. This seems to be relevant to SCAD patients, given the lower prevalence of the condition. However, SCAD survivors should be aware of any privacy issues that may become problematic if there is a breech in the forum. Additionally, participants on social media do not necessarily present evidence-based information about SCAD. HCPs should educate patients to be aware of the source of information and to make sure to caution themselves to not rely on the information as medical advice. Luckily, as described above, most of the participants seemed to be aware of the need to be wary of the source of the information and relied on the SCAD specialist for medical advice. However, strategies to ensure other SCAD survivors are following the same pattern need to be implemented. It will be important, moving forward, for SCAD survivors to have an understanding of the risk and benefits of social media as a form of social support.

**Conclusion**

The findings that emerged from this study of seven women’s experiences with lifestyle management after being diagnosed with SCAD indicate that there are challenges for this unique
population. Some of the results were similar to the experiences of women with AACS and included the need for more information during diagnosis and recovery and understanding why the cardiac event occurred in order to prevent it from happening again. What sets SCAD apart is that it is a rare and unfamiliar cardiac event that occurs mainly in young, previously healthy women and there is minimal evidence-based information available to help women with their recover afterwards. Additionally, patients with SCAD do not fit the typical pattern of patients with AACS; therefore, strategies to reduce risk factors, treatment options, and management approaches are often not applicable. The participants in this study found their lives to be on hold because they lacked the knowledge and understanding about SCAD to manage their condition and they had to wait an extended period of time to see the only HCP who had the specialized knowledge on their diagnosis. The surprising role of social media gives HCPs insight into the depth and nature of the social and emotional needs of these women affected by SCAD. Attention also needs to be paid to the potentially negative impact of social media as a form of social support, including issues around privacy and the reliability of the information. Overall, this study adds to our knowledge of women’s lifestyle experiences with SCAD. The next chapter will discuss some recommendations for HCPs to better support women with managing their lifestyle after their new diagnosis of SCAD.
Chapter 6: Study Implications and Conclusion

It is well documented that women are under-researched, under-diagnosed, and under-treated with regards to heart disease (The Heart and Stroke Foundation of Canada, 2018). Spontaneous coronary artery dissection (SCAD) is a form of acute coronary syndrome (ACS) that predominantly affects women under the age of 55 years (Saw, Mancini, & Humphries, 2016). In addition to women being under-researched when it comes to atherosclerotic ACS, SCAD is a diagnosis that has received attention only recently; therefore, there is not a lot of literature available to help us understand the condition and, more specifically, how to support patients in their recovery. Given the challenges faced by women with heart disease and the unique younger age of the patient population of SCAD, this study was conducted to improve our understanding of the experiences of SCAD survivors with regards to lifestyle management after their cardiac event.

Summary of the Research

Using interpretive description (ID) as a methodological approach, seven women, 55 years old or younger, were interviewed 3-18 months after their SCAD. The participants openly shared their experiences with their illness trajectory and the challenges they faced when being diagnosed and while at home managing their lifestyle after SCAD. From the study participants’ descriptions, the idea of being lost in an unfamiliar diagnosis presented throughout the data, making it the overarching theme. From there, four subthemes arose which included: being diagnosed with a rare disease, swirling in an information vacuum, finding something to hold on to, and reconstructing life. The women discussed how they were lost because they had been diagnosed with a rare condition that even their health care professionals (HCP) had little expertise or experience in managing. This lack of knowledge left them swirling in an
information vacuum. The participants described finding something to hold onto when they saw the SCAD cardiology specialist, attended cardiac rehabilitation (CR), and/or accessed social media as a form of social support. Finally, after gaining the necessary information, the women were able to begin re-constructing their lives and making the lifestyle changes needed as a result of this life altering event.

There were findings that were consistent with what is known about women’s experience with atherosclerotic ACS. For example, the participants shared the experience of missing key information at discharge and having the need to understand why the event occurred in order to prevent it from happening again. Importantly, there were some findings that were unique to the SCAD context. The participants in this study went from being healthy younger women to being diagnosed with a rare, spontaneous and serious event about which little is known. Given the rarity of SCAD, many of the findings in this study aligned with some of the current literature on experience with other rare diseases, in that patients did not receive the necessary informational or emotional support from HCPs to help them manage their diagnosis (Baumbusch, Mayer, & Sloan-Yip, 2019). Additionally, since SCAD is physiologically different from atherosclerotic ACS, the study participants reported having challenges with management after the event because most of the pre-established care guidelines for ACS did not apply to their recovery. Unfortunately, because of this lack of information and applicable management guidelines, the participants’ lives were on hold until they were able to find reliable information sources. In many of the women’s cases, the appointment with the SCAD specialist -- several months after their discharge from hospital -- was the first time they were provided with the detailed information they greatly needed to resume a more normal way of life. Cardiac rehabilitation (CR) was another source of support but it seemed that the women only utilized the exercise
component offered by the program, as most of them stopped attending the program after they felt comfortable exercising independently. This suggests that there is a need for supervised strategies to help SCAD survivors reintegrate physical activities into their lives but that perhaps the other supports offered by CR did not meet the needs of women with SCAD, or that they were not necessary. Many of the women shared that they did receive social support through social media, indicating that there may be benefits from enhanced peer-to-peer support. Overall, this study revealed that lack of information on SCAD, HCPs’ lack of familiarity related to the rarity and early stage of research of the condition, and the different pattern than other ACS patients could have greatly contributed to the participants’ experiences with their lives being on hold in their recovery. With this finding, we can begin to consider possible strategies that could be put in place to improve the experiences of women with SCAD with lifestyle management after their event.

**Study Implications**

This study provides us with a starting point to begin exploring possible recommendations to improve the SCAD patient experience. The findings of this study highlight challenges for women with SCAD and their HCPs related to knowledge and understanding of the condition’s process, treatment, and management strategies. This knowledge gap seems to be a major contributing factor as to why the participants felt as though their lives were on hold after their event. Therefore, the recommendations in this chapter will focus on considering strategies to enhance our knowledge and understanding about SCAD and patients’ access to information after SCAD.
Growing the Body of Literature

Given the rarity and early stages of research of SCAD, there is a pressing need for more research to help build the current body of knowledge about women’s experiences with lifestyle management after this cardiac event. In addition to the development of care guidelines, there are opportunities to engage SCAD survivors as experts in their condition and recovery. Studies have shown that patients and/or involved family members with rare diseases often become experts in their disease and point to the need for patients to be partners in developing disease management strategies (Morel & Cano, 2017). Nurses could conduct more research to better understand the lived experience with the burden associated with managing life after SCAD. Some areas that researchers may want to explore may be to expand on the lifestyle challenges experienced by women after SCAD, including analyzing the effectiveness of the SCAD-specific CR program and comparing it to the standard CR programs, evaluating the women’s needs related to resuming physical activity, and examining the usefulness of various forms of social or peer support. A combination of qualitative and quantitative research designs could help answer these questions and provide nurses and other HCPs with a more comprehensive and holistic understanding of the condition and experiential processes of SCAD. For example, qualitative designs could contribute to a better understand of patient experiences while quantitative research could enhance our understanding of condition’s process and treatment options.

The Addition of an Advanced Practice Nurse

The information that was given to the participants by the SCAD specialist provided them with the tools they needed to begin reconstructing their lives; therefore, it seems that we do have some information about SCAD to support survivors after their event. However, there was a delay in participants accessing this information. Improving the timing of patients’ access to
information may significantly reduce the time patients spend in a holding period after their SCAD. One option to address this could be the addition of a SCAD clinical nurse specialist (CNS) to the health care team. A CNS is an advanced practice role that involves influencing patient care at the client, practice setting, and organizational levels (Canadian Nurses Association, 2014). Included in the CNS role are strategies to improve patient health with education, research, leadership, consultation, collaboration, and organizational system reviews (Canadian Nurses Association, 2014). Based on the findings of this study, it seems that SCAD survivors would benefit from changes to the discharge process, the development of clinical guidelines for managing SCAD, and better coordination of care. A potential starting point for the CNS could be a review of the current discharge process used by hospitals and what information is provided to patients. After the review, the CNS could standardize the information to ensure that all women with SCAD are given relevant, evidence-based information at the time of their discharge. Additionally, since frontline nurses are often actively involved in the discharge process of patients from hospital, the CNS could implement strategies that target the frontline nurse’s ability to improve patients’ access to information during discharge. A CNS could help unit educators facilitate education of frontline nurses about SCAD and how it differs from atherosclerotic ACS. With more education, frontline nurse would be better equipped with the knowledge of SCAD’s condition’s process and thus would allow them to better support patients with SCAD by engaging them in conversations about risk of reoccurrence and management of their condition. The CNS could support unit educators with organizing “lunch and learns”, in-services, and/or sharing of published articles about SCAD. They could also help integrate information on SCAD in the orientation process for new staff members. Furthermore, given that the study participants usually stayed in hospital about five days and identified the need
to learn more about SCAD a few days prior to discharge so that they had time to reflect and ask further questions to HCP, the CNS could ensure processes are in place so that patients are provided with information immediately after their angiogram rather than waiting until the day they are going home. Furthermore, they could also make sure that SCAD survivors have ongoing access to information about their condition so they can manage their diagnosis as outpatients. This could include collaborating with the patients’ primary care provider to ensure they have the resources to coordinate care. The CNS could also continuously update the available information as new literature and knowledge emerges and work with the SCAD specialist to develop provincial care guidelines. Finally, the CNS could keep track of what other questions come up for the SCAD survivors during their recovery and identify if there are things missing from their discharge package. They could gather information about how they felt at the time of discharge and while they are managing at home. By surveying what the most prominent issues are for SCAD survivors, research questions could be generate and studies could be conducted to further explore the issues and create more evidence-based literature. The CNS could take a lead role in conducting more studies but also engage frontline nurses and other HCPs in the research process.

**Targeting Community-based HCPs**

After the participants were discharged home, the first HCP they typically saw as outpatients was their GP. The women reported that often their GPs had limited experience and expertise about SCAD and were not a good source of information. This seems to point to the need for better access to knowledge for GPs and other primary health care providers that are responsible for coordinating care. GPs are tasked with the challenge of managing a variety of patients with a number of health conditions, so it cannot be expected that they have specialized
knowledge about every disease. This is why consideration of GPs’ access to information sources may be necessary. If GPs knew where to go to quickly review information on SCAD and could collaborate more with the specialist, they may have a better understanding of SCAD and could be better able to support patients after their event. Perhaps it would be useful for women with SCAD to be given a package at discharge from hospital to deliver to their GPs. Additionally, there are initiatives such as the RACE program (Rapid Access to Consultative Expertise) which provides GPs with access to specialists for medical advice on specific speciality services. If there were specialist available to share knowledge with GPs about SCAD through avenues such as these, it could be easier for GPs to coordinate women with SCAD’s care because the GP would have access to a reliable and credible source of information. Finally, other information sharing forums such as the “This Changed My Practice” newsletter, which is sent to front line GPs, could be explored as a way enhance their access to knowledge.

Based on some of the participants accounts, there also seems to be need to for increased expertise across cardiology about SCAD. Similar to their experiences when visiting their GPs, the participants who were followed by general cardiologist, expected answers during these appointments but did not receive many because most of the cardiologist did not have the knowledge about the condition. It seems that strategies need to be consider to educate cardiologists about SCAD and to encourage them to become experts with this condition. Therefore, some of the strategies discussed above could also be implemented with general cardiologists to enhance their knowledge and understanding of SCAD. Furthermore, cardiologists could attend SCAD conferences and other information sharing forums within the division of cardiology. The SCAD CNS could help facilitate some of these options for
information sharing and could be also be a good source of knowledge to support general cardiologists.

**Social Media as a Form of Social Support**

The findings of this study identified the surprising role of social media as a form of social support for the participants. This could indicate that there is a need for access to social support or peer-to-peer support for women after SCAD. However, what is of concern is the potential danger associated with accessing information and support online on forums such as Facebook. Research on information available on the internet for rare diseases suggests that the quality of the information is very low (Pauer et al., 2017). This indicates that there is a need for education for women with SCAD about the potential dangers of online information. This could be another task taken on by the CNS by ensuring that education is in place for SCAD survivors that addresses the pros and cons of social media and seeking information online. The CNS could review the current websites and determine if they are a good source of information, and thus could be utilized by SCAD survivors. Furthermore, other reliable websites could be developed that would provide patients with access to information that is evidence-based. Since women with SCAD could be considered experts in their condition, they could have input as to what is on the website and a design that would be user friendly. Finally, all SCAD survivors should know about Facebook pages and the support it could offer, but they should be cautioned about potential negative impacts of these forums. Research on rare diseases indicates that there is benefit to peer support with disease management (Anderson et al., 2013; Baumbusch et al., 2019; Wallenius et al., 2009). However, attention will need to be paid to the potential dangers of accessing this support through online forums.
Limitations

There are some limitations of this study. First, given the methodological approach, this study produces knowledge about women’s experiences with lifestyle management after SCAD in a very specific context. The goal with using ID was to produce an individual account of women’s experiences with SCAD (Thorne, 2016). Additionally, the women were recruited from one specific SCAD clinic; therefore, only patients from one province in Canada were included. Even though the aim of this study was not to create generalizable knowledge similar to a quantitative approach, a smaller sample size and restricted access to a diverse patient population are also limitations.

Conclusion

This study has served as a meaningful starting point for gaining a better understanding of women’s experiences after SCAD. The findings point to a major deficit in evidenced-based information which has contributed to the participants feeling lost in their unexpected and unfamiliar diagnosis. The implications arising from this study are that there may be a need for an CNS to improve what information is given to patients and the timing of this information. More qualitative and quantitative research needs to be conducted to better inform the development of SCAD management strategies. Additionally, if provided with better information, the CNS could implement strategies to help frontline nurses and primary health care providers become excellent sources of guidance and support, which could help reduce the time participants felt their lives were on hold after their event. A CNS could be involved with enhancing education and facilitating collaboration between the specialist and GPs and general cardiologists and help develop a supportive discharge plan from hospital for SCAD patients. There also appears to be a need to examine SCAD survivors’ needs for social support and to
provide education around the pros and cons of social media. The experiences of women after SCAD as reported in the findings of this study serves as a beginning to providing HCP with valuable information to help them develop better management strategies after the event. By attending to the unmet needs of this patient population and implementing beginning strategies to reach out to them with information and support, we could see an improvement in how women manage their lifestyle and learn how to cope after SCAD.
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Appendix A

Are you a woman who has been diagnosed with Spontaneous Coronary Artery Dissection (SCAD) in the last 3-18 months?

We are conducting a research study examining the experiences with lifestyle management of younger women after SCAD

We are looking for women who:
- Are under the age of 55 years old
- Have been diagnosed with SCAD in the last 3-18 months
- Are interested in sharing their experiences regarding lifestyle management after SCAD

What is involved?
- One 45-60 minute interview
- Questions about your experiences with lifestyle management after being diagnosed with SCAD
- A $25 gift card as an appreciation of your participation

What are the objectives of the study?
- To learn about younger women’s lifestyle management after being diagnosed with SCAD so we may be able to make improvements to supporting patients going home after SCAD

If you are interested in participating in this study or have further questions, please contact Connie Clark * at

*Please note that this study is being completed as part of Connie Clark’s Master of Science in Nursing degree
Appendix B

Informed Consent

Spontaneous coronary artery dissection (SCAD): What can we learn from women’s experiences regarding lifestyle management after diagnosis?

I. STUDY TEAM: Who is conducting the study?

Principal Investigator:
Dr. Sally Thorne, University of British Columbia, School of Nursing
Ph: 604 822 4782 or email: sally.thorne@nursing.ubc.ca

Co-investigators:
Connie Clark*, University of British Columbia, School of Nursing
Dr. Sandra Lauck, University of British Columbia, School of Nursing
Dr. Martha Mackay, University of British Columbia, School of Nursing

*This study is being completed as a partial requirement of Connie Clark’s Masters of Science in nursing degree

II. SPONSORS: Who is funding the study?

None

III. INVITATION AND STUDY PURPOSE- Why are we doing the study?

You are being invited to participate in a study because you are 55 years old or younger and in the last 3-18 months have been diagnosed with a spontaneous coronary artery dissection (“SCAD”).
The purpose of this study is to learn more about what it was like for you after your SCAD. More specifically we want to learn more about your experiences with any impact this may have had on your lifestyle and how you managed any lifestyle changes that you experienced after the event. We plan to use this information to help patients with SCAD prepare for and manage their lifestyle in the future.

IV. STUDY PROCEDURES- How is the study done?
If you decide to participate in this study you will be asked to complete one 45-60 minute interview with Ms. Clark. All interviews will be conducted one-on-one in a place that you will be comfortable with (for example at your home or work or at a coffee shop or other public place). You will be asked questions such as, “What changed for you when you went home and how did you feel about that change?” All interviews will be audio-recorded, transcribed to written form, then looked at for common themes. Interviews are audio-recorded to ensure that we gather all of your experiences, thoughts, and ideas. The transcription will be done by a transcriptionist and they will only document what is said during the interview. Personal information such as your name or other names will NOT be transcribed and will be omitted from the document. If you do not wish to be audio-recorded during the interview, only written notes will be taken at that time.

V. STUDY RESULTS- How will the results be communicated?
The results of this study will be reported in Ms. Clark’s thesis. The main findings may be reported in a published journal article or presented at conferences. Your name or other ways of identifying you or others will not appear in the thesis or other publications.

If you would like a copy of the final results please include your email or mailing address at the bottom of this form.

No other use of the data will occur without your consent.

VI. POTENTIAL RISK OF THE STUDY- Is there any way that this study could be bad for you?
Since we would like to learn more about your experiences with lifestyle management after SCAD, some of the questions we ask may be sensitive and they could upset you. You do not have to answer any questions you don’t want to. Also, you can choose to stop the interview at any time and you will not need to provide the investigators with a reason. If you choose to not enrol in the study or you withdraw at any time, there will be no negative impact on the health care you receive at Vancouver Coastal Health.

Information on free counselling services will be provided to you prior to starting the interview.

VII. POTENTIAL BENEFITS OF THE STUDY- Is there any way that this study could be good for you?
There will be no benefit to you by participating in this study. However, you will be given the opportunity to discuss your experiences with SCAD. Your shared experiences may contribute to the development of ways to help future patients who are diagnosed with SCAD.
VIII. CONFIDENTIALITY- How will your identity be protected?
Your confidentiality will be protected. All names will be removed from the data. Instead, you will be assigned a unique number to help the investigators keep track of the participants. As previously stated, a transcriptionist experienced with confidential research transcribing will ensure all names have been removed from the transcribed documents. All documents will be stored in a locked cabinet or on a password-protected computer. None of the data will be uploaded onto websites or other shared access forums. Only the four investigators listed at the top of this document who are involved with this study will have access to the data. All documents will be destroyed 5 years after the research is completed.

IX. PAYMENT- Will you be paid for your time?
You will not be paid for your time to participate in this study. However, as an appreciation of your time you will receive a $25 gift card. This gift card will be given to you at the start of the interview and if you choose to withdraw from the study at any time, you may still keep your gift card.

X. CONTACT FOR INFORMATION ABOUT THE STUDY- Who can you contact if you have questions about the study?
If at any time you have questions about the study, please contact the principal investigator, listed at the top of this document.

XI. CONTACT FOR COMPLAINTS- Who can you contact if you have complaints or concerns about the study?
If you have complaints and/or concerns about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance email RSIL@ors.ubc.ca or call toll free 1-877-822-8598
XII. PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your care as a patient or access to health care services at Vancouver Coastal Health.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature below indicates that you consent to participate in this study

___________________________________________________________________
Participants Signature Date

___________________________________________________________________
Printed name of the Participant signing above

If you would like to receive a copy of the study results please enter your email or mailing address below (if not please leave blank)

___________________________________________________________________

___________________________________________________________________
Appendix C

Interview guide

1. Introduction
   Thank you for participating in our study. Is it ok if I record our interview so that everything you say is used to help us understand SCAD? Also, is it ok if I take some notes during our interview to help me remember certain things you say? You are welcome to read them at the end of the interview if you would like. First let’s get started by learning more about you and what happened at the time of your SCAD

   1. Please tell me more about yourself. For example: where do you live, what is your occupation, who do you live with?

   2. Describe for me what happened around the time when you started experiencing SCAD.

2. Lifestyle management
   Let’s move on now to discuss what life was like for you after SCAD

   1. How did you feel at the time of your discharge from the hospital?

   2. How would you describe your emotions between after your discharge from hospital and now? (hint to interviewer: write down the main emotions described so connections can be made later in question 3).
      ○ Probe: How did you respond to these emotions?

   3. Please describe for me your experiences with changing lifestyle after being diagnosed with SCAD? More specifically, what changed for you when you went home after SCAD?
      ○ Probe: How did the changes you are describing make you feel?
      ○ Probe: How did the emotions you described in the last question influence your ability to make lifestyle changes? (remind the participant of the emotions they described from question 2 under lifestyle management)
      ○ Probe: Please tell me more about the support you received or didn’t receive to help you make changes to your lifestyle?

   4. Did you attend cardiac rehabilitation after your SCAD? What influenced your decision to attend/to not attend a cardiac rehabilitation program?
5. For those who attended CRP: What were the benefits of CRP? What did you think was missing?

6. If you could describe one thing that you would like newly diagnosed women with SCAD to know about managing their lifestyle, what would that be?

3. Conclusion
   Thank you for sharing your experiences with me. Is there anything else you would like to add that you feel is important to share about your experiences with lifestyle management after SCAD?
Dear Patient,

Re: Research Study: Women’s Descriptions of Their Experiences Regarding Lifestyle Management after Spontaneous Coronary Artery

I am writing to inform you of a study about how women manage their lifestyle after experiencing spontaneous coronary artery dissection (SCAD). Because you are under the age of 55 and have experienced SCAD in the last 18 months, you may be eligible to participate.

The study is being led by Connie Clark, who is a registered nurse completing her Master of Science in Nursing at the University of British Columbia.

The research team is trying to gather information on how women manage their lifestyle after SCAD in order to better understand how health care providers can support patients during this stage of their recovery.

Participation would include one 45 – 60 minute interview with Ms. Clark, in which you would be asked questions such as “what changed for you when you went home after SCAD?” Your name would not be used in the data and your identity would be kept confidential. As an appreciation of their time, participants will be given a $25 gift certificate.

Please note that participation in this study is voluntary and your current care at the Vancouver General Hospital SCAD Clinic will not change, no matter what you decide.

In this package, along with this letter, you will find a recruitment flyer, an informed consent document, and how to contact Ms. Clark.

For more information about the study and/or to arrange for your participation, contact Connie Clark directly at cell: [Redacted]

Sincerely,

Dr. Jacqueline Saw, MD, FRCP(C)