The Pre-diagnosis Symptom Experience of Patients with Atrial Fibrillation

by

Ryan Wilson

B.Sc. in Nursing, UBC Okanagan, 2008

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

Doctor of Philosophy

in

THE COLLEGE OF GRADUATE STUDIES
(Interdisciplinary Graduate Studies)

THE UNIVERSITY OF BRITISH COLUMBIA
(Okanagan)

April, 2019

© Ryan Wilson, 2019
The following individuals certify that they have read, and recommend to the College of Graduate Studies for acceptance, a thesis/dissertation entitled:

The Pre-diagnosis Symptom Experience of Patients with Atrial Fibrillation

submitted by Ryan Wilson in partial fulfilment of the requirements of

the degree of Doctor of Philosophy

Dr. Kathy Rush, Faculty of Health and Social Development, School of Nursing

Supervisor
Dr. Linda Hatt, Irving K. Barber School of Arts and Sciences, Department of Psychology

Supervisory Committee Member
Dr. Colin Reid, Faculty of Health and Social Development, School of Health and Exercise Science

Supervisory Committee Member
Cynthia Mathieson, Barber School of Arts and Sciences, Department of Psychology

University Examiner
Dr. Kathryn King-Shier, University of Calgary

External Examiner

Additional Committee Members include:
Dr. Carol Laberge, Provincial Health Services

Supervisory Committee Member
Atrial Fibrillation (AF) is the most common arrhythmia worldwide, with five million new cases diagnosed every year. If left untreated, AF significantly increases the risk of stroke, heart failure, and death. Despite the increasing prevalence of AF, little is known about the symptom experiences of patients prior to receiving their AF diagnosis, and the influence of these experiences on health care seeking. Therefore, the purpose of this interpretive descriptive study was two-fold: i) to explore the pre-diagnosis AF symptom experience of adults ≥ 19 years of age; and ii) to examine the influence of age, and gender on the AF symptom experience. Eligible participants were recruited from outpatient AF clinics and a cardiac rehab centre. Consenting adults (n=26) with newly diagnosed AF participated in semi-structured interviews that accessed their pre-diagnosis symptom experience and specifically their perceptions, evaluations, and responses to their symptoms. Participants’ pre-diagnosis symptom experience was highly complex involving interconnected perceptions, evaluations and response to symptoms following the onset of AF. Perception involved participants’ variable awareness of bodily sensations (changes) from imperceptible noticing to commanding attention, with rest and activity heightening symptom awareness. Evaluation reflected participants’ intense cognitive work of judging, making sense of, and finding explanations for their bodily sensations and symptoms. In evaluating symptoms participants formed personal theories, gathered evidence to support/refute their theories, and re-theorized disrupted theories. Responses represented the actions/activities employed, in responding to, and dealing with their symptom(s). Dominant responses included: non-treatment, self-treatment, and health seeking; responding with non-treatment and self-treatment protracted the pre-diagnosis time, with periods lasting from weeks to years. Gender, age (≤ 67 vs ≥ 68 years), and the timing of AF diagnosis (early or late) played important roles in participants’ symptom experiences. Women experienced greater symptom severity than men, yet were more inclined to dismiss their symptoms, to perceive lower AF risk, to prioritize caregiving responsibilities over attending to their health, and reported frustration and anger with their physicians associated with
diagnosis delays. This research offers key insights into how gender and age influence the symptom experience, and highlights the importance of clinicians accounting for these differences in practice, to minimize the pre-diagnosis time.
Lay Summary

Every minute a person with an irregular heartbeat condition does not have proper medical attention, the risk of stroke, heart disease, or death increases exponentially. This study looked at the symptom experiences of adults diagnosed with atrial fibrillation (AF), a condition which can cause a rapid or irregular heartbeat. Study goals were aimed at understanding how patients perceived, evaluated and responded to their symptoms, and whether experiences differed by gender or age. The majority of participants waited for periods ranging from several weeks to years before health care seeking. In essence, this extended period, before health seeking, is the result of individuals’ not having enough information to make an informed evaluation, the subtlety, variability and intermittency of symptoms, and the overall lack of concern about the symptoms of AF. Women reported inequities in receiving adequate treatment following health care seeking, even though they reported more severe symptoms. This study identifies the need to assist the public in recognising and responding urgently to the symptoms of AF. This in turn might greatly reduce the negative outcomes associated with the non-treatment of this very treatable condition.
Preface

This dissertation is original, unpublished work of the author, Ryan Wilson. The writing of this research was done in collaboration with Kathy Rush, Linda Hatt, Colin Reid, and Carol Laberge. The research was approved by the University of British Columbia’s Behavioural Research Ethics Board (Certificate # H15-02443).
# Table of Contents

*Abstract* ................................................................. iii

*Lay Summary* ........................................................... v

*Preface* .................................................................. vi

*Acknowledgments* ..................................................... xiii

*Dedication* ................................................................. xiv

**Chapter 1: Introduction** ............................................. 1
  1.1. Background ....................................................... 2
  1.2. Problem Statement ............................................... 5
  1.3. Statement of Purpose and Aims ................................. 6
  1.4. Theoretical Perspective .......................................... 7
      1.4.1. The Symptom Experience Model ......................... 7
      1.4.2. The Symptom Experience Model in AF ................. 9
  1.5. Significance of the Study ....................................... 12

**Chapter 2: Review of the Literature** ........................... 14
  2.1. AF Pathophysiology ............................................. 14
  2.2. AF Symptoms .................................................... 15
  2.3. Management and Treatment of AF ............................ 15
      2.3.1. Prevention of Systemic Embolization ................ 16
  2.4. Literature Search ................................................ 17
      2.4.1. Symptom Experience in AF .............................. 18
      2.4.2. Symptom Perception and Evaluation ................... 18
      2.4.3. Symptom Responses ....................................... 20
          2.4.3.1. Cognitive Responses ................................. 20
          2.4.3.2. Emotional Responses ................................. 21
          2.4.3.3. Limitations in Daily Life ......................... 24
      2.4.4. Age .......................................................... 25
      2.4.5. Sex and Gender ............................................ 26
  2.5. Limitations of the Current AF Literature .................... 30
  2.6. Summary .......................................................... 31

**Chapter 3: Methodology** ............................................. 34
  3.1. Research Design ................................................ 34
      3.1.1. Motivation for Choosing Qualitative Research ........ 34
      3.1.2. Interpretive Description .................................. 35
  3.2. Theoretical Perspectives ...................................... 36
      3.2.1. Locating Theoretical Allegiances ....................... 37
      3.2.2. Disciplinary and Personal Knowledge .................. 38
3.3. Sampling and Recruitment

3.3.1. Participants

3.3.1.1. Inclusion Criteria

3.3.1.2. Exclusion Criteria

3.3.2. Sample Size

3.4. Data Collection Strategies

3.5. Data Management Strategies

3.6. Data Analysis

3.7. Ethical Considerations

3.7.1. Informed Consent

3.7.2. Benefits

3.7.3. Privacy and Confidentiality

3.8. Strategies Used to Maintain Methodological Rigour

3.9. Summary

Chapter 4: Findings

4.1. Introduction

4.2. Sample

4.3. Aim 1: Exploring AF Symptom Perceptions

4.3.1. Noticing

4.3.2. Imperceptible Noticing - “Feel Something, but Nothing Really”

4.3.3. Commanding Attention.

4.3.4. Rest and Activity

4.3.4.1. Rest

4.3.4.2. Interfering/Arresting Activities

4.4. Aim 2: The Evaluation Process

4.4.1. Speculating- Individual Symptom Theories

4.4.1.1. It is nothing really - My heart is just being funny.

4.4.1.2. I’m just getting older.

4.4.1.3. I must be stressed or anxious.

4.4.1.4. All too familiar - chronic health conditions.

4.4.1.5. It’s my fault – weight and diet.

4.4.1.6. Just pushing myself too hard - physical activity.

4.4.1.7. Something is wrong with my heart.

4.4.2. Taking Shape - Influences Shaping the Evaluation Process

4.4.2.1. Expectations

4.4.2.1.1. I’m too healthy to have heart disease - I expect to be healthy.

4.4.2.1.2. My family history and illness experience shaped my expectations.

4.4.2.2. Symptom characteristics

4.4.2.3. Inside knowledge - experience in health care.

4.4.2.4. I didn’t know - knowledge gaps.

4.4.3. Finding Support for their Theories

4.4.3.1. Comparing self with others.

4.4.3.2. Testing

4.4.3.3. Eliminating possibilities.

4.4.3.4. Reaching out - asking for help from friends and family.
List of Tables
Table 1: Summary of all Themes in the AF Symptom Experience ........................................55
List of Figures

Figure 1-1. The Symptom Experience in AF.................................................................10
Acknowledgments

There are so many people I must acknowledge, who have supported me, pushed me, and believed that I could accomplish this important work. First, I wish to thank Dr. Kathy Rush; your kindness, encouragement, and attention to detail, have guided me through the many ups and downs that are involved in working on a project of this scale. Thank you for the countless hours that you have given to this work. You are an incredible mentor Kathy! Secondly, to Dr. Linda Hatt - thank you for supporting me, for always offering encouragement, and speaking practically to the many problems that I encountered in this journey. Next, Dr. Colin Reid - your keen eye and attention to detail in the writing and planning of this research have been exceptional. Thank you for all your guidance! Dr. Carol Laberge - thank you for kindness and support, for believing in me, and for joining me in Vancouver to present this research at the Canadian Cardiovascular Conference. Finally, I want to offer a special thanks to Dr. Patricia Mark - you believed in me, encouraged me, and supported me to start this process - for that, I am so thankful!

This research would not have been possible if not for the support of my family. To my wife Kelsey, you have sacrificed so much to allow me to pursue this degree! I cannot thank you enough for all the love and encouragement you have given me. Many times, when I felt overwhelmed, you helped me carry on! To my parents (Elsie, Morley), thank you for helping me start this journey in nursing many years ago, and for always encouraging me to be the best version of myself. Your love and support have been steadfast! Jack and Bernice, you have offered so much support through these last years; from always ensuring I am taking care of myself, to watching our three beautiful children so I could concentrate on my studies. To my children - your energy, love for life and joy have been an enormous strength. Thank you for sacrificing your time with me, to allow me to accomplish this degree. I love you all!

Finally, to my friends and colleagues at UBC Okanagan, you have all supported me immensely in this journey, from always checking in on how things are going, to juggling your schedule or workload to allow me to concentrate on my research.
Dedication

I dedicate this work to my father Morley Wilson. The wisdom and strength you gave to me in our time together will guide me for all my life. You will be forever missed!
Chapter 1: Introduction

Every minute a person with an arrhythmia does not have proper medical attention, the risk of stroke, heart disease, or death increases exponentially (Kirchof et al., 2016). Atrial fibrillation (AF) is the most common form of arrhythmia and accounts for approximately one third of all hospital admissions worldwide for cardiac dysrhythmia (Claes et al., 2012). AF is a serious cardiac condition; an estimated 33.5 million people worldwide live with the condition and five million new cases are diagnosed every year (Chugh et al., 2014). Furthermore, experts predict that the prevalence of this rapidly-growing condition will increase two-and-a half-fold, by 2050 (Naccarelli et al., 2009). The median age for AF sufferers is 75 years old, with a prevalence of 2.3% at age 40, 6% at age 65 (Rho & Page, 2005), and 16% in those 85 years and older (Fitzmaurice et al., 2007). The widespread increase in AF is being driven by factors such as the aging population and the improved survival rate of patients suffering from co-morbid cardiovascular conditions, such as heart failure, hypertension, and valvular heart disease (Frewen et al., 2013; McCabe, Chamberlain, Rhudy & DeVon, 2016a; Rho & Page, 2005).

AF has extremely varied symptoms, both in their timing and nature. This symptom variability creates challenges for patients to identify and label them, and for practitioners to diagnose them (McCabe et al., 2016a). Although difficult to estimate, approximately 10 to 40 percent of patients diagnosed with intermittent AF do not report any significant, recognizable symptoms (Rho & Page, 2005), even though symptoms may still be present (Phang & Olshanksy, 2015). Phang and Olshanksy describe that asymptomatic patients report significant improvements in their quality of life (QOL) following effective treatment, suggesting the probability of symptoms they did not recognize. Given AF’s growing prevalence, together with the numerous risks associated with the elapsed time prior to diagnosis, there is an urgent need for more research that aims to understand the symptom experience, from the patient’s perspective. Moreover, there is a need to understand the factors that influence
patients’ evaluations of AF’s symptoms, as well as the reasons behind the differences in patients’ responses, following the onset of symptoms.

1.1. Background

The National Heart, Lung and Blood Institute (NHLBI) in the United States, the Canadian Stroke Network (Gladstone et al., 2014) and the Stroke Alliance for Europe (“Signs Against Stroke in Atrial Fibrillation,” 2010) have all identified AF prevention and early detection as an international research priority (Benjamin et al., 2009). A key factor in the early detection of AF is patient recognition that AF’s symptoms require medical attention. However; patients who experience AF symptoms frequently misinterpret or fail to recognize them as indicators of a serious condition, predisposing them to risks such as stroke, and postponing the seeking of medical care (Dilaveris & Kennedy, 2017, Lane et al., 2006, McCabe et al., 2015, 2016a, 2017). AF is readily treatable, in most community settings, if individuals seek medical attention soon after the onset of symptoms (Frewen et al., 2013). However, if left untreated, beyond periods ranging from as little as five hours (Glotzer et al., 2009) to twenty-four hours (Van Gelder et al., 2017), there is an estimated five-fold increase in the risk of stroke (Manning & Singer, 2018). Furthermore, in AF, the risk of dementia doubles, of heart failure (HF) triples, and there is an overall increase in the risk of mortality, ranging from forty percent to ninety percent (Benjamin et al. 2009; Camm et al. 2012; January et al. 2014; Kirchhof et al., 2016; Manning & Singer, 2018). Additionally, recent evidence indicates that patients experiencing periods of AF, lasting from one up to five-and-a half hours per day, have a two-fold increased risk of thromboembolism, compared with those who had no recorded AF (Boriani et al., 2014; Glotzer et al., 2009; McCabe et al., 2016a).

Patients with AF often have significant problems identifying their symptoms as stemming from a cardiac condition. The cardiac literature indicates that when symptoms do not resemble a typical cardiac event, treatment seeking is delayed (Horne et al., 2000; King & McGuire, 2007; McCabe et al., 2016a; Ruston et al., 1998; Zerwic, 1998). The problem is compounded by limited
public knowledge about AF and its symptoms, such that patients have few points of reference for evaluating their symptoms (McCabe et al., 2011, 2016a). Furthermore, the symptoms that most individuals with AF experience are extremely varied in their nature, frequency, timing and severity (Reynolds, Lavalle, Essebag, Cohen, & Zimetbaum, 2006). Typically, patients with AF experience one or more symptoms, including palpitations, dyspnea, fatigue, syncope, a sensation of skipped heartbeats, and, less frequently, chest pain, and dizziness (Buccelletti et al., 2013; January et al., 2014). Symptoms may be intermittent, constant, insidious, vague, mild, moderate, or severe and debilitating (Hickey et al., 2013; McCabe et al., 2016a). Although difficult to estimate, as many as one third of all AF patients report being asymptomatic prior to diagnosis; in other words, they experience no symptoms that they recognize as AF-related, prior to diagnosis (Benjamin et al., 2009; Camm, Corbucci, & Padeletti, 2012; Rho & Page, 2005). The extreme variability and the insidious nature of many AF symptoms add to the challenges patients experience in recognising the symptoms as requiring medical treatment. Moreover, it may be difficult, particularly for older adults, to distinguish AF symptoms from symptoms associated with existing comorbidities, such as heart failure, coronary artery disease, or fatigue syndromes (Hickey, 2013; McCabe, Schumacher, & Barnason, 2011).

Age-related influences, on symptom experiences in AF, remain understudied and their characteristics, under-developed. Seniors with AF are often less symptomatic than non-seniors, but they face more daily variability in symptom intensity, duration and frequency (Hickey et al., 2013). The physiological and psychological changes older adults experience may create further difficulties in assessing and responding to their bodies’ symptoms. Additionally, older adults often suffer from impaired sensory and symptom perception, as well as memory and comprehension losses (Hickey et al., 2013). Furthermore, pre-existing mental schemas may influence seniors’ responses to illness (Hickey et al., 2013). For example, following myocardial infarctions (MI), seniors often delay seeking professional care, because of learned behaviours of self-management and self-treatment from other chronic diseases (Lefler & Bondy, 2004). The increased prevalence of AF with aging leaves a

3
predominantly older adult population challenged with evaluating and responding to the often subtle and varied symptoms. Older adults are not a homogenous population (Lowsky, Olshansky, Bhattacharya, & Goldman, 2013) and there is often greater variability within the age sub-groups (65-74, 75-85 and > 85-year olds) that are likely to manifest differences in the AF symptom experience. However, no studies have investigated this age phenomenon in the AF population. Although direct comparisons cannot be made (between patients with MI and those with AF), AF researchers often look to the extensive work already done with patients suffering from MIs because of the similar nature of some of the cardiac-based symptoms (McCabe et al., 2015).

Women with AF differ from men in the type of symptoms they experience and report, in their health care seeking responses, and in how practitioners manage these (Reynolds et al., 2006). Women also suffer inequities when it comes to receiving treatment for their AF symptoms, as they are undertreated, in terms of rate control, anticoagulation, and electrocardioversion (Potpara et al., 2012; Yarnoz & Curtis, 2008). As a result, they may suffer from more symptoms on a daily basis (having been undertreated) and experience a decreased quality of life (QOL) compared to men (Reynolds et al., 2006). Previous studies have primarily focused on sex differences, or physiological differences between males and females with AF, rather than the learned behaviour that are associated with gender roles. For example, research indicates that females have higher resting heart rates, which corresponds to more rapid, uncontrolled rates of AF and more severe symptoms (Michelena, Powell, Brady, Friedman, & Ezekowitz, 2010). Other symptom differences include more palpitations, fatigue, and chest pain reported by women than by men (Potpara et al., 2012; Yarnoz & Curtis, 2008). Men develop AF at one-and-a-half times the rate of women; however, with increasing age women account for a greater proportion of the total number of cases (Michelena et al., 2010; Rich, 2009).

Despite evidence of the important role gender plays in the evaluation and response to symptoms in patients experiencing MIs (Moser et al., 2006), little is understood about these differences in the experience of AF. Two studies have explored the role of gender in symptom evaluation and response to AF, but only one of them has produced any significant findings (Deaton et
al., 2003; McCabe et al., 2016a). Deaton and colleagues found that women’s health care providers (HCPs) often did not take their AF symptoms seriously, either dismissing them or attributing them to menopause or stress. This study will begin to address the gaps in our understanding of how the AF symptom experience may differ not only by sex (biological), but also by gender.

1.2. Problem Statement

Despite the growing prevalence of AF, there is a significant gap in the literature regarding the symptom experiences of patients, prior to receiving their AF diagnosis, and how these experiences influence treatment seeking. Studies indicate that there are substantial delays in treatment seeking for AF, with the average person waiting over one week, to seek treatment following symptom onset (McCabe et al., 2015; 2016a). Prolonged delays in treatment seeking for AF contribute to substantial risks is a serious problem that must be addressed (Benjamin et al. 2009; Camm et al. 2012; Dilaveris & Kennedy, 2017; January et al. 2014; Manning & Singer, 2018; Siontis et al., 2016).

The influences of sex, gender roles, and age on the initial symptom experience prior to diagnosis are also poorly understood (McCabe et al., 2015). Many questions remain unanswered, concerning how individuals create meaning from the symptoms they experience. Additionally, limited information is available about the influences on patients’ evaluations of their AF symptoms, the potential barriers to their treatment seeking, and the reasons for varied responses during the pre-diagnostic period.

Finally, there are gaps in our understanding of what patients experience when they report having ‘no’ symptoms (asymptomatic) during the pre-diagnostic period. Recent literature supports the idea that occasionally, patients with symptoms report having no symptoms at the time of their AF diagnosis (Phang & Olshanksy, 2015). In these instances, the patient may have not recognized the experienced symptoms as being AF-related and, therefore, misattributed the symptoms to other conditions. Previous research (McCabe) has excluded asymptomatic patients, yet this gap eliminates a
perspective that is important for obtaining a more complete understanding of the pre-diagnostic symptom experience.

All these gaps point to a clear need to investigate, further, how patients experience, evaluate and respond to symptoms, especially given the large numbers of AF patients who are at risk of adverse health effects. It is critical to explore the meaning that patients give to their symptoms, and how these interpretations may impact the timeliness of treatment seeking.

1.3. Statement of Purpose and Aims

The overarching purpose of this descriptive, qualitative study was to explore, retrospectively, AF symptom experiences in the pre-diagnosis period of AF, and to interpret the reasons for the decisions made. The pre-diagnosis period was defined as the time from onset of the heart arrhythmia to the AF diagnosis from a health care provider. This study compared the AF symptom experiences among groups of adult participants, determined by age and gender. The study’s results may serve to promote earlier identification of AF symptoms, and may lead to the formulation of appropriate strategies to increase awareness of AF’s symptoms and treatment.

This study had three specific aims:

1. To explore the symptom-related perceptions of adults (>19 years of age) during the pre-diagnosis period of AF.
   i. To identify and describe the symptom-related perceptions of AF patients preceding diagnosis.
   ii. To compare symptom-related perceptions, based upon age and gender.

2. To explore individuals’ evaluations of their AF symptoms during the pre-diagnostic period.
   i. To identify and describe individuals’ evaluations of their AF symptoms, preceding diagnosis.
   ii. To compare their symptom evaluation, based upon age and gender.
3. To explore individuals’ responses to their AF symptoms during the pre-diagnostic period.
   i. To identify and describe adults’ responses to their AF symptoms
   ii. To explore how the perception and evaluation of their individual AF symptoms influence their choice of response (misinterpretation of symptoms, symptom severity, transient nature of symptoms).
   iii. To compare the responses to symptoms, based upon age and gender.

1.4. Theoretical Perspective

The epistemological foundations of this study were based on the constructivist perspective, where individuals, who are facing acute illness, seek to make or construct their own meaning from their situation (Corbin & Strauss, 2008). The process of meaning making in illness is highly individualized and context dependent. In constructivism, each person’s right, to make their own truth based on their interpretation of their experiences, is respected (Munhall, 2007). For example, some may construct the meaning of their AF symptoms as a condition which needs urgent medical attention, while others may interpret their symptoms as an insignificant inconvenience in their daily lives. Using this perspective, this study took an emic (insider’s) viewpoint, exploring how individuals perceived, evaluated and responded to symptoms.

1.4.1. The Symptom Experience Model

This study used a symptom experience model (SEM) to define and describe patients’ experiences of AF symptoms. The SEM describes three separate, yet interrelated, processes: the perception of symptoms, their evaluation, and the response to them, while acknowledging the external influences that may affect the symptom experience. The SEM, itself, is a synthesis of two earlier models: (1) the symptom management model (SMM), (Dodd et al., 2001), and (2) the symptom experience model used by Bruno (2013), to study acute coronary syndrome. A short explanation of each of these contributions follows before the SEM is examined in more detail (see figure 1).
Larson and associates (1994) originally created the SMM to guide knowledge construction concerning the symptom experience, its management and outcomes, as well as to provide a framework for research and clinical practice. The model depicts an interconnected web of variables that work together to describe and predict how individuals respond to symptoms. Dodd et al. (2001) later revised the model, incorporating the dimensions of nursing science, which are the person, the environment and health and illness. These dimensions provide the contextual influences to be considered, when investigating symptoms and illness behaviour (Dodd et al., 2001). Researchers from the University of California, San Francisco (UCSF) have also performed rigorous testing on, and made modifications to the model since its creation (Dodd et al., 2001). Although no specific study has yet tested the entire model, the SMM has provided a valuable research framework, for application to specific clinical populations such as those suffering from cancer, HIV or breathlessness (Humphreys et al., 2008). Carrieri-Kohlman et al. (2005) used the model to guide their research in understanding the management of symptoms, healthcare use, and the enriched symptom descriptions of patients experiencing dyspnea. Other successful applications of the model have included battered women’s symptom experiences, the role of genetic predictors in symptom manifestation, the variety of symptoms experienced by those with bronchoconstriction and the relationship between symptom experience and prayer (Humphries et al., 2001). The model has also been used to explore the symptom experience in several cardiac conditions, such as coronary artery disease and unexplained chest pain (Jerlock, Welin, Rosengren & Gaston-Johansson, 2007), or reasons for seeking care in heart failure (Patel, Shafazand & Schaufelberger, 2007; Stephen, 2008); although this body of research remains limited.

Although the SMM significantly informed the SEM in AF and was essential for underpinning the structure of the SEM, this study did not use the SMM in its entirety. There are several reasons for this. First, when compared to models in psychology, the SMM did not offer a framework that allowed a cognitive construction of illnesses or symptoms. Rather, it identified the person, the environment,
and the status of health and illness, as influences in the perceptions of symptoms, without addressing the cognitive constructions of illness. The symptom experience is a complex dynamic process that should be inclusive of cognitive and social processes, and should consider contextual and environmental variables (Biddle et al., 2007). Subsequent adaptation of the SEM has strengthened the cognitive aspect of the model through the integration of mental schemas (Bruno, 2013). Given that the SMM was designed as a focused, specific model, which provided guidance for practitioners (nurses) to develop care plans and strategies to manage symptoms (Larson et al., 1994), several adaptations were needed for the current study, to address the symptom experience effectively, in patients with AF. For example, this study’s AF SEM model incorporated some of the adaptations that Bruno (2013) made to Dodd et al.’s version of the SMM model. Bruno (2013) narrowed the model’s focus, to include only the concepts that pertained to symptom experience and eliminated the aspects that related to the health care providers’ management and evaluation of symptoms and treatments. Bruno’s model addressed the cognitive evaluation of symptoms, and added the concepts of mental schemas, expectations about the nature of symptoms and risk perceptions.

1.4.2. The Symptom Experience Model in AF

The SEM’s central concepts related to symptom experience, namely perception, evaluation and response (see figure 1-1). This experience is influenced by the domains of the environment (physical, social, cultural); health and illness (health status, disease and injury); and the person (demographics, psychological, sociological, physiological, developmental). Environment refers to external physical and socio-cultural factors, whereas the person domain encompasses an individual’s being, characterized by consciousness, rationality and moral sense (Bruno, 2013). The health and illness domain investigated current health status and existing disease, and/or injury. Additional domains included risk perception and mental schemas. Risk perceptions are the subjective judgement that people make about the characteristics and severity of a risk (Bruno, 2013). Mental schemas are ideas, or beliefs, about what the symptoms may mean, based on previous illness experiences (Dodd et
al., 2001); of which expectations about the treatability and possible outcomes of symptoms are formed. All of these domains provide the contextual influences that are to be considered, when investigating symptoms and illness behaviour (Dodd et al., 2001). Furthermore, these supporting domains guided the exploration of the complex subjective process of experiencing and responding to symptoms, which had multiple overlapping influences, based upon an individual’s life experiences.

The first central concept in the model is the perception of symptoms. This is an individual’s awareness of physical or psychological changes, which are different from their normal state (Armstrong, 2003; Dodd et al., 2001). Physical (body) sensations are a part of everyday life and signify the constant processing and functioning of our internal state. Most of the time, these sensations occur subconsciously, although some individuals experience a heightened consciousness of them (Pennebaker, 1982). Many factors may alter an individual’s awareness of these internal sensations, including the strength of the stimulus, beliefs held about the meaning of symptoms, and the individuals’ own propensity to paying attention to internal sensations (Pennebaker, 1982).

**Figure 1-1. The Symptom Experience in AF**

It is important to differentiate between a sensation and the perception of a symptom. Perceptions are how the brain gives meaning to sensations, leading to awareness, and they are

---

influenced by psychosocial factors, age, gender, and cultural factors (Rookes & Willson, 2005). Studies that explored symptom perception, in patients with MIs, found that both age (Miller et al., 1990) and gender (MacInnes, 2006) could influence perception. Conversely, sensations stem from the stimulation of a sensory receptor and, therefore, are a biological process (Rookes & Willson, 2005).

The next central concept in the model is the evaluation of symptoms. This includes judgments about the symptoms’ severity, cause(s) and treatability, as well as the overall effect that the symptom(s) may have on daily life (Dodd et al., 2001). However, this is highly dependent on recognising a sensation in the perception phase. Symptoms only become ‘symptoms’, to be evaluated, once individuals recognize a bodily signal as abnormal (Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010). Therefore, if the person does not perceive a sensation, the evaluation phase will not take place. In the evaluation phase, individuals explore the meaning of the symptom(s) further and evaluate its (their) potential causes. Individuals may develop a list of perceived causes, may rate the seriousness of the symptoms and assess the level of risk that the symptoms may pose (Dodd et al., 2001). These initial evaluative steps lead to ideas about the treatability, and possible outcomes, of the presented symptoms (see mental schema in figure 1) (Dodd et al., 2001; Leventhal et al., 1983; Robbins & Kirmayer, 1991).

The response phase in the symptom experience process is defined as the coping mechanism(s) initiated to deal with the threat (symptom). The evaluation of the symptom(s), the risk perception and the mental schema, guide the individual towards the selection of an appropriate response (coping) mechanism (Cameron, Leventhal, & Leventhal, 1993). Theorists have identified the critical role that one’s past experiences play in shaping the responses to symptoms (Leventhal, Diefenbach, & Leventhal, 1992). One’s own past experiences of illness are structured into a complex form of memory, which is used to analyse and organize illness knowledge. The knowledge gained from this process then leads to the formation of mental schemas and expectations, which guide choices of behaviour (Dodd et al., 2001; Dracup et al., 1995; Leventhal et al., 1992). Therefore, what
has worked, or not worked, in the past treatment of similar symptoms will guide how people respond to symptoms in the present.

The experience of symptom(s) is dependent upon the context of where and when the symptom(s) occurs. For example, Humphries et al. (2001) argue that a woman who experiences the sudden onset of a ‘hot flash’ and diaphoresis, will respond very differently if she is at home in bed versus a boardroom meeting. Severity, frequency and the level of distress of the symptoms also contribute to the symptom experience (Humphreys et al., 2008). Responses to symptoms may include the choice of self-care versus seeking treatment from a health care provider.

It should be noted that all the variables, within the symptom experience, operate in bi-directional relationships; “both evaluation and response can modify perception” (Dodd et al., 2001, p. 671).

1.5. Significance of the Study

Previous AF studies have found that the varied, atypical or subtle symptoms which accompany AF, combined with low public knowledge about AF, may influence the misattribution of the origins of symptom, leading to a prolonged evaluation phase and delayed treatment seeking (McCabe et al., 2015). Current understanding of how patients experience, evaluate and respond to their AF symptoms is limited. Until now, AF researchers have focused on 1) characteristics of the symptoms (Buccelletti et al., 2013; Shavadia, Yonga, Mwanzi, Jinah, Moriasi & Otieno, 2013); 2) QOL associated with symptoms (Hagens et al., 2004; Ong et al, 2006; Paquette et al., 2000; Reynolds et al., 2006); 3) sex differences (Humphries et al., 2001; Rienstra et al., 2005; Yarnoz & Curtis, 2008); and 4) psychological effects of depression and anxiety on symptoms and treatment seeking behaviour (Kupper, Broek, Widdershoven & Denollet, 2013; Lange & Herrmann-Lingen, 2007; Thrall, Lipp, Carroll & Lane, 2007). The current study will expand on this body of knowledge by exploring the symptom experiences of patients prior to their diagnosis, namely perception, evaluation and response to symptoms. This study will provide a foundation for future research to be developed,
aimed at understanding this critical time period in the AF. This research is important as it may serve to facilitate the early identification of AF symptom(s), and lead to the formulation of appropriate strategies to increase awareness of AF symptoms and treatment to prevent the devastating complications of AF (e.g., stroke).
Chapter 2: Review of the Literature

This chapter provides an overview of the existing literature on Atrial Fibrillation (AF) related to symptom experience. A brief overview of pathophysiological changes, management and treatment relevant to the symptom experience is also presented, as a basis for understanding the potential severity of the condition, and the benefits of reducing the amount of time prior to seeking treatment from a HCP. Following this, the chapter is organized according to the components of the theoretical model used for this paper: The Symptom Experience Model (SEM) in AF, which includes the perception and evaluation of, and response to, symptoms. It subsequently discusses gender and age, as influences on symptom presentation, and diagnosis and treatment delay.

2.1. AF Pathophysiology

AF is a heart condition that features an irregular heartbeat, originating in the upper chambers of the heart – known as the atria. Normally, the sinus node (SA), called the heart’s pacemaker, initiates the stimulus for each heartbeat. In AF, the stimulus no longer originates from the SA node at a regular and controlled rate. Instead, the atria begin to generate multiple erratic signals, causing an increase in heart rate, which is characterized by an irregular rhythm. The irregular rapid heart rate, wherein the atria and ventricle fall out of synchronization, combined with a loss of normal atrial functioning, precipitates many of the symptoms seen within AF (Hardin & Steele, 2008).

There are multiple potential causes for AF’s developing, most of which stem from the development of atrial fibrosis (Hardin & Steele, 2008). Atrial fibrosis is a result of atrial dilation (enlargement), occurring over time. Conditions that can cause atrium dilation include hypertension, heart failure, coronary artery and valvular heart disease (Verma et al., 2014). Genetic links have also been established. Other non-cardiac triggers of AF include sleep apnea, obesity, thyroid problems and alcohol ingestion (Verma et al., 2014).
2.2. AF Symptoms

In AF, some patients may experience no symptoms at all, while others have reported debilitating symptoms such as shortness of breath, fatigue, and palpitations, and in extreme cases, loss of consciousness (Benjamin et al., 2009; Buccelletti et al., 2013; January et al., 2014; Rho & Page, 2005). AF symptoms are primarily a result of several mechanisms.

First, and particularly in patients with pre-existing heart disease, atrial fibrillation causes a decrease in cardiac output, as a result of the rapid heart rate that does not allow adequate time for ventricles to be filled between contractions (Hardin & Steele, 2008). Secondly, the atria contribute up to 30% of the total cardiac output by working in unison with the ventricular contractions. In normal heart functioning, the atria contract just before the ventricle, and fill it with blood, allowing for an efficient cardiac contraction. In AF, this synchronized contraction does not occur because the atria are contracting rapidly, at a rate of 300-600 times per minute (Rich, 2009). Combined, the increased ventricular heart rate and loss of the unified atrial contraction result in a loss of total cardiac output. The loss of cardiac output correlates with a lack of oxygenated blood reaching vital organs such as the heart, lungs and brain. For these reasons, the most often observed symptoms, such as dyspnea, fatigue, chest pain, and syncope, are caused by insufficient oxygen reaching the tissues. Secondly, the symptoms of palpitations or the feeling of a racing heart are a result of the rapid heart rate.

2.3. Management and Treatment of AF

AF is typically managed according to presented symptoms, with initial treatments being dependent upon the severity of symptoms. For example, if patients have severe symptoms, such as chest pain or syncope, direct current cardioversion (DCCV) will be initiated. This procedure applies an external shock to the heart, in order to restore its normal rhythm (Phang & Olshansky, 2015). Conversely, if the patient reports very mild symptoms, there is less urgency for a rapid intervention (Beck & See, 2012). Treatment priorities for the ongoing management of AF include the prevention of systemic embolization (stroke or other emboli) and a choice between rhythm or rate control.
strategies (Phang & Olshansky, 2015). The next section will summarize the management of systemic embolization, in order to give a basic understanding of the requirement for urgency, when responding to AF symptoms.

2.3.1. Prevention of Systemic Embolization

The greatest risk for patients with AF is a thromboembolism. Because of this, every patient should be evaluated for their appropriateness for antithrombotic therapy, in order to prevent systemic embolization (Becker, Eisenberg & Turpie, 2001; Hardin & Steele, 2008). Unfortunately, strokes from AF are common and devastating. They occur in 5% of patients under 65, 8% of patients, aged 75 and in 23.5% of patients aged 80-89 (Rich, 2009). An astounding 70 to 80% of patients, who suffer AF related strokes, die or become disabled (Gladstone et al., 2014). The Canadian Cardiovascular Society (CCS) determines the guidelines that Canadian practitioners should follow for the prevention of thromboembolism. In the 2014 guidelines, the CCS recommended, “elements of the Congestive Heart Failure, Hypertension, Age (>75 years), Diabetes, Stroke/Transient Ischemic Attack, Vascular Disease, Age (65-74 years), Sex (Female) (CHA2DS2-VASc) schema be incorporated in an algorithm for the selection of antithrombotic therapy” (Verma et al., 2014, p. 1115). In the CHA2DS2-VASc schema, patients receive one point for the comorbid conditions listed above, one point if female, two points a history of thromboembolism, and a maximum of two 2 points if aged greater than 75 years of age. The stroke risk is determined from this score. A score of zero is considered to be very low and anything above two is considered to be high. Verma and associates (2014) recommend oral anticoagulants should be given to anyone with a score of one or greater (scores range from 0 to 9) (Verma et al., 2014). It is also recommended that all patients who are being considered for cardioversion, by either DCCV or pharmacological, begin antithrombotic therapy (Phang & Olshansky, 2015). Finally, all patients whose risk of embolization, based upon the CHA2DS2-VASc score, exceeds the risk of bleeding should be considered candidates for long-term antithrombotic therapy.
2.4. Literature Search

The researcher searched MEDLINE, PubMed, PsychINFO, and CINAHL for studies published between 1985 and 2018. Both controlled language and keyword searches were used, and combinations of the following terms were sought: symptom(s), arrhythmia(s), atrial fibrillation, cardiovascular diseases, cardiac, perception, age, gender/sex, and experiences. The study’s inclusion criteria comprised studies published in English, which explored the experiences, symptoms, perceptions and responses to AF in adults nineteen years of age and older. Given the limited number of studies pertaining to the pre-diagnosis period only, studies exploring the symptom experience within the post-diagnosis period were also included in this review. Discussion or opinion articles were excluded from this review, as were studies that focused primarily on the biological conditions, rather than elements involved in the experience of symptoms. Fifty-two studies were identified that investigated the symptoms of AF. However, the foci of the majority of these studies were on the identification of symptoms, the influence of AF on the patients’ QOL, and connections between AF symptoms and depression, anxiety, and socioeconomic status.

In total, only seven studies were identified which explored the symptom experiences of patients who had AF, a further thirteen explored the influence of gender or sex on symptoms in AF, and eleven investigated age-related influences on symptoms in AF. These studies will be explored in the following sections. It should be noted that this study’s review of the literature, exploring the experiences of patients with AF, relied heavily on four studies conducted by McCabe and associates (2011, 2015, 2016a, 2016b). This is because: 1) this topic area remains underdeveloped, with very few studies available; 2) of the studies available, the aims of McCabe and associates’ studies were closely aligned with the concepts of perception and evaluation within the SEM; and 3) of the studies available, McCabe and colleagues’ studies provided the most depth, in their exploration of the response to AF symptoms.
2.4.1. Symptom Experience in AF

The following sections will discuss what is known, in the literature, about the first two concepts in the SEM, namely the perception of symptoms, and symptom evaluation (discussed earlier in detail in chapter 1). The study’s rationale for exploring perception and evaluation together, within this review, comes from the blurring of these two concepts within the existing literature. The SEM posits that perception, evaluation and response are separate, but related concepts. However, the relevant literature has tended to combine perception and evaluation, rather than treating them as separate concepts.

2.4.2. Symptom Perception and Evaluation

Before individuals can evaluate their symptoms, perception of an abnormal sensation must occur. No studies were found that isolated the influence of symptom perceptions during the pre-diagnosis period of AF. However, several of the AF symptom experience studies combined the perception and evaluation of symptoms in the reporting of their findings. In these studies, several themes emerged, which demonstrated how patients with AF perceived and evaluated their symptoms. The first notable theme was that patients had difficulty interpreting the symptoms that occurred following the onset of AF. For example, McCabe and colleagues (2016a) found in their study (N=150) that in the pre-diagnosis period of AF a third of patients reported that their initial interpretation of their symptoms was non-illness related, and 20% of patients were unsure about the cause of their symptoms. Patients readily attributed their AF symptoms to other conditions or non-illness related reasons such as aging, excess stress, and physical deconditioning (McCabe et al., 2016a). Similar findings were reported by several patients, post ablation, and following the resolution of their symptoms (Withers et al., 2015). Patients in this study indicated that prior to ablation, they had wrongfully attributed their AF symptoms, such as fatigue and breathlessness, to aging. This misattribution of symptoms, as being non-illness related or associated with other co-morbidities, was a significant factor associated with delays in seeking care (McCabe et al., 2016a).
A second theme was feelings of uncertainty (Withers et al., 2015). Uncertainty over the meaning of symptoms was particularly prominent when patients experienced vague or transient symptoms (McCabe et al., 2011). Furthermore, when the cause(s) of the experienced symptoms was not obvious, the result was often a long evaluation process, fear, anxiety and potentially erroneous conclusions about the nature of symptoms (Ekblad et al., 2013; McCabe et al., 2011). Patients’ uncertainty over both the origin and the meaning of the AF symptoms contributed to a prolonged pre-diagnosis period (McCabe et al., 2016a).

A third theme was that the misattribution/misinterpretation of AF symptoms was associated with a lack of knowledge or awareness about AF and its symptoms (McCabe et al., 2016a; Thrysoee et al., 2018). In another study (McCabe, Rhudy, & DeVon, 2015,) reported that 66% (n=41) of the participants had heard of AF prior to their diagnosis, however, the majority of these patients were not knowledgeable about the symptoms, or the potential seriousness, of the condition. This was in contrast to the public’s awareness of other cardiovascular conditions (McCabe et al., 2015). In North America, mass media campaigns have led to a greater public awareness of the symptoms associated with MIs and strokes; however, this has yet to occur for AF (McCabe et al., 2015; Moser et al., 2006). Given this lack of knowledge about what occurs following the onset of AF, patients reported few points of reference, to evaluate and form meaning about the symptoms they experienced (McCabe et al., 2011, 2015).

A fourth theme that emerged from the literature, and that related to the evaluation process, was something some patients described as turning points (McCabe et al., 2011). Patients reported that, in the pre-diagnosis period, specific influential turning points changed their evaluation of their symptoms. For example, the severity of the symptoms influenced some patients to decide that they needed to seek treatment from a HCP. Other patients stated that when the symptoms evoked feelings of extreme anxiety or fear, their evaluation of them changed and they sought treatment. Still, other patients continued to dismiss their symptoms until partners or family members recognized and evaluated the seriousness of their symptoms, and urged the patient to seek care (McCabe et al., 2015).
Often, the HCP themselves added to the undervaluing of symptoms, telling patients not to worry, and reassuring them that the symptoms they were experiencing were not associated with a heart condition (McCabe et al., 2015).

The final theme, elicited from the literature, was the influence of previous experiences of illness on how patients evaluated their AF symptoms (McCabe et al., 2015). For example, during the pre-diagnosis period, patients readily attributed their AF symptoms to their past illness history. Having experienced previous symptoms, which patients associated with a non-serious condition, made them more likely to assess their AF symptoms as benign and to delay seeking care. However, if previous experiences had led to a serious assessment of symptoms, patients were more likely to evaluate the symptoms as a threat to their health, and to urgently progress into the response phase of the symptom experience (McCabe et al., 2016a).

2.4.3. **Symptom Responses**

The responses to AF symptoms can be classified as either cognitive-behavioural or emotional (McCabe et al., 2016a). Each of these categories will be explored in the following sections.

2.4.3.1. **Cognitive Responses.**

Cognitive-behavioural responses are those that involve conscious thought, leading to deliberate action (McCabe et al., 2016a). Survey data, in McCabe and associates’ (2016a) study (N=150) showed that 73% of patients responded by waiting and further evaluating the symptoms (wait and see approach). In their study, the often-vague, intermittent symptoms such as dyspnea and fatigue were associated with an increased pre-diagnosis time (McCabe et al., 2016a). Patients reported that the erratic nature of their symptoms led to erroneous conclusions about their symptoms’ origins, and contributed to the labelling of the symptoms as being non-illness based, which in turn contributed to delays in seeking care (McCabe et al., 2011; 2015; 2016a).

In contrast to the above, the fact of patients’ associating their symptoms with an MI, as well as experiencing intense, severe, and sudden symptoms was associated with a decreased pre-diagnosis
time (McCabe et al., 2016a).

Other cognitive responses, reported in the pre-diagnosis period of AF, included a combination of the following: letting the symptoms take care of themselves (71%), sleeping (37%), ignoring them (36%), consulting family member or others (31%), relaxing (20%), or self-medicating with over-the-counter medications (14%). Furthermore, 82% of patients believed that their symptoms could be self-managed. McCabe et al. (2015) reported that patients chose several self-care responses to their AF symptoms. These included resting, taking more time to accomplish activities, avoiding certain activities and increasing exercise to improve physical fitness.

Seeking treatment from a HCP was the final reported response to AF symptoms, seen in the literature. This last response represented patients obtaining and then acting upon a formal diagnosis by undergoing treatment, following symptom onset.

Additionally, after patients chose to seek care, the intermittent nature of AF symptoms frequently influenced a physician’s ability to diagnose AF. If the arrhythmias were not present during the physical exam, some patients reported that their symptoms were dismissed by their physician (McCabe et al., 2011). Delayed diagnosis, which will be discussed in further detail under emotional responses, was a major source of frustration for patients, and was also a significant contributor to the overall delay experienced by many (McCabe et al., 2011).

2.4.3.2. Emotional Responses.
The second category of responses to the onset of AF symptoms, observed in the literature, was emotional and psychological responses; the most frequent of these were anxiety, fear, frustration, anger and hopelessness. Each of these responses will be discussed separately in the following sections.

Anxiety was a common response for those who suffered AF symptoms (Deaton et al., 2003; Ekblad et al., 2013; McCabe et al., 2011, 2015; Withers et al., 2015). For example, Ekblad and colleagues found that 100% of the patients in their study (N=25) experienced anxiety as an emotional response to AF symptoms. Similarly, Withers and associates reported that 80% of the patients in their
study (N=25) reported ongoing anxiety associated with their AF, which intensified during palpitations. In their study (N=118), Kupper and associates’ (2013) found that 42% of AF patients reported clinically relevant (p < .001) levels of anxiety, compared to 11% of the age-and-gender matched healthy controls. Additionally, patients who experienced anxiety often reported their symptoms as more severe and occurring more frequently than those without anxiety (Gehi et al., 2012; Garimella et al., 2015; Kupper et al., 2013; Thompson et al., 2014; Thrall et al., 2007). This body of research suggested a reciprocal relationship between anxiety and AF: the presence of anxiety was associated with patients’ reporting more severe and frequent symptoms, and in turn the occurrence of AF was associated with higher levels of anxiety. Lastly, in the Thompson and colleagues’ study (N=378), anxiety (p < 0.001) was a predictor of both AF symptom severity (AFSS), and of a lower QOL.

Fear emerged as a response to AF symptoms in all seven of the qualitative studies (Deaton et al., 2003; Ekblad et al., 2013, McCabe et al., 2011; 2015; 2016a; 2016b; Withers et al., 2015). Some patients expressed fear that was ongoing, intense and extremely burdensome (Withers et al., 2015). Others expressed a fear that the symptoms of AF, which included a rapid heart rate, shortness of breath, and/or palpitations, would cause irreversible heart damage (McCabe et al., 2011, 2015). Even when patients had received a diagnosis and had been assured that the risks, associated with their AF could be managed with anticoagulants, symptoms such as palpitations would still precipitate fear and anxiety in some patients (Ekblad et al. 2013, Withers et al., 2015). Ekblad and colleagues noted that patients’ emotional responses to AF symptoms influenced their overall emotional well-being and QOL, notwithstanding that the development of an emotional response, such as fear or anxiety, was often associated with patients seeking HCP care sooner (Burnett, Blumenthal, Mark, Leimberger, & Califf, 1995; McCabe et al., 2011). Finally, some participants reported that their anticipatory fears and anxiety, about AF episodes, led to avoidance behaviours that interfered with exercise, work, social, and recreational activities (McCabe et al., 2011).
Frustration and anger were other common responses in patients trying to decipher the meaning of the symptoms occurring within their bodies. For example, patients reported frustrating delays in having their AF diagnosed, through either a physical examination or an electrocardiogram (ECG or EKG), because of the potentially transient nature of the arrhythmia (Deaton et al., 2003; McCabe et al., 2011). Emotions such as frustration, anger and discouragement may escalate when HCPs dismiss patients’ symptoms (Deaton et al., 2003; McCabe et al., 2011, 2015; Withers et al., 2015). This is exemplified in both Withers and Deaton’s findings, with patients reporting that primary care providers, as well as some cardiologists, often addressed the symptoms of AF with a nonchalant attitude. Others reported that, during the pre-diagnosis period, their physician simply did not believe their reported symptoms because of a lack of any obvious symptoms, and the difficulty of obtaining a definitive diagnosis via ECG (Withers et al., 2015). This dismissive attitude could be attributed to the belief that AF is not a complex cardiac condition, when compared to other cardiac conditions such as heart failure or MI (McCabe et al., 2011). For this reason, some physicians may have minimized the significance of the condition and may have failed to provide the needed support and guidance to deal with the daily symptoms of AF. Following their appointments, some patients were told that there was no objective explanation for their symptom(s), and that they could be the result of stress, anxiety, panic attacks, or working too hard. The subtleties in symptoms and the elusiveness of obtaining a diagnosis intensified patients’ feelings of frustration, uncertainty, and illegitimacy (McCabe et al., 2011).

Hopelessness coincided with the feelings of uncertainty and frustration, as some patients had to endure long periods of waiting for answers to their symptoms (Deaton et al., 2003; Ekblad et al., 2013; McCabe et al., 2015; Withers et al., 2015).

Some patients also expressed feelings of loneliness and isolation because they limited their social contact out of fear that their symptoms might return (Withers et al., 2015). Conversely, other patients expressed feelings of validation and hope after the diagnosis of AF was made (McCabe et al., 2011). Furthermore, patients reported that the AF diagnosis, by a physician, gave them a sense of
relief in that they were not “crazy” or imagining all the symptoms they had experienced. The diagnosis of AF also allowed them to reconcile the uncertainty they were experiencing by providing an explanation for their symptoms.

2.4.3.3. Limitations in Daily Life.

Following the development of AF, many patients responded to their symptoms by limiting the activities associated with daily life (Deaton et al., 2003; Ekblad et al., 2013; McCabe et al., 2011; Withers et al., 2015). The degree to which activities were limited varied by person. Some patients experienced a severe lack of energy, because of their diminished cardiac function, which rendered them unable to carry out the activities of daily life, and caused severe disruptions in their working life (Deaton et al., 2003; Withers et al., 2015). In addition, some patients reported that AF symptoms limited their daily activities to the point of influencing their relationships with others (Withers et al., 2015). Other patients experienced relatively few alterations to their daily lives, because of their AF symptoms (Ekblad et al., 2013). For example, Ekblad and colleagues found that 46% of patients with AF did not report a reduced capacity in everyday activities. However, the presence of symptoms was not the only variable that limited patient activity. Some patients, who experienced very few episodes of AF symptoms, limited their activities out of fear and uncertainty about when the next symptoms would begin (Ekblad et al., 2013).

In contrast to the experiences of fear, uncertainty and hopelessness, some individuals ‘pushed’ back against the symptoms of AF, demonstrating resilience and persistence, to continue to meet the demands of daily life (Deaton et al., 2003; Ekblad et al., 2013). Some patients reported ignoring their symptoms of AF for years prior to seeking treatment from a HCP (Deaton et al., 2003). Similarly, others demonstrated difficulty in giving up various roles in their daily lives, even when it was becoming increasingly challenging to maintain normal functions because of their AF symptoms. Deaton et al. describe it this way: “There was a sense of trying to create a balance between the individual’s determination to continue and the acceptance that some losses were inevitable” (p. 295).
Patients reported their determination to carry on, in spite of their symptoms, as an attempt to maintain normalcy in their lives (Deaton et al., 2003).

### 2.4.4. Age

Two studies of the AF population demonstrated that age was a salient factor which could alter the experience, evaluation and response to AF symptoms. First, Reynolds and colleagues (2006) found in their Fibrillation Registry Assessing Costs, Therapies, Adverse events and Lifestyle (FRACTAL) study (n = 963), that age was a significant predictor of the types of AF symptoms experienced. Older adults with AF (> 65) were more likely to experience dyspnea (p = 0.02) and fatigue (p = 0.03) compared to younger patients (≤ 65), who were more likely to experience dizziness (p = 0.05) and palpitations (p < 0.01). Furthermore, the results of their FRACTAL study suggested that older patients with AF suffered less prominent disease-specific impairment to their QOL scores than younger patients. These findings were corroborated by data from the RACE study, which looked at the differences between rate control treatments in AF patients and electrocardioversion (Hagens et al. 2004). Symptom influence on the QOL in younger patients (< 69) in the RACE study was rated significantly lower (p = 0.05) than in older adults (≥ 69) suffering from AF.

In older adults it can be difficult to differentiate AF symptoms from the symptoms of other chronic diseases. For example, an underlying arrhythmia can be very difficult to distinguish because of the potential for overlapping symptoms (Dracup & Moser, 1997). Some older adults suffer from fatigue that is associated with aging, anaemia or CHF, which in turn makes the evaluation of fatigue associated with new onset AF difficult (Leventhal & Crouch, 1997).

Moreover, older adults may experience impaired sensory and symptom perception, as well as memory and comprehension losses (Hickey et al., 2013). These potential physiological and psychological changes make it more difficult for older adults to assess and respond to bodily symptoms (Gehi et al., 2012; Hickey et al., 2013). Blum et al. (2017) suggested that older adults developed a tolerance to their symptoms over time and, as such, that they noticed fewer and less
severe symptoms. These combined factors underscored the challenges seniors face when attempting to evaluate and respond to the symptoms of AF.

Finally, some older adults dealt with cardiac symptoms, including AF, differently to younger patients suffering from the same symptoms (Lefler & Bondy, 2004). Specifically, Lefler and Bondy noted that older adults, and those with comorbidities, delayed seeking professional care because of their learned behaviours of self-management and self-treatment. Additionally, Elias and Lowton (2014) found that, in general, older adults had lower expectations for health. They also minimized the impact of illness based upon their ability to perform the activities of daily life. Therefore, the delays in treatment seeking seen in older adults may have stemmed from their ongoing day-to-day management of chronic illness, their self-reliance behaviours and their self-regulation of symptoms.

2.4.5. **Sex and Gender**

Recent evidence, particularly within the MI literature, indicates sex and gender can shape the symptom experience. Although sex differences were well described in the AF literature (Dagres et al., 2007; McCabe et al., 2016a, Michelena et al., 2010; Paquette et al., 2000; Potpara et al., 2012; Reynolds et al., 2006; Rienstra et al., 2005; Yarnoz & Curtis, 2008), very little evidence was available to describe the role of gender in the symptom experience. The following section will describe what little is known about the roles of sex and gender in the symptoms experienced within the AF population.

There were many blurred lines in the literature between the biological influences of sex, versus the socially constructed and learned behaviour associated with gender, and their effects on the presentation and course of the symptom experience (Sobo & Loustaunau, 2010). Within the current literature, related to AF and its associated symptoms, gender has often been used interchangeably with sex. This has contributed to inaccuracies in describing symptom experience. Considering sex and gender as distinct influences is important to enhance a nuanced understanding of the unique role of biological ‘sex-related’ variables, and masculine/feminine gender-variables on the symptom
experience. Despite this acknowledgement of their distinctiveness, the boundaries between gender and sex are not black-and-white, but more often converge, to shape the symptom experience. For example, although Potpara et al.’s (2012) research suggested that women experienced more palpitations and greater fatigue than men, following the onset of AF, it was unclear whether the findings were the result of actual biological sexual differences or if gender influenced how and what men and women chose to report.

In terms of biological differences in symptoms, compared to males, females had higher resting heart rates, a greater prevalence of rapid uncontrolled rates of AF, and more severe symptoms (Michelena, et al., 2010; Paquette et al., 2000). Women also had more frequent recurrences of paroxysmal (intermittent) AF, after successful cardioversion (Humphries et al., 2001). Men developed AF at one-and-a half times the rates of women; however, with increasing age women accounted for an increased proportion of the total cases (Michelena et al., 2010; Rich, 2009). In the Framingham Heart Study, results indicated that women had a higher risk of dying from AF, with an odds ratio for death of 1.9 versus men who had an odds ratio of 1.5 (Wolbrette & Patel, 1999). Furthermore, women experienced a higher risk of stroke, CHF, and valvular heart disease, as a result of AF, whereas men had a higher incidence of MI associated with AF (Wolbrette & Patel, 1999). The presence of AF was associated with a 10–15% increase in all-cause mortality in men and a 20–25% increase in women (Rich, 2009).

Gender differences were observed in how men and women reported and sought care for AF-related symptoms (Potpara et al., 2012). Women had an increased frequency of reporting symptoms, and they sought medical help for their symptoms at a higher rate, even when health care visits related to the maternal experience (prenatal, intra and postnatal) were excluded (Van Wijk & Kolk, 1997). Women who experienced AF were typically older, compared to men, and they had a lower QOL, were more symptomatic, and were more undertreated, in terms of rate control, anticoagulation, and electrocardioversion (Potpara et al., 2012; Yarnoz & Curtis, 2008).
Finally, there was evidence of women’s having increased symptomatic events compared to men (Potpara et al., 2012; Schnabel et al., 2017). Potpara et al. reported that 54% of women with AF experienced palpitations compared to 43% of men (p = 0.001). 53% of women reported fatigue as compared to 43% of men (p = 0.004) and 15% of women had chest pain compared to 9% of men (p = 0.005). Sex differences were also noted in a landmark European study (n = 5333), where women reported significantly more palpitations (p = 0.001), dyspnea (p = 0.001), and chest pain (p = 0.01) following the onset of AF (Dagres et al., 2007). Similarly, both the Rate Control versus Electrocardioversion (RACE) study (Rienstra et al., 2005) and the QOL study by Paquette et al. (2000) confirmed differences in the symptom experiences by sex. Finally, one recent study by McCabe et al. (2016a) reported that women experienced more palpitations or skipped heartbeats than men (p = 0.03) in the pre-diagnosis period of AF.

Though limited, studies have described the role of gender, in the AF symptom experience. McCabe and associates’ conducted a quantitative study (2016a) of differences in men and women’s response to AF, in the pre-diagnosis period. The results showed no significant differences between men and women’s cognitive or behavioural responses to the symptoms of AF. Conversely, a quantitative study by Streur et al. (2017) found that gender could influence aspects of the symptom experience, including both the perception and evaluation of AF symptoms. Specifically, they found that women were more likely to experience symptomatic AF (e.g., fatigue, palpitations, and weakness) and symptom clusters. Their findings suggested that these differences were not attributed to sexual or biological differences but arose from differences between men and women that were unrelated to their heart, such as neuropsychiatric variables. Finally, in the McCabe et al. study (2016b), significantly more women than men indicated that potential embarrassment was a factor in their decision to delay treatment seeking from a HCP (p = 0.01).

Gender inequity in the diagnosis and treatment of AF is a theme which is becoming increasingly manifest within current literature. For example, in a small qualitative study (N = 11), all three women in the group reported that when they responded to their symptoms, they were not taken
seriously by their HCP, and their symptoms were dismissed and attributed to either menopause or stress (Deaton et al., 2003). Additionally, one young woman, in her early thirties, reported that her HCP implied that she was trying to get out of work, and that she needed to lose weight and exercise, to counteract the tachycardia she was experiencing. In this study, symptoms were more likely to be suspected as cardiac in nature, and appropriate treatment to be initiated, when males presented with the symptoms. Similarly, gender inequity is documented in relation to post-diagnosis AF care, with women reporting that they had a lower QOL and more severe symptoms, but were undertreated, in terms of rate control, anticoagulation and electrocardioversion (Blum et al., 2017; Potpara et al., 2012; Schnabel et al., 2017; Yarnoz & Curtis, 2008).

In contrast to these findings, other (i.e., non-AF literature) cardiac literature, concerning patients who experienced MIs, described the role of gender in the symptom experience more clearly. For example, Van Wijk and Kolk’s (1997) investigation of men and women responding to cardiac symptoms, found that women delayed seeking help, compared to men, even when the women experienced more frequent daily symptoms. Similarly, other large studies, conducted by Canto et al. (2000) \((N = 434,877)\), Gibler et al. (2002) \((N = 27,849)\) and Sheifer et al. (2000) \((N = 102,339)\), demonstrated that women experienced and evaluated the symptoms associated with cardiac illness differently than did men and delayed their decision to seek care.

Therefore, an important question arises: Why did women with cardiac symptoms evaluate, respond and, thereafter, delay treatment longer than men, even though they may have been experiencing more severe and frequent symptoms? One answer to this question might be found in the expectations women had regarding the nature of their symptoms, i.e., men and women had different expectations regarding the perceived risk of cardiac illness. For example, in two different studies, researchers found that women were more likely to experience symptoms that did not match their expectations, because of perceptions of women’s low risk for heart disease (Davis et al., 2013; Leifheit-Limson et al., 2015). Because of this, some women may have delayed, may have lacked a
sense of urgency, or may have been reluctant to seek treatment for cardiac symptoms, because they did not perceive themselves as being in the population of those at risk from cardiovascular illness.

Conversely, men, although reluctant, often relied on partners or close family to help with the evaluation and response phases of their illness (Noureddine et al., 2010). This reluctance and reliance on others is demonstrated in O’Brien, Hunt, and Hart’s (2005) qualitative study, that focussed on men’s accounts of their health seeking. The results suggested that men commonly demonstrated their masculinity through ignoring minor symptoms, as a way to show their stoicism. In this study, participants minimized the seriousness of their cardiac condition, questioning whether they were sick enough to require medical treatment, and often waited until a close ‘other’, such as a wife, recommended treatment (O’Brien et al., 2005). When compared to women’s demonstrated reluctance to seek care, in the Davis et al. (2013) study, the findings of the O’Brien and colleagues’ study indicated a clear gender difference, in the reasoning behind reluctance to seek care.

2.5. Limitations of the Current AF Literature

Research exploring the symptom experience was primarily qualitative in nature and focused on participants in the post-diagnosis period (Deaton et al., 2003; Ekblad et al., 2013, McCabe et al., 2011; Withers et al., 2015). In these four post-diagnosis qualitative studies, patients shared their experiences of living with AF over the course of the illness and, therein, described the symptoms they encountered. However, as these studies were not limited to the pre-diagnosis period of AF alone, it was unclear whether their findings were comparable to those studies that focused exclusively on the pre-diagnosis timeframe. For example, in the post-diagnosis period, patients were likely to experience reduced uncertainty about the meaning of symptoms, because a definitive AF diagnosis had already been made. Additionally, the reported experiences of AF patients in the post diagnostic period were influenced by various interactions with healthcare providers (McCabe et al., 2015), and in some cases, by the multiple failed attempts to reverse or control their condition (Ekblad et al., 2013). Finally, the accuracy of the experiences, as reported by patients, in each of these studies may have
been subject to recall bias, as some interviews occurred years after the first onset of AF (McCabe et al., 2015).

Research addressing the patient’s experiences during the pre-diagnosis period was very limited. As reported in the previous section, only three recent works by McCabe and associates (2015, 2016a, 2016b) focused on the pre-diagnosis period. Participants in these studies were limited to those who were hospitalized for their AF, and who had received care from a cardiologist, which was the minority among patients with AF (McCabe et al., 2015, 2016a). Furthermore, patients who were hospitalized for AF tended to have more significant comorbidities and symptoms that required urgent care, than those who received treatment on an outpatient basis. Finally, McCabe and associates’ (2015) study focused on the interactions between the HCP and patients who were symptomatic, and excluded patients who (reportedly) were asymptomatic. Excluding asymptomatic patients, eliminated a perspective that might have been important in obtaining a more complete understanding of the pre-diagnosis symptom experience.

Although the limited research provided initial insights into the overall experiences of patients with AF, much remained unknown about the patient symptom experience in the pre-diagnosis period. Gaps also existed in understanding how gender influenced the symptom experiences of AF patients. Despite evidence of the important role that gender played in the evaluation and response to symptoms in patients experiencing MIs (Moser et al., 2006), the AF literature was limited to only two studies (Deaton et al., 2003; McCabe et al., 2016b). A second major limitation in the current body of knowledge was the blurring of lines between the biological influences of sex, versus the socially constructed and learned behaviour associated with gender, and their effects on the presentation and course of the symptom experience.

2.6. **Summary**

In summary, the current literature regarding the symptom experience indicated that there was significant variability in the symptoms experienced by patients with AF. Although limited by the
small number of AF studies, current understanding indicates that individuals form unique perceptions about the symptoms they experience. These perceptions influence the evaluation of what their symptom(s) may mean to their health.

Themes that emerged from the literature on AF symptom perception and evaluation included 1) individuals have difficulty interpreting meaning; 2) they experience uncertainty; 3) they frequently misinterpret meaning; 4) they experience turning points, in the experience of symptoms, which influence the evaluation of symptoms; and 5) they rely on previous illness experience to evaluate their AF symptoms.

Individuals formed both cognitive and emotional responses, following the evaluation of AF symptoms. The majority of people indicated that their symptoms could be self-managed, and therefore they responded by waiting, ignoring, consulting family members, relaxing, and self-medicating (McCabe et al., 2016a). Emotionally and psychologically, individuals responded with anxiety, fear, frustration, anger, and hopelessness.

Although not specific to the pre-diagnosis period, this review of the literature indicated that older AF adults (≥ 65) tended to experience more dyspnea and fatigue, whereas younger AF patients (< 65) tended to experience more dizziness and palpitations. Furthermore, older AF patients may have suffered less prominent disease-specific impairment in their QOL scores than younger patients. Finally, older adults may have had more difficulty differentiating the symptoms of AF from other chronic diseases, and were more likely to self-manage their symptoms, for longer periods, before seeking care.

Sex and gender differences played a significant role in shaping the experience, evaluation and response to AF symptoms. When compared to men with AF, women tended to be more symptomatic and suffered from higher rates of fatigue. In similar cardiac literature about patients with MIs, women were shown to delay longer in seeking treatment, following the onset of symptoms. No studies were found that have confirmed this trend within the AF population, however, the cardiac MI data seems to suggest that women may have delayed longer in responding to arrhythmias, as well. In other cardiac
literature, both men and women demonstrated hesitancy in responding to cardiac symptoms; however the motivation or reasons for this indecision varied, and some studies suggested that men relied on women to initiate the care seeking process.
Chapter 3: Methodology

This chapter describes the methodology and research design used in the study. It gives an overview of interpretive description and discusses its theoretical underpinnings as well as the relevance for using interpretive description to address the research questions. It also describes the study’s planning and implementation procedures, and addresses the protection of human subjects and the methods that were undertaken to ensure rigour and trustworthiness.

3.1. Research Design

This study chose to follow a qualitative research approach. Qualitative inquiry provides a holistic, patient-centred approach to research, called for when empirical knowledge about human phenomena is required to provide depth and contextual understanding (Thorne, Taylor & Francis, 2008). This study used interpretive description, a qualitative method developed by Thorne, Kirkham and MacDonald-Emes (1997) as a way to generate clinically relevant knowledge for health disciplines.

3.1.1. Motivation for Choosing Qualitative Research

Until recently, the quantitative approach has predominated in the exploration of AF symptoms; listing symptoms that accompany AF, its consequences, the effectiveness of treatments, and the coping mechanisms obtained through survey data (Hohnloser, Kuck, Lilienthal, & PIAF Investigators, 2000; Lévy et al., 1999; Wazni et al., 2005). However, these quantitative studies failed to uncover the reasons why patients experienced, labelled, and reported certain symptoms, but not others. They did not detail how individuals evaluated their symptoms, deciding if they were health threats or dismissing them as irrelevant. Quantitative studies also did not explain why certain responses to symptoms were chosen, and how these responses influenced the length of time that was allowed to pass prior to care seeking.

Qualitative studies have been completed with AF patients, recently; however, their focus was either on participants in the later stages of AF, who shared their experiences over the course of their
atrial fibrillation (Deaton et al. 2003; McCabe et al. 2011; Ekblad et al. 2013), or was more focused on the interaction with the HCP (McCabe et al., 2015). These studies did not target the early patient experience, nor their perception, evaluation and response to symptoms, in the pre-diagnosis period.

That being said, two recent, quantitative studies by McCabe et al. (2016a; 2016b), explored the symptom experience of participants in the pre-diagnosis period, and offered a foundation for building a greater understanding of the symptom experience from the participant’s perspective. Building upon McCabe’s work, the present qualitative study aimed to uncover patient experiences further, provide context and meaning to patients’ beliefs about their symptoms, interpret the reasons for the decisions made, and lay the foundation for the development of strategies that will reduce the pre-diagnosis time within the AF population.

3.1.2. Interpretive Description

Interpretive description focusses on advancing disciplinary knowledge and improving practice, through a process of generating themes and patterns from the subjective experiences of patients. Practice-based disciplines are often unsatisfied with description alone, and therefore are well suited to interpretive description, which promotes the application of knowledge within the clinical setting (Thorne, Kirkham, O’Flynn-Magee, 2004). Finally, interpretive description is strongly influenced by aspects of grounded theory, naturalistic inquiry, ethnography, and phenomenology (Thorne et al., 2004). This was a useful criterion when considering the aims of this study: to explore symptom-related perceptions, evaluations and responses. Interpretive description philosophically aligned with a constructivist perspective, in which individuals faced with acute illness construct their own meaning of their situation (Corbin & Strauss, 2008). The process of meaning making in illness is highly individualized, socially constructed and context dependent (Thorne et al., 2008). In constructivism, each person’s right to make their own truth, based on their interpretation of their experiences, is respected (Munhall, 2007).
Interpretive description is also grounded in the naturalistic context, which assumes that absolute objective knowledge is unattainable through empirical analysis, but rather espouses multiple realities and truths that are subjectively constructed (Hunt, 2009, Thorne, 2008). Finally, it assumes that in the world of understanding human experience, the relationship between the knower and the known is inseparable and the researcher plays a role in creating the meanings attached to that which is being studied (Denzin & Lincoln, 2005; Thorne, 2008).

All of the reasons above confirmed that interpretive description resonated strongly with the aims of this study. Thus, through the use of interpretive description, the study’s findings were able to move past mere descriptions of the symptoms, to allow for an exploration of the pre-diagnosis symptom experience, and to offer possible explanations of why differences or similarities may or may not exist among the study participants (Thorne et al., 2008). Additionally, a thematic integrative description of patients’ symptoms was possible, without ignoring the complexity of human experiences (Thorne, 2008, pg. 75). The theoretical perspectives will be covered in greater depth in the following section.

3.2. Theoretical Perspectives

This research project was informed by two critical elements, described by Thorne (2008) as “theoretical scaffolding,” and included 1) the literature review and 2) the locating of self within the study (p. 64). The literature review in Chapter 2 provided the needed scaffolding for the interpretive description design by 1) grounding the study within existing knowledge; 2) offering a critical reflection on what is known and not known; and 3) critically examining the strengths and weaknesses on the overall body of knowledge (Thorne et al., 2008). Following this examination of the current literature (Chapter 2), it was determined that very little was known about the symptom experiences of AF patients, particularly within the pre-diagnosis period. One notable weakness in the body of AF literature was the interchangeable use of the terms sex and gender. Therefore, this study built upon...
the empirical, a priori knowledge of AF symptom experience, and addressed the issues that related to accurately exploring gender and age-related differences.

The second critical element that was considered, within the theoretical scaffolding of an interpretive descriptive study, was the locating of self within the research. Thorne (2008) indicated that, within interpretive description, it was important for the researcher to locate themselves within the field and in the theoretical perspectives that surround the phenomenon under study. Unlike quantitative designs, which attempt to control the influence or biases of the researchers, interpretive description recognizes that the researcher and study participants interact and influence one another (Thorne et al. 2004). Therefore, interpretive description used the researcher as an instrument within the research process. This was done through the following elements as described by Thorne (2008):

1. Locating theoretical allegiances on entering the study
2. The locating of self within a discipline and identifying the personal relationship to the ideas expressed in the study (p.64).

### 3.2.1. Locating Theoretical Allegiances

Thorne et al. (2004) have indicated that the role of theory, within interpretive description, provides a preliminary framework where the researcher can make decisions about sampling, design and early analysis. However, the goal of interpretive description is to move beyond the initial theoretical scaffolding “in order to fully engage the processes of inductive reasoning, including testing and challenging preliminary interpretations, and conceptualising an ordered and coherent final product” (Thorne et al., 2004, p. 3). As discussed in Chapters 1 and 2, the primary theoretical scaffolding of this study comes from the work of Dodd and colleagues (2001) in the SMM, and Bruno’s (2013) SEM in patients suffering from MIs. The SEM in AF was created from these two models, which in turn informed the research design, the formation of the questions, the structure of the literature review, the collection of data, and guided the preliminary approach to the data analysis.
3.2.2. **Disciplinary and Personal Knowledge**

Another important aspect that relates to locating self within the research process is recognizing the influence of disciplinary knowledge and the researcher’s personal relationship to the ideas expressed within the study. Thorne (2008) wrote that disciplinary knowledge represented a form of theory within the applied sciences, as it inevitably shaped what the researcher decided to observe in the field, what was seen during the observations, and the interpretations that were constructed from the data. Therefore, disciplinary knowledge acts as part of the theoretical scaffolding that shapes this study. Nurses are the frontline workers who witness the experiences of patients suffering from all types of symptoms. For example, this researcher’s disciplinary experiences as a nurse, caring for patients suffering from strokes resulting from untreated AF, influenced the development of this research. While caring for these patients, I began to question why many patients failed to recognize or respond to the symptoms associated with AF, quickly, or to seek early treatment. Understanding this disciplinary perspective helped to clarify the motivation for the study and may assist in identifying potential uses for the findings (Thorne et al., 2008).

Interpretive description is well suited to addressing problems that are clinically based, as the overall intent of the method is to change practice, as compared to other methods with the primary purpose of theorising (Thorne et al., 2008). It is important to note that nursing is unique in that it values aesthetic knowledge, which is based upon experience, intuition, knowledge and instincts (Chinn & Kramer, 2011). For example, nurses commonly report making decisions about patient care, based on ‘gut’ intuition. This study recognized that interpretive description is designed to study problems within the clinical field, and that value is placed on the clinical experience, such as the aesthetic knowledge that nurses bring to the research process. Therefore, interpretive description uses the researcher, and the practice knowledge acquired in their experiences (e.g., aesthetic), as an instrument that shapes the research process (Thorne et al., 2008). In practical terms, this meant that my previous knowledge, intuition and experience as a nurse assisted in shaping design issues such as the research focus and aims, and the questions within the interview guide. Furthermore, the
interviewing skills I developed, through years of triaging patients within the ER, facilitated the data collection process. Finally, my experiences as a nurse helped me recognize themes and patterns within data, in the analysis.

Although disciplinary knowledge contributed to the scaffolding of this study, it was important to keep biases in check (Thorne et al., 2008). By the use of constant reflection, as a researcher, I tried to ensure that I stayed true to what the data were saying, and I was careful not to form conclusions, based upon preconceived notions of what I thought the data should mean. Even though I was an instrument within this process, I did not allow my own perspectives to influence the experiences that patients shared. To keep these biases in check, and as Thorne (2008) recommended, as a student researcher, I engaged in reflective journaling, or documentation, throughout the duration of the study. Furthermore, my biases were checked by keeping an open mind both during the data collection and analysis, discussing emerging ideas and themes from the data with my committee members, and by asking members to assist in challenging my personal beliefs and assumptions throughout the analysis (Thorne et al., 2008).

3.3. Sampling and Recruitment

Sampling in qualitative research keys in on the identifying and selecting participants who can offer information-rich data about a particular phenomenon, by the most effective means (Palinkas et al., 2015). This study used purposeful criterion - based on a sample of convenience, which “involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest” (Palinkas et al., 2015, p. 2). The criterion used to select the sample specified that all patients must have had a recent AF diagnosis, with recent being defined as having occurred within the past twelve months. This timeframe was chosen deliberately, as research into recall bias indicated that increasing the amount of time, in which participants are asked to recall something, decreased their recall accuracy (Auriat, 1993). Specifically, periods greater than one year increased the inaccuracy of recalled events (Stanton, McClelland, Elwood, Ferry & Silva,
Given that researchers did not have access to medical records and, therefore, could not obtain the official date of diagnosis, the twelve-month timeframe was determined by the estimated date, identified by the participants, when they received a diagnosis of AF, from their HCP.

The findings of the literature review indicated that AF patients experienced symptoms for varying durations of time, prior to receiving an AF diagnosis, from their HCP. McCabe and colleagues (2016a) (N=150) found that timeframes for seeking care ranged from hours to years, and 69% of their study group waited more than a week, after the onset of symptoms, to seek treatment. Notwithstanding this, the present study chose to explore only the symptom experiences of patients for up to twelve months after diagnosis, regardless of the duration of their symptoms prior to the AF diagnosis. This decision was made to help facilitate an accurate reflection of the pre-diagnosis symptom experience.

3.3.1. Participants

Physician involvement through cardiology practices and a general practitioners office were initially approached to serve as recruitment sites, but all participants were recruited from three primary locations. These three locations provided services for a broad spectrum of patients with AF, but targeted patients with newly diagnosed AF. Recruiting from these three settings was intended to reach a broad, diverse sample of men and women of varying ages.

(1) an AF clinic located within KGH that saw newly diagnosed AF patients throughout the Okanagan interior

(2) a Rapid Access to Cardiac Evaluation clinic (RACE), also located within KGH, which saw newly diagnosed AF patients from both the community and the ED

(3) a cardiac rehabilitation centre located in Kelowna that received referrals for patients with newly diagnosed AF

Key stakeholders were identified at each of the potential recruitment sites, which included a nurse practitioner at the AF clinic, a nurse, nurse practitioner and occupational therapist at the cardiac
rehabilitation centre, and the patient care coordinator of the RACE clinic. Each of these key stakeholders was given a letter inviting them to participate in the recruitment process (see Appendix A). Knowledge users/key stakeholders at the AF clinic, RACE and cardiac rehabilitation centres were asked to identify adult patients with newly diagnosed AF, to briefly introduce the study using a script (see Appendix B), to distribute a letter of permission to be contacted by the research team (see Appendix C), and to provide them with the participant consent form (see Appendix D). The key stakeholders asked the AF patient to provide their contact information, in the space provided, on his or her own permission-to-contact form. Additionally, at the cardiac rehabilitation centre, the student researcher attended the monthly education meetings which were being offered to patients with newly diagnosed AF. During this meeting, the student researcher briefly introduced the study, and asked that any interested participants fill out a permission to contact form (Appendix C).

Key stakeholders, at each recruitment site, were asked to keep the permission-to-contact forms in a secure location, until they were collected by the PI. The student researcher checked in, regularly, with the stakeholder to collect any new permission-to-contact forms. The student researcher contacted interested patients, by phone, after ensuring at least a twenty-four hour period, in order to allow potential patients adequate time to read the consent form, have any questions answered and to make an informed decision about participation. During this initial phone call with potential study participants, the student researcher introduced the study’s purpose and aims, provided additional information about the study, using a screening script (see Appendix E), answered any questions and arranged a time for an interview. Potential participants were subject to inclusion and exclusion criteria, as follows.

3.3.1.1. Inclusion Criteria

All consenting AF patients met the following criteria.

(1) They had self-reported diagnoses of AF in the last 12 months, or less, from a HCP (confirmed by electrocardiogram).
(2) They were at least nineteen years of age, or older.

(3) They were able to speak and understand English (if reading challenges were apparent, some support was given by the interviewer).

(4) They were able to give their own consent to participate in this study.

(5) They were able to complete a form with minimal assistance;

(6) They were willing to participate in a sixty to ninety minute, face-to-face interview as well as a possible confirmatory interview lasting thirty minutes.

3.3.1.2. Exclusion Criteria

Patients were excluded based on the following criteria.

(1) Individuals who demonstrated cognitive or communication problems, because of conditions such as dementia, Alzheimer’s, or cerebral vascular accidents. Also, patients for whom problems with memory and recall prevented them from describing their AF symptom experience. This was determined during the initial screening interview by asking the patient, “Have you ever had difficulty with your ability to think (cognition), or communicate that is associated with dementia or a stroke?” Secondly, cognitive screening for impairment was determined at the time of the interview, by having participants complete the Mini-Cog (see Appendix F) screening tool (cognitive impairment <3 on the Mini-Cog) (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000).

(2) Individuals who had an uncompensated hearing impairment

(3) Individuals who had experienced the first symptoms of atrial fibrillation within the context of a procedure, surgery, or high endurance sporting activities.

(4) Individuals that lived further than ninety kilometres from the UBC Kelowna Campus.
3.3.2. Sample Size

Within interpretive description, sample size can be an ambiguous estimation; however, the researcher estimated that approximately twenty-thirty participants were needed (Thorne et al., 2008). Justification for this number was established, by comparing the numbers of participants used in other qualitative studies exploring AF experiences; such as the McCabe et al. (2011) study (fifteen participants), and the Ekbald et al. (2013) study (twenty-five participants). The upper number of thirty was based upon other non-cardiac studies using interpretive description, which used between twenty-three (Robinson, Pesut, & Bottorff, 2012) and thirty-two (Olsen, Bradley, Lomborg & Nortvedt, 2013) participants. However, these were estimates and data collection continued until saturation was reached, at twenty-six participants. In qualitative research, data saturation is the process of collecting data until there is a thick, rich description of each emerging theme, and repeated sampling leads to a repetition of findings (Richards & Morse, 2012). The researcher had no way of knowing how many men and women would be recruited, however as much as possible, a balanced number of men and women were sought. Opportunely, 13 men and 13 women were recruited when data saturation was reached. The multiple recruitment sites and the extended time frame for recruitment (7 months) undoubtedly facilitated some of this balance. Lastly, to address the influence of age on symptom experiences, a wide distribution of ages was sought. However, since convenience-sampling strategy was used, researchers did not turn away potential participants, based on age or gender.

3.4. Data Collection Strategies

Data collection began, after obtaining harmonized approval from the behavioural research ethics board (BREB) of the University of British Columbia and Interior Health [approval number: H15-02443]. Participant consent was obtained at the time of data collection following opportunity to review details of the consent and have questions answered to their satisfaction, (see Appendix D). If the participants asked for a support person (family or friend) to be present, to assist with the
recollection of events during data collection, consent from the support person was also obtained at that time (see Appendix G).

Effective data collection required patients to reflect on what they had experienced following the first onset of their illness or recognizable symptoms. To engage in this recall and reflective activity, patients had to have normal cognitive function. Cognitive screening for impairment was determined by having participants complete the Mini-Cog (see Appendix F) screening tool (cognitive impairment <3 on the Mini-Cog) (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000) prior to data collection. During this cognitive test, participants were asked to remember and recall 3 items (banana, sunrise and chair), and to draw a clock with all the numbers in the circle and the hands set to ten after eleven. All participants scored a four or five on the Mini-Cog, indicating that cognitive impairment was unlikely.

Interviews are the most commonly used method of data collection within qualitative research, including interpretive description. Often, interpretive description uses other data sources, such as researcher journals, literature, and field notes, to support interviews (Thorne et al., 2008). Data collection included a combination of interviews, demographic and health history information, and information about the frequency and severity of AF symptoms.

This study used interviews to understand participants’ experiences with AF symptoms in the pre-diagnosis period (Tetley, Grant & Davies, 2009; Thorne, 2008). Semi-structured interviews were conducted in several locations, including participants’ homes and various coffee shops. These locations were selected by the student researcher based upon convenience for the participant and the available privacy to conduct an interview. The interviews were all conducted within one year of their AF diagnosis. An interview guide, based broadly on the SEM, was developed with questions to access the perceptual, evaluative and response processes while still allowing participants to share their pre-diagnosis symptom experiences and detailed stories freely (see Appendix H). The interview guide was piloted to assess participant understanding of the questions, whether the questions elicited information pertinent to the research aims, and the effectiveness of the researcher in using self to
engage with the participant to obtain rich, quality data (Thorne et al., 2008). Questions were deemed highly effective in producing relevant data and were used without modification for subsequent interviews. However, since the goal of interpretive description was to move beyond the initial theoretical scaffolding, the interview questions were changed, occasionally, during the interview, in order to capture particular information that the participant was presenting (Thorne et al., 2008). For example, several times during the interviews, participants began to describe feeling disadvantaged in terms of their knowledge or awareness of AF, because of their gender. The following is one example of how student researcher was sensitive to voice of the participants and probed for further details:

“RW: Going back to the gender thing. Did you feel, do you think that because your idea. You said, you didn’t think women maybe had as much heart disease or maybe have as many heart attacks. Do you think that might have shaped your impression of some of these, the heart fluttering and stuff like that”?

Each digitally recorded interview took approximately sixty to ninety minutes. Participants were given the option to take breaks throughout the interview process, if necessary, because of tiredness, unexpected interruptions, or any other reasons. However, no participants needed a break during the interviews. All of the interviews were conducted face-to-face, to allow for the observation of non-verbal cues.

A demographic and health history questionnaire was used (see Appendix I), to collect information about each participant’s age, sex, marital status, as well as pertinent comorbidities, medication history and information regarding first professional health practitioner sought for AF related symptoms (e.g., doctor, physiotherapist, chiropractor, naturopath). The information gathered from this demographic form was used to complete a CHA2DS2-VASc stroke risk assessment form, in order to assess the characteristics of the participant sample further (see Appendix J). A score of zero is considered to be very low and anything above two is considered to be high risk of stroke if not anticoagulated.
Participants completed the Symptom Checklist (SCL) – Frequency and Severity data collection form (see Appendix K) (Bubien, Knotts-Dolson, Plumb & Kay, 1996; Jenkins, 1993). The SCL form asked participants to report on the frequency of symptoms, from 0 (never) to 4 (always). The suggested symptoms were: tiredness/ lack of energy, heart fluttering or skipping, heart racing, light-headedness or dizziness, headache, trouble concentrating, difficulty in catching a breath, shortness of breath, feeling warm/flushed, sweating, weakness, poor appetite, nausea, difficulty sleeping, chest pain when the heart is racing or fluttering, and chest pain when the heart is not racing or fluttering. Frequency scores had a possible range from 0 to 64, and higher scores indicated more frequent symptoms. The SCL form also recorded the severity of the reported symptoms, from 1 (mild) to 4 (extreme). Severity scores had a possible range of 0 to 48, with higher scores indicating more severe symptoms. The internal consistency of the SCL was estimated, using Cronbach’s α with ranges of .87 to .92 for symptom frequency scale and .89 to .93 for the symptom severity scale (Jenkins et al., 2005). The information gleaned from the SCL form, used during the interview, was a way of further probing the symptoms participants were experiencing and the complete score was used within the final analysis.

Detailed field notes were made, following each interview. These notes provided context, background, and reflections of the interview (Thorne et al., 2008). In line with Morse and Field (1995), the field notes included who was present, the location and environment of the interview, any pertinent content that stood out in the interview (e.g., keywords, topics, phrases), and nonverbal behaviour (e.g., tone, posture, affect, eye contact, hand gestures). Additionally, these field notes were used to document preliminary analysis such as hunches themes and trends. For example, in the field notes, the researcher began to take note of how many of the women described feeling frustrated with their inability to gain any answers for their symptoms from the HCP. As the interviews progressed, this was a growing trend which emerged into a very significant finding. Lastly, researcher reflexivity was captured within the field notes, by documenting personal influence, reaction or biases on both the interviews and the analysis. For example, it was challenging for the student researcher to move away
from using the medical model to “medicalize” the data. During the initial interviews, the student researcher honed in on the details of when the symptoms happened, how severe they were, or how frequent, and perhaps missed some of the experiences that participants wanted to share. As the interviews were reviewed and reflected upon, the researcher learned that some of these medical details had to be put aside, in order to hear the voices of the participants.

3.5. Data Management Strategies

Following the interviews, the digital audio file was uploaded to a secure UBCO server. Digital audio recordings were transcribed verbatim, and the transcriptions were checked for accuracy. All notes and data were coded (with a five-digit number) to remove any personal identifiers and were kept in a locked cabinet in the PI’s office, in order to protect patient confidentiality. The list of names, as they correspond to five-digit codes, was stored separately, in a locked cabinet in the student researcher’s office, and will be kept for a minimum of five years and possibly up to seven years.

3.6. Data Analysis

The Nvivo (version 10.2.0) software package was used to code and manage the field notes and transcriptions. The student researcher met regularly with committee members, during the data collection and analysis process, to discuss the transcripts and emerging ideas. Minutes and notes were kept from these meetings, which helped inform the analysis process in various ways, such as identifying categories and themes, changes or additions to questions to guide subsequent interviews, and plans for ongoing data analysis (Thorne et al., 2008).

The goal of interpretive description is to work within and beyond the analytic model (SEM) towards abstracted interpretations that will illuminate the symptom experiences within the pre-diagnostic period (Thorne et al., 2004). Thorne et al., described the process as iterative and inductive; it challenged the researchers’ preconceived notions, which were included in the theoretical framework, to produce a conceptualized, meaningful, orderly and coherent final product. As per interpretive description methods, concurrent data collection and analysis was used throughout, which encouraged...
engagement with the data, as well as the exploration of new conceptualizations of the phenomenon. The concurrent data collection and analysis also promoted reflection, deepened the meaning of subsequent interviews and allowed for the exploration of emerging themes (Thorne et al., 2004; Thorne, 2008).

An immersion in the data (reading and re-reading), prior to the initiation of coding, helped the researcher to stay connected to the data (Thorne et al., 1997). During this immersion process, memo and note taking were used make sense of what was going on in the data. For example, in looking at gender and the symptoms experiencing, key observations were documented after each interview, such as how some of the men looked to their partners to help explain how they evaluated and responded to their symptoms. This reliance that men demonstrated towards their partners became a significant evaluative gender theme. This process of using memos and notes followed the research aims of interpretive description, where a coherent conceptual description of a phenomenon is developed, and is expressed in thematic patterns that characterize the commonalities and variations within the experience (Thorne et al., 2004).

Thematic analysis was used to abstract themes from the data. The initial open coding began with a line-by-line reading of the transcripts for words, phrases, paragraphs that reflected each of the SEM processes (perception, evaluation, response). Common codes within each of the SEM processes were clustered to form a preliminary framework or template (Olsen et al., 2013). Once a framework was finalized, all the interviews were re-analysed and compared using this framework. Modifications to the coding framework occurred as data collection proceeded and new codes emerged. Another important aspect of the analysis was to look for gender and age-related differences among the participants’ ideas about their symptom experiences. Based on the themes that emerged within the data, a comparison matrix was created using age, gender as well as early versus late health seeking responses (Richards, 2009). Inductively, other tables were created to assist with the analysis and development of the emerging ideas that were being abstracted from the data. The Findings chapter will discuss how these comparison tables generated new knowledge about the participants’ symptom
experiences.

As interpretive description is an inductive approach to qualitative research, it was important, at all times, to remain true to participants’ data. Even though the analysis was influenced, initially, by the preliminary structure of an a priori theory (SEM in AF), the researcher acknowledges that no pre-existing theory was likely to account for all the realities that were encountered within the data (Thorne et al., 2004). Thorne and associates (2004) cautioned against allowing an analytic structure to overwhelm data collection and analysis. In interpretive description, analysis of data presents a dialectic between the theory and the data. In this dialectic, the researcher avoided “theoretical imposition on the one hand, and a theoretical description on the other, in the quest for a coherent rich interpretation that allowed a priori theory to be changed by the logic of the data” (Thorne et al., 2004 p. 6). For this reason, in the early stages of the analysis, the student researcher remained cognizant of the nature and shape of the preliminary theoretical scaffolding used to construct the study, while remaining open to relinquishing an existing theory and to creating new or alternative conceptual meanings to view the patients’ symptom experiences (Thorne et al., 2004). In the current study, the medical bias of the student researcher, which assumed that patients first perceive, evaluate, and then respond to symptoms, was challenged, when participants moved with fluidity throughout these three theoretical concepts. This stretched the researcher to move beyond the theoretical model, into a more cyclical experience within each of the core concepts of the model.

3.7. Ethical Considerations

In qualitative research, a number of ethical issues must be considered and planned for, throughout the research process. According to the Canadian Institutes of Health Research (CIHR) (2010), the first is to determine what potential risk or harm may be associated with participating in the study. CIHR defines harm as anything that has a negative effect on the welfare of the participants, and which may be social, behavioural, psychological, physical or economic. CIHR defines risk as a function of the magnitude or seriousness of the harm, and the probability that it will occur. This study
posed very little potential harm and minimal risks, to the participants involved. Apart from patient fatigue, related to a long interview, no anticipated or known physical risks were associated with this research. However, there was some potential psychological risk, in that an interview might cause a patient to revisit symptom experiences that were related to an upsetting event. No reported fatigue or emotional unrest arose during the interview or in the weeks that followed the interviews.

3.7.1. Informed Consent

As per the ethical guidelines, outlined in the CIHR (2010) ethics document, participants signed an informed consent form, written in plain language. It identified all the researchers involved, the research purpose, any funders or sponsors, the expected duration of the research procedures, and explained the responsibilities of the participant. Furthermore, research participants were made aware that: (a) consent was given voluntarily; (b) consent was an ongoing process; (c) consent could be withdrawn at any time without any affecting their ongoing treatment from their HCP.

3.7.2. Benefits

The benefits of participating in the research included the potential for participants to increase their awareness and knowledge of AF symptoms, as well as any possible gratification and/or satisfaction that might be found in contributing to research, which may enhance understanding of the pre-diagnostic time and, thus, improve care.

3.7.3. Privacy and Confidentiality

Participants were made aware of their rights to privacy and confidentiality, within the research process. Recorded and printed interviews were made available only to members of the research team. Participants were informed that the data from the interviews would be used in the analysis process, and would be kept between five to seven years, stored securely in a UBC facility (kept in a separately locked cabinet in the student researcher’s office). Only code numbers were used to identify any material related to personal information. Made-up names were used in conjunction
with the information provided during the interviews. No names or identifiers were used in any reporting of the results in the study.

A summary of the findings will be offered to each of the study participants.

3.8. Strategies Used to Maintain Methodological Rigour

In interpretive description, as in other qualitative approaches to research, particular attention must be paid to the overall quality or rigour of the research design. Thorne (2008) described four key evaluative criteria that should be used to assess an interpretive descriptive study.

The first is the degree to which the overall study demonstrates epistemological integrity, i.e., where there is a “defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained” (Thorne, 2008, p. 223). The proposed study clearly articulated the researchers’ epistemological standpoint (constructivist perspective), which was in congruence with the research question, the theoretical framework and the interpretive description approach.

The second aspect is representative credibility, when evaluating qualitative research (Thorne et al., 2008). Representative credibility relies on congruency between the sample and the conclusions of the research. Furthermore, Thorne (2008) suggested that credibility of the research is enhanced by including maximal variation in the sample, prolonged engagement with the sample, triangulation of various data sources, and multiple angles of knowledge construction. To account for representative credibility, this study used maximal variation, by purposively sampling the population in order to obtain as much diversity of ages and genders as possible. Demographics were collected, and shared in the findings, as a means of informing the reader of the representativeness of the sample, in relation to the conclusions reached within the study. Additionally, interviews were conducted over a sixty to ninety-minute timeframe, to allow for the best engagement with the participants. Multiple data collection strategies were used for the purposes of triangulation, including in-depth interviews, field notes and a symptom checklist and severity questionnaire. Finally, the research team met regularly,
during the concurrent data collection and analysis process, to ensure that the findings represented the various constructions of knowledge.

In addition to epistemological integrity and representative credibility, Thorne (2008) described analytic logic as a third evaluative criterion. Analytic logic requires that any pre-understanding of a phenomenon be made explicit, and that the interpretations and knowledge claims are logically based in the findings in the data. Moreover, the decision-making process must be transparent enough to allow the reader to evaluate the finding’s credibility. In order to ensure transparency in every aspect of this study, all data collection techniques, analysis, origins, patterns and evolutions of emerging themes are presented in the dissertation.

Thorne’s (2008) fourth evaluative criterion is interpretive authority. This is described as the insurance that the analytic interpretations are trustworthy, that biases are considered and made explicit within the interpretations, and that the findings are grounded in the data. To address this criterion, this study used dual or multiple coding on the various interview transcripts, as a form of assurance that the codes were grounded within the data. Secondly, participants were asked for consent, to contact them following the interview, should any further information or clarification be required, after the analysis of the first interview. Finally, and to ensure that interpretations were trustworthy, the student researcher immersed himself in the data; by completing all the interviews, writing field notes following each interview, completing multiple read-throughs of the transcripts, and by memo taking throughout the analysis, as interpretations were made.

3.9. Summary

This chapter described the methods and processes employed in this research study, which included sampling, recruitment data collection, data management, data analysis, human subjects’ protection and rigour in qualitative research. The evaluative criterion of epistemological integrity, representative credibility analytic logic and interpretive authority strengthened the study’s qualitative research findings. Interpretive description provided the scaffolding to explore the symptom
experiences, of adults encountering AF in the pre-diagnosis period of AF. The following chapters will contain the study’s analysis, discussion, and conclusions.
Chapter 4: Findings

4.1. Introduction

This chapter details the findings based on the data collected from twenty-six semi-structured interviews with participants reflecting on their pre-diagnosis period of AF. This study used thematic analysis to generate themes consistent with the experiences of the participants. The themes, thus identified, expanded upon each of the unique, but interrelated, processes that occurred following the onset of AF. These processes included symptom perception, which involved participants’ variable awareness of bodily sensations (changes) from imperceptible noticing to commanding attention, with rest and activity heightening symptom awareness. Next, evaluation reflected participants’ intense cognitive work of judging, making sense of, and finding explanations for their bodily sensations and symptoms. It consisted of participants forming personal theories, gathering evidence to support/refute their theories, and re-theorising when their theories were disrupted. Lastly, responding represented the actions/activities that participants employed, in responding to, and dealing with their symptom(s).

Participants had three significant responses to their symptoms: non-treatment, self-treatment, and health seeking; responding with non-treatment and self-treatment protracted the pre-diagnosis time, with periods lasting from weeks to years (See Table 1 for a summary of all themes).

Despite the three distinct processes identified, the pre-diagnostic symptom experience was often characterized by an interconnectedness of all three stages of the SEM. Perception, evaluation and response rarely occurred in a linear fashion, but rather happened cyclically and often overlapped in patients’ experiences of their symptoms. For example, it was not uncommon for a participant’s evaluation to influence their response and thereafter (alter) their perceptions. Additionally, if a participant’s response did not effectively alleviate or explain the symptom, the participant would return to the evaluation process to re-evaluate the meaning of their symptom. At times participants characterized the three processes as happening simultaneously/fluidly.
Table 1: Summary of all Themes in the AF Symptom Experience

<table>
<thead>
<tr>
<th>AF Symptom Perception</th>
<th>The Evaluation Process</th>
<th>AF Symptom Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Noticing</strong></td>
<td><strong>Speculating- Individual Symptom Theories</strong></td>
<td><strong>Non-Treatment.</strong></td>
</tr>
<tr>
<td>Imperceptible Noticing-“Feel Something, but Nothing Really”</td>
<td>• It is nothing really- My heart is just being funny.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I’m just getting older.</td>
<td>• Waiting, watching, and hoping it will go away.</td>
</tr>
<tr>
<td>Commanding Attention</td>
<td>• I must be stressed or anxious.</td>
<td>• Talking Themselves Out of Being Sick.</td>
</tr>
<tr>
<td>Rest and Activity</td>
<td>• All too familiar- chronic health conditions.</td>
<td><strong>Self-Treatment.</strong></td>
</tr>
<tr>
<td>• Rest</td>
<td>• It’s my fault – weight and diet.</td>
<td>• Stop, rest, or lay down.</td>
</tr>
<tr>
<td></td>
<td>• Just pushing myself too hard-physical activity.</td>
<td>• Coughing or deep breathing.</td>
</tr>
<tr>
<td></td>
<td>• Something is wrong with my heart.</td>
<td>• Lifestyle changes.</td>
</tr>
<tr>
<td></td>
<td><strong>Taking Shape- Influences Shaping the Evaluation Process</strong></td>
<td>• Modifying activity.</td>
</tr>
<tr>
<td></td>
<td>• Expectations</td>
<td>• Changing jobs.</td>
</tr>
<tr>
<td></td>
<td>• I’m too healthy to have heart disease- I expect to be healthy.</td>
<td>• Dietary changes.</td>
</tr>
<tr>
<td></td>
<td>• My family history and illness experience shaped my expectations</td>
<td>• Relaxation.</td>
</tr>
<tr>
<td></td>
<td>• Symptom characteristics</td>
<td><strong>Health Care Seeking</strong></td>
</tr>
<tr>
<td></td>
<td>• Inside knowledge- experience in health care.</td>
<td>• Repeat health care seeking.</td>
</tr>
<tr>
<td></td>
<td>• I didn’t know- knowledge gaps.</td>
<td><strong>Finding Support for their Theories</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Disrupting Theories</strong></td>
<td>• Comparing self with others.</td>
</tr>
<tr>
<td></td>
<td>• Comparing self with others.</td>
<td>• Testing.</td>
</tr>
<tr>
<td></td>
<td>• Testing.</td>
<td>• Eliminating possibilities.</td>
</tr>
<tr>
<td></td>
<td>• Eliminating possibilities.</td>
<td>• Reaching Out- asking for help from friends and family.</td>
</tr>
<tr>
<td></td>
<td>• Reaching Out- asking for help from friends and family.</td>
<td><strong>Non-Treatment.</strong></td>
</tr>
</tbody>
</table>

However, there were some exceptions to this cyclical journey, through perception, evaluation and response. In some instances, participants described situations where there was a confluence of perceptual, evaluative, and responsive phases, such as when the severity of AF symptoms evoked all three phases simultaneously, or when there seemed to be no evaluative component but participants leapt from perception to response. Others did not become aware of their symptoms until they
reflected on the pre-diagnostic period, following their AF diagnosis; without awareness, evaluation or response phases were not discernible.

Lastly, and in keeping with the aims of the study, the influences of age and gender were examined in relation to perception, evaluation and response. Additionally, time frames from first AF symptom awareness until receipt of an official AF diagnosis varied across participants. Participants in the late diagnosis group (LDG) (n=20) included those who received a diagnosis more than forty-eight hours after first becoming aware of their symptoms. Twelve of the twenty participants in the LDG waited over one year, following their first symptom(s), before receiving a diagnosis. The early diagnosis group (EDG) (n=6) included those participants who obtained a diagnosis within a forty-eight-hour time period. An end-point of forty-eight-hours was selected for the EDG, based on recent evidence which suggests that delaying treatment beyond this time frame substantially increases the risk for certain conditions such as stroke, HF and dementia (Glotzer et al., 2009; Manning & Singer, 2018; Van Gelder et al., 2017). Differences in the symptom experience between these two groups are threaded throughout this chapter. Therefore, and based on the increased risk for severe health effects, it is important to understand the differences between these two groups of participants as it pertains to the symptom experience (perception, evaluation and response).

4.2. Sample

The study sample consisted of 26 participants, who had all received an AF diagnosis within the twelve months prior to the interviews. Participants, self-identified as Caucasian, and included thirteen women and thirteen men, ranging in age from forty-three to eighty-five years; the mean age was 67.1. The majority of participants were married and lived with their partners (73%), had completed some, or all, of a college/university degree (65.4%), were retired (70%) and had incomes greater than $50,000 (62%). Although participants had a range of chronic conditions the most common conditions were hypertension and arthritis. Nearly two-thirds of participants had CHADS-VASC scores of two or greater, reflecting high risk of stroke. Three-quarters of the sample were
receiving anticoagulants, 19% in the form of warfarin, and 54% in the form of the new oral anticoagulants (post diagnosis). Further details of sample demographics and health history appear in Appendix L.

4.3. **Aim 1: Exploring AF Symptom Perceptions**

The first aim of the study was to explore adults’ (≥19 years) perceptions of their AF symptoms, in the pre-diagnosis period. In the perception stage, participants became consciously aware of and focused on internal bodily sensations, thoughts, and feelings that represented physical or psychological changes, different from their normal state. Participants reported perceiving a wide variety of symptoms – cardiac, gastro-intestinal, neurological, and respiratory – which differed by both gender and age (see Appendix M). Findings related to Appendix M are integrated throughout the following themes.

Participants experienced somatic sensations associated with cardiac, neurological, respiratory and gastro-intestinal body systems. Somatic sensations related to the heart were the most common, with 92% of participants (n=24) experiencing at least one cardiac-related symptom during the pre-diagnostic period. Although cardiac symptoms were pervasive, participants also experienced neuro, respiratory, and GI sensations. Eighty percent of participants (n=21) experienced some degree of light headedness or dizziness from mild “bit of light headedness” to severe dizziness, where, “literally everything spins.” Perceived shortness of breath (SOB) was among the first sensations/symptoms that study participants experienced with 69% (n=18) reporting difficulty in catching their breath. Only women (n=3) experienced GI symptoms, such as nausea, vomiting and diarrhea.

4.3.1. **Noticing**

Noticing was an over-riding theme that described participants’ variable degrees of awareness of body sensations and symptoms. Participants’ awareness ranged from those who were unaware to those highly aware of their bodily sensations as well as those whose awareness fluctuated between
these two extremes. Some like Henry had always been aware, noticing his heartbeat, even as a small child: “Like I said I feel my heart beat. So, I knew it was irregular… I am very aware of my heartbeat”. In contrast were those who acknowledged little awareness of symptoms under normal circumstances, such as Margret who denied sensing her heartbeat, “Only if I’m trying to pay attention to [the heartbeat] it otherwise no. It’s there. Don’t hear it. Don’t feel it”.

4.3.2. Imperceptible Noticing - “Feel Something, but Nothing Really”

As many as 69% of participants (n=18) described symptoms that were not readily perceptible in the pre-diagnosis period and, consequently, were outside their conscious awareness. Vague, subtle, and elusive symptoms, such as low energy throughout the day or mild activity intolerance did not evoke awareness and often went unnoticed for long periods. Two-thirds of participants in the LDG, compared to EDG participants experienced a higher number of vague symptoms, such as weakness, lethargy and fatigue (11 versus 2) and activity intolerance (7 versus 0), that blunted symptom awareness and prolonged the pre-diagnosis time frame. For example, Karen experienced vague symptoms of fatigue and SOB during exercise for approximately six months before her diagnosis that remained totally outside her awareness until she learned about her diagnosis.

I’d go for a walk. You don’t realize it until you’re walking on hills. It doesn’t take a very big hill to take you out of breath. I didn’t think I felt that bad. I didn’t really know there was anything wrong. Like it’s really hard to tell.

It was common for participants to describe being aware of something not right in their body but the experience of symptoms so fleeting, and difficult to decipher, made it difficult to pinpoint whether they were real, abnormal, or signalled a problem. Participants grappled with this partial awareness of experiencing “something” but “nothing” According to Farah, “often I would just feel something but nothing really” while Monty described his shortness of breath saying, “Just a bit but nothing incredible, you know. Just. Nothing I’d put down to other than you can watch a horror film and have a moment when you go oh, and then nothing more than that”. For some like Isaac, this
partial awareness extended for over a year: “You know, you sort of think hey, what’s going on. I mean, when you think what’s wrong, it’s gone.” Ben similarly admitted difficulties in ascertaining whether the symptoms he experienced while playing golf were a problem,

Yeah, and I don’t know where one organ ends and the other one starts. So, I just thought sometimes that was that maybe a little bit, you know, drinking too much beer the night before playing golf. That sort of stuff. You know, eating the wrong thing. So, yeah, there was no real recognition that there was a problem.

Reflecting post-diagnostically, participants expressed regret, embarrassment, self-blame, and even felt foolish for their lack of pre-diagnostic awareness. This was particularly evident in the LDG (4 versus 1), as Karen’s self-deprecating comments reveal,

I’m just thinking about how dumb I was [for not recognising her symptoms]. I should have known better. Yeah. And of course, at that time too I didn’t have a blood pressure or a pulse machine. Now I do and I take it. So, and I do it morning and night.

4.3.3. Commanding Attention.

In contrast to imperceptible noticing, other symptoms commanded participants’ attention. Symptoms commanded attention because of the highly visceral sensations they evoked, their origin/sources, or symptom onset or change that was sudden, severe and intense. Overall cardiac sensations, tended to command the greatest attention as they evoked strong visceral bodily sensations. Several participants described vivid images that conveyed their somatic experiences of seeing, feeling and hearing their cardiac sensations (bodies) such as: “palpitations and my shirt actually moves”, or feeling ‘butterflies’ in my chest, or “my heart jumping around like a frog in my chest”, or hearing “it [heartbeat] in my ears.”

Participants often experienced multiple bodily sensations that heightened awareness. Experiencing two or more bodily senses promoted awareness, such as Anne who described feeling and seeing sensations, “No, it was a pounding, you know, pounding. They call it flutter. It’s more
than a flutter. I could see my chest going up and down”. Similarly, Farah described a progression of sensations that she both felt and heard,

“Well, I just in the very beginning I just had fluttering like felt like butterflies in my heart or something. And then I come along and just feel a big flop”. “And my heart beats really loud when that happens, too. I can hear it in my ears”.

So distinctive were some of the heart-related symptoms (e.g., pounding) participants were easily able to isolate their origin. Dan couldn’t imagine anything but his heart to physically account for his symptoms:

There’s nothing else out there that’s going to cause that feeling, so. Pretty well, yeah, I pretty well figured well, it’s got to be something to do with the heart. And that’s why we didn’t wait too long in order to go.

Symptoms, such as dizziness, light-headedness and syncope often occurred so suddenly (without warning) and with such dramatic somatic effects that participants had no choice but to pay attention. For example, participants described feeling so dizzy that their eyes became blurry, or experiencing dizziness so severe they had to halt activities, or said that they fell down while skiing or dropped to the floor while walking to the bathroom. Clinton described how he suddenly became light-headed and fainted, while at home with his wife. “I was in the kitchen, had lunch. I walked over and as I was going to sit down, I yelled and I fell into the chair and I passed out. The ambulance came and took me to the hospital”.

Despite twice as many participants from the older group describing dizziness, participants from the younger group perceived their dizziness to be more severe (see Appendices N and P) and commanded greater attention, such as 63-year old Joyce:

Got up at six o’clock, had a cup of coffee, walked 10 minutes to vote. Stood in line at the voting station and felt that I tripped on something and I blacked out. 911 is called. I was only out for very briefly. Pretty well hit the ground and then awake.

Sudden and severe shortness of breath prompted an immediate awareness of their symptoms.

“So, I go to bed, went to bed effectively early, laid down on the bed and thought this is
ridiculous. Can’t breathe. At that point we called the ambulance” (Monty). Likewise, Margret described shortness of breath so severe, that she labelled them as ‘attacks.’ “After that, probably two years ago, about two years ago I started getting the attacks to the point where I felt like I was going to pass out like I wasn’t able to catch my breath. I had to sit on the couch”. Helen described respiratory sensations, such as “I just felt like I couldn’t fill my lungs” (Helen). Only women experienced GI symptoms that in some cases were intense. Irene described the intensity of her stomach sensations, “Felt as if the stomach was coming out. The stomach then it was just a rumbling inside… Like it was a pounding in the stomach…I thought it felt more in the stomach than anything else”.

A progression or a change in existing symptoms or the development of new symptoms that produced extreme physical sensations were considered serious and elicited a new awareness especially for those in the LDG. Several participants reported chest pain that they had never experienced before, using descriptors such as substernal pressure and heaviness, radiating down their arms and neck. Ellen described how it was chest pain, which finally piqued her awareness, after months of dealing with palpitations and shortness of breath:

Like shredding or something underneath your breast plate kind of but up high. And then I thought that is just bizarre. And so, I went and sat on the bed and that didn’t feel good. And I laid down and that didn’t feel good. It was still doing it. And then my arm started to hurt like my left arm but not, again just like when you do too much and your muscle is sore.

Monty described finally noticing a change in leg swelling that had subtly progressed over several days, “Noticeably, I mean, maybe it started a lot more and I hadn’t noticed. But certainly, it became noticeable a few days before I had. Subtly I was beginning to blow up”.

Women reported more severe symptoms than men did on the SCL. An independent samples t-test indicated a significant gender difference (p=0.02) in the severity of AF symptoms. The average severity score for men was 13.6 whereas women’s average score was 19.5 (out of a maximum score of 48). Not only did women experience more severe and dramatic symptoms (GI symptoms,
syncope), but they appeared to experience more frequent symptoms; although these differences were not statistically significant (p=0.09).

### 4.3.4. Rest and Activity

Participants described becoming aware of, or noticing their symptoms during periods of rest and/or during a range of other activities, such as playing sports, physical activity (walking, running), activities of daily living, and work-related activities. For some, activity precipitated multiple types of symptoms (respiratory, cardiovascular and neurological), whereas rest primarily precipitated an awareness of heart-related symptoms. Some participants experienced symptoms regardless of the activities they were performing. A summary of the awareness of symptoms associated with activity can be found in Appendix O).

#### 4.3.4.1. Rest

Rest was an important precursor of awareness. Seventy-one percent of participants (n=17), who experienced heart related symptoms, such as racing heart or palpitations, reported rest as instrumental in their symptom awareness. Several participants first became aware of their abnormal heart rhythm or rate while sitting or lying down, such as Neil’s awareness of his heart racing at night, “Like I can feel it more at night when I relax for whatever reason I can sometimes feel it even in my carotid artery. I wake up and feel my heart racing”. Likewise, Edward’s awareness peaked at night, “As soon as I would lay down at night it would start to fibrillate and kind of like blood rushing from one side to the other or whatever.”

The awareness of abnormal heart-related sensations occurred in both men and women, as demonstrated in Helen’s experience. “It [pounding heart] generally would happen at night. Sometimes I would wake up with it and sometimes it was when I went to bed and laid down, it would really start pounding away in my chest”. However, the sleeplessness and accompanying restlessness or interrupted sleep, which was reported by 73% of participants, occurred more frequently among women in the older age group (four women compared to one man). A racing
heartbeat thumping in their chest and pulsing in their ears made it difficult to fall or stay asleep and contributed to daytime fatigue. Participants in the LDG compared to the EDG experienced enhanced awareness of their symptoms with stillness (11 versus 0), but both groups were equally affected by symptoms awakening them from sleep (2 versus 3).

4.3.4.2. Interfering/Arresting Activities.

In contrast to rest, fourteen participants described awareness of their AF symptoms across a range of activities, including activities of daily living, work-related activities, and leisure and recreational activities. Twelve of these fourteen participants were in the LDG. Participants became increasingly aware of the troubling symptoms that made normal activities more difficult, such as shortness of breath and difficulty keeping up. In particular, symptoms which were noticeable during stair climbing (up and down) or climbing hills during trail walking or golfing, forced them to stop. Karen elaborates on her growing SOB,

Well, it was getting so my shortness of breath was getting worse. Because when I walk I go around on a trail and as I’m coming up there’s quite a hill. And that’s when I really noticed it because I couldn’t make the hill. I’d have to stop halfway up and get my breath back.

Greg first experienced a heightened awareness of his AF symptoms while exercising on vacation.

Every day we did three or four-hour walking at all these different points of interest. And I found I was dragging behind everyone. And I was puffing and pulse was right up there high. And I’d never had that before.

Women tended to experience more SOB, fatigue and generalized weakness (five compared to two) as compared to men and noticed it during different kinds of activities. For example, women more often perceived activity intolerance in relation to daily activities, such as walking, climbing stairs, and doing yard work or cleaning the house. Karen described noticing her SOB, when it limited the amount of time she could spend gardening,
Probably getting more tired and more short of breath. And I noticed I was taking more breaks. Like I’ll do something for a while and if I’m tired I’ll stop and rest. I’d have to go in the house and rest if I was gardening.

In Ellen’s experience, her symptom awareness was heightened by her inability to exercise or do house work,

Like yeah. I was just going gosh. Yeah because it was getting worse and worse. Dang, I’m exercising more. It should be getting better. And it’s hard to motivate because I’m exhausted. I’m exhausted and I just don’t feel very good. Even cleaning the house. I don’t want to bend over. Or I just get out of breath so easily.

Conversely, although men noticed symptoms during walking or hiking, they described becoming more aware of symptoms in conjunction with sporting activities, such as golfing, swimming or tennis. Len’s experience illustrated how the interruption of a sporting activity intensified his awareness of his symptoms:

I’ve been playing tennis for many years. I kind of know what my body can do. And it was just doubles. I was serving and between serves I could not catch my breath. And to the point that I was holding up the game. That happened about three times. I finally said I have to quit because between serves I could not catch my breath.

Bodily symptoms that interfered with mental activities also heightened participants’ symptom awareness. A lack of mental acuity and/or an inability to concentrate was common. Participants reported how being more forgetful interfered with some of their activities, such as meal preparation.

Yeah. I just, you know, making a big family dinner and I forget things in the fridge. I mean, I always used to forget something in the microwave but. Now I’m forgetting stuff in the fridge, too. This is getting crazy (Helen).

Awareness of symptoms during an activity of daily living, such as showering, was reported by three participants,
It hit me in the shower. I was washing my hair and suddenly my heart was beating a mile a minute. And I felt like I was going to pass out. And I was home alone. That was the only one that really caused me distress. So, I sat down on the edge of the tub and had to wait for a good five, ten minutes before my heart calmed itself down and got out of the tub and went to the doctor. (Margret).

Lastly, three participants indicated that their awareness of their symptoms was heightened with workplace stressors, such as learning a new skill at work, or a demanding job. For example, Fred noticed his inability to concentrate on learning how to operate the cash register during his work at a hardware store, “Yeah. Like, you know, I was on the till at work and, you know, put under pressure still learning to do the till. And it started beating funny. It’s like I can’t do this right now”. Farah was aware of her heartbeat while working as a librarian and experienced what she described as a ‘flop’ in her chest as if someone had startled her:

I think it was because I was quite stressed at work for a period. And I think it started getting worse then because I can remember saying to my people I worked with oh, I’m feeling really stressed. My heart’s funny and, you know.

4.4. Aim 2: The Evaluation Process

Participants’ evaluation of their symptoms was a complex process aimed at making sense of, and finding explanations for the bodily sensations and symptoms they were experiencing. The evaluation process was a highly cognitive process in which participants engaged in in-depth and ongoing speculation as they sought to determine the significance of their symptoms that often defied explanation. Three themes described participants’ pre-diagnosis evaluative process: speculating and forming personal symptom theories, finding support for their theories, and disrupting theories. A fourth theme, taking shape, detailed several factors that influenced and shaped the evaluative process. Finally, and similar to the perception section of this chapter, the influence of age and gender, and the
differences in evaluation amongst participants in the EDG versus the LDG, is threaded throughout the entire evaluation section.

4.4.1. Speculating- Individual Symptom Theories

Speculating summarizes the process of forming tentative theories or conjectures, to account for the symptoms experienced, when there was insufficient evidence to form a steadfast explanation for the symptoms. Forming personal theories represented the process of participants’ speculating and giving explanation to their sensations/symptoms. Speculating involved participants searching for answers to questions such as ‘why is this happening to me,’ ‘what do these symptoms mean,’ and ‘what is the cause of these symptoms’? Participants used these questions to create personal theories to explain their symptoms. Even though many of the participants knew something was not right with their heart, very few were able to determine the origin and cause of their symptoms and generated tentative theories to explain them. The process of speculating occurred almost immediately after participants became aware of their symptoms, and is illustrated in the following quote:

I finally said I have to quit [the tennis game] because between serves I could not catch my breath. It took a while. That’s never happened before. And we [friends/family] started speculating. Like I was new to the city, new to the job. You know, I’ve been hearing people talk about environmental sensitivities. Somebody said difference in altitude, you know. Oil refinery out there. Who knows what, what happened to me?

Questioning the meaning and nature of their symptoms was employed as an aspect of the speculating process, in order to shed light on the perplexing symptoms they were experiencing. Some participants were able to form a theory for their symptoms quickly, whereas others had a more arduous journey of formulating questions and searching for answers. Specifically, 69% (n=18) reported difficulty in forming a plausible theory for symptoms, that were described as confusing, puzzling, subtle or elusive. Greg’s experience, during the evaluation of his intermittent SOB, provides an illustration of the questions that were formed during the speculating process:
I wasn’t relating it to Afib. I just thought, you know, I was thinking what possibly this could be. I was thinking when that bee bit. I was thinking gee could this be. Am I getting Lyme’s disease? Or am I getting something like that?

The generation of multiple theories was another hallmark of the evaluation process. The cycling of theories continued, until a reasonable explanation was obtained; an explanation which satisfied the participants’ need to understand the cause of their symptoms. In other words, by the time a participant received their final diagnosis and obtained a definitive answer for the symptoms they were experiencing, they had often generated multiple theories. Eventually, participants settled on some constructed idea of why they were experiencing their symptoms. Participants varied in the length of time for which they considered any given theory to be plausible – lasting from hours to years. Those participants in the LDG cycled through many more possible theories than did those in the EDG.

Women were more challenged to find clear explanations than men were. Women described confusing, subtle or elusive symptoms twenty-one different times compared to only eight such occurrences for men. The following examples illustrate some of the experiences of the women in the study: “They just happen [palpitations], yeah. No rhyme or reason to it. There’s no pattern that I could pinpoint” (Margret); and

So, my theory. Okay. My theory was I had had the flu just prior to that happening. And I’d had the flu and I just thought okay well I never completely got over it and whenever I get run down, you know. But I don’t know. There never was a concrete diagnosis on those dizzy spells. Very elusive because, you know. If I had spontaneously gone back to sinus rhythm which is what must have happened, you know (Brenda).

Farah’s interview also illustrated the elusiveness of trying to find a reasonable explanation for the fleeting nature of the symptoms: “Since it went away I didn’t really think much of it. I mean, I did but I thought by the time I get to emergency it’ll be gone and then they’ll say nothing’s wrong,
so”. Conversely, although men did have symptoms which were difficult to pinpoint, these experiences were reported less frequently than with the women.

The following section explores the most common theories generated by the participants to explain or account for their symptoms during the pre-diagnosis period of AF. As such, these theories are not ‘formal’ theories, but are individually derived explanations for their symptoms. The word ‘theory’ as a theme was adopted to stay ‘true’ to the language used by several of the participants during the interviews. The initial theories describe the ‘non-cardiac’ reasons which might have accounted for the symptoms they experienced, and conclude with the theories which pertain to an actual ‘heart’ problem. The first theory is called ‘it is nothing really’, followed by ‘I’m just getting older,’ ‘I must be stressed or anxious,’ ‘all too familiar- chronic health conditions,’ ‘it’s my fault,’ ‘just pushing myself too hard,’ and ‘something is wrong with my heart.’

4.4.1.1. It is nothing really - My heart is just being funny.

Fifteen (58%) of the participants believed their symptoms to be nothing more than their heart just skipping a beat or being ‘funny’; a theory seen in equal numbers among both men and women. Initially, these fifteen participants refused to recognize or take their symptoms seriously, beyond acknowledging the presence of an unusual symptom: “I never thought anything of it actually. I just thought maybe I was doing something overexerting myself or something that time but yeah, and then I never did anything about it.” (Donna). Participants considered their symptoms fleeting or passing with no bearing on their overall health.

Participants developed several different forms of ‘it is nothing really’ theories, to account for their symptoms. The development of an ‘it is nothing’ theory which was free of any illness label was more prevalent amongst those in the LDG (N=14) versus the EDG (n=1). Irene was the only participant in the EDG group who initially likened her symptoms to ‘nothing really;’ to explain her stomach symptoms. Everyone else in the LDG spent a considerable amount of time theorising that their symptoms were not ‘abnormal’ or ‘worrisome’, and therefore they could continue with normal life. Several examples of participants’ developing ‘it’s nothing’ theories for the symptoms they were
experiencing included: ‘I’m just not motivated’ (Helen), or ‘I’ve put too much on my plate’ (Lydia) and ‘this is all to do with grief – I just lost my son’ (Cathy). Lastly, John’s story provided an excellent illustration of the participants’ search for a non-illness theory to account for his symptoms:

I really didn’t think too much of it at all because I thought oh well, I’m just a little excited, you know, because I can watch football or something or sports that, you know, I get a little excited. And I could feel my heart thumping pretty hard. It didn’t seem to make me feel sick or sweat or anything like that.

The ‘nothing really’ theory was often exemplified in participants’ theories giving lifelike attributes to their hearts, as if their heart was in some way in charge of deciding to be ‘funny,’ or ‘act up.’ More than half of the participants (n=11) with symptoms that they knew came from their heart, indicated that originally, they felt there was nothing abnormal about their symptoms. For example, Ellen’s initial theory assumed that her heart was acting up, for no real reason: “I just thought that my heart is being stupid and so what. But then it would, you know it would just go away. I mean, it’s not like something bad”.

### 4.4.1.2. I’m just getting older.

Age, or ‘just getting older,’ was the second most common theory participants constructed to explain their symptoms. Eleven participants, six men and five women, speculated that the ‘normal’ aging process was the explanation for their AF symptoms. Seven participants in the older group assumed their symptoms were a normal aspect of aging compared to four in the younger group. Aging was the cause assigned to vague non-specific AF symptoms, such as fatigue, poor sleep, and exercise intolerance. For example, when asked whether he thought his symptoms were related to his heart, Greg (age seventy-two) responded with “No. No, I just thought well, maybe I’m just getting older”. Likewise, sixty-eight-year old Edward assumed his lack of motivation and increasing desire to take naps was age-related rather than an indication of a disease. Ellen (age fifty-nine), similarly, speculated that her exercise intolerance was related to aging and poor physical fitness,
Like getting tired and then sometimes because I do a lot. I like to do a lot of stuff and thinking I guess I’m just getting old... I was like really, I just don’t feel good. I’m just so tired. And just thinking well, you know, you’re getting old.

Theorising symptoms as age-related was associated with a prolonged pre-diagnosis time – as theorising age as the cause of symptoms was seen exclusively in the LDG (9 versus 0). Connecting their symptoms with an event beyond their control – such as aging – precipitated a passive approach and premature closure where other possibilities were not considered in the symptom theorising:

And I just thought, you know, get up and get on with it like. And so, that was my attitude. Get up and get on with it, you know. There’s nothing wrong. There’s nothing wrong. It happens occasionally but things happen when you get older. You just learn to live with it (Helen).

Speculating that their AF symptoms were due to ‘normal’ aging was not always an acceptable explanation for participants. Older participants expressed a greater willingness to attribute their symptoms to ‘age-related’ reasons, consistent with the natural course of their ‘bodies breaking down’ and their ‘age catching up with them:’ “Yeah. You know, when you get old you just think part of the aging process. Oh well, you know, after all I am seventy-six. I am seventy-seven. I am seventy-whatever” (Cathy). In contrast, some younger participants resisted having to live with their ‘age-related’ symptoms, refusing to attribute their symptoms to their age, as Ben (age 59), illustrated, “If I were seventy-eight years old I wouldn’t worry about it. But I’ve got, hopefully, another twenty years, you know” and Farah, (age 64), who resisted age as an explanation, “I don’t like sitting around because I’m not old yet. I don’t want to be old”.

4.4.1.3. I must be stressed or anxious.

When heart-related symptoms occurred, thirty-five percent (n=9) of the participants considered their symptoms to be caused by either too much stress or anxiety. Twice as many women as men (6 versus 3), across all age groups regarded ‘stress or anxiety’ as a transient cause of their
symptoms that they anticipated would eventually disappear. Helen perceived stress as the most likely theory to explain her racing heart,

Well, I knew it was my heart racing, but I didn’t know why. And I never knew about atrial fibr. I didn’t know there was such a thing. So, I just presumed it was, you know, anxiety or. And yet, I didn’t know of anything I was anxious about.

For others, stress-related theorizing was specific to work, relocation, and caregiving. Len justified his theory based on several simultaneous sources of stress occurring along with a racing heartbeat and shortness of breath:

And the stress of moving to a new city, the stress of a new job, the stress of giving up the job and security and stuff. So, you know, it all made sense that, you know, this could be stress related. And so, like I say I was hopeful it would go away.

Only the women in the study talked about the burden and stress of caregiving as an obvious explanation for their symptoms. Stressors originated from the loss of a pet, caring for a spouse with chronic disease, and even positive stress such as planning for a wedding. Gillian shared her theory of stress:

Yeah, so, I was on the trip which is a good stress but you’re still jet lagged and stuff. So, I came home. Our dog was sick. So, then I was dealing with getting the dog better. So, that day I went into atrial fibr that was the day we had to put the dog down. And then the next Monday my husband went into the hospital with CHF. And then he got a bed sore when he was there. He’s paraplegic. So, then he was home for a week. And then he had to go back into the hospital. And then that night I had another bout of it. So, that’s why I’m thinking it’s kind of stress related. And then my dad is out of town. So, I’m like trying to feel like I should go down there and help him out. And then my husband’s sick in the hospital. I’m not feeling very well because my heart’s not working well. And the dog just died. It’s like oh my God. So, yeah (Gillian).
Five participants speculated that their initial AF symptoms were anxiety-related because they either had a medical diagnosis of anxiety or had family members with anxiety and therefore recognized its manifestations. John spent four years thinking that his symptoms, of heart racing, palpitations, and pre-syncope were anxiety-related:

I just thought, oh, it’s just anxiety attack. Probably I think that’s what I was thinking. It was anxiety. Just anxious about something because I probably had a little bit on my plate that I wanted to get done or something. And maybe it was anxiety.

Some of these theories were so deeply-rooted that even when participants experienced severe symptoms such as fainting, several still maintained the belief that nothing was wrong, and that a condition such as anxiety was the cause of their symptoms. This was the case for Gillian, who described, “And I got up one night and I had one of my little fainting bouts. And I thought oh, it’s probably a panic attack”.

4.4.1.4. All too familiar - chronic health conditions.

Women, more than men (6 versus 2), theorized that their AF symptoms were a manifestation of pre-existing medical conditions, such as asthma, COPD or MI – despite a marginally healthier baseline (fewer number of comorbidities). Furthermore, women described the difficulty in differentiating their AF symptoms from similar symptoms associated with their other chronic health challenges. It was common for participants to identify one specific comorbid condition which accounted for their symptoms. For example, Cathy associated her extreme dizziness (to the point of almost fainting), to her previous concussions, without considering the possibility of other medical reasons. “I’d had two concussions in the previous couple of years. And I just thought it was, you know, something to do with the fact I’d had a couple concussions. I never thought it was something to do with my heart” (Cathy). Donna, similarly, theorized her ongoing SOB related to pre-existing asthma, “I always thought I was having an asthma attack but if I look back at it I was having more than that. I think it’s all related to this [AF]”. Irene’s previous MI in 2007 clouded her ability to
theorize her symptoms as something new. Even after her AF diagnosis, she was convinced her pre-AF symptoms had been caused by coronary artery blockages:

No. The only thing I related it to was the blockage of the veins. Because it was very similar to it. I was a little tired and a little bit of pain. Exactly the same then as 07.

Of the men, only Fred and Monty considered their symptoms to be associated with a comorbid condition. Similar to Donna’s experiences, and over a period of several years, Monty theorized that his breathlessness was nothing more than an exacerbation of his COPD, rather than anything cardiac related:

I didn’t think it was actually to do with my heart. I thought it was the whole thing was to do with my chest in general whether it was lungs or what have you. But because I’d already been diagnosed with COPD I thought something or other had flared as far as the lungs etc. were concerned. I didn’t actually attribute it as being specifically heart.

4.4.1.5. *It’s my fault – weight and diet.*

Several participants (n=9) theorized that factors under their control, including their body weight and diet, could explain the symptoms they experienced. Four participants blamed themselves for their symptoms, stating it was because they were overweight. Women’s language used to describe their weight gain was often very critical, harsh, and unforgiving as Ellen exemplifies:

Yeah. Like just shut up and power through it [symptoms of AF?]. And then looking back like there was a couple times going up the stairs at home I would think God, you have gotten so fat. Now, you can’t even go up the stairs. Because I’d be really out of breath. And I was like, well, you’ve got to get rid of the weight. I kept, I blamed a lot on my weight.

Even though men and women assumed that their pre-diagnosis symptoms were related to their body weight, the men’s language was more matter of fact. Monty described how he assumed his symptoms were all weight-related rather than an indication of an arrhythmia:
I was perfectly convinced it was entirely because of the fact that I was actually overweight and having trouble getting up these hills which was making me breathless and therefore, you know.

Men (n=4) and women (n=3), of all ages, theorized that the foods or beverages they were ingesting were responsible for the symptoms they were experiencing. Ben thought food and drink seemed a reasonable explanation for his symptoms:

I had gone out and had jalapeno peppers on your pizza or whatever. You know, I just attributed it to that… So, I just thought sometimes that was that maybe a little bit, you know, drinking too much beer the night before playing golf.

Other participants also posed a range of possible dietary explanations for their AF that were highly specific, such as spicy food (two of the men) magnesium deficiency (Margret), a food additive found in ice-cream (Neil), and too much caffeine (Ellen). Clinton theorized he was overeating (gaining weight) and not drinking enough water. In his mind, dehydration was leading to his dizziness, and his appetite was leading to swollen ankles.

4.4.1.6. Just pushing myself too hard - physical activity.

Three participants thought their palpitations and SOB were a by-product of their pushing themselves too hard during physical activity, “Maybe I was pushing myself too hard. I thought oh, maybe at seventy you’re not supposed to be running for an hour a day or jogging. I quit that and started walking instead” (Greg). Conversely, two other participants felt their symptoms (SOB, activity intolerance), reflected their lack of physical fitness, rather than a medical condition such as AF: “I thought it was more respiratory than it was… Lungs just weren’t in very good shape. I don’t know. I don’t know what you can do to make that better other than just carry on, you know” (Helen).

4.4.1.7. Something is wrong with my heart.

All of the aforementioned theories explored how participants speculated on non-cardiac reasons which might account for the symptoms they had experienced. As previously described,
twenty-one of the twenty-six participants (81%) indicated that they knew their symptoms were associated with their heart. However, the majority of these participants (n=13) did not feel their symptoms indicated a dysfunction in their heart, rather they viewed them as occurring secondary to another condition such as too much stress or weight gain. Only eight (of the twenty-one) participants viewed the cardiac symptoms they were experiencing as being primarily or directly related to an actual dysfunction of their heart. ‘I’m having a heart attack’ (Farah, Brenda) was the most frequent theory held by those who thought their symptoms might suggest an actual problem with their heart. However, for these participants this theory was often unsubstantiated, as they frequently wavered in their search for a more plausible explanation for their symptoms. Despite knowing their symptoms were associated with their heart, and even after speculating that their symptoms might be an indicator of a severe cardiac problem, alternative explanations seemed to supersede the ‘something wrong with my heart’ theory. This speculation was evident, as participants such as Lydia grappled with the thought of having a heart attack or stroke: “No. I don’t know. I mean, I never like to think of the worst but in the back of mind it could be a heart attack”. Similarly, John wrestled with the idea that he might be experiencing some severe heart condition, commonly seen amongst others in his age group:

   As you get older you can have heart problems. And so, I knew it was heart because it wouldn’t beat so heavy and then sort of flutter for a while. So, I knew there was something haywire. So, I knew that it was probably to do with the heart.

   Beyond those who theorized they could be having a heart attack, arrhythmias were the next most frequent heart associated theory. Three participants recognized that their symptoms might be associated with some type of heart condition, which causes an irregular or rapid heart rate, such as AF: “Yeah. I knew it was my heart. There was no question about it… because I had something similar (an athletic heartbeat)” (Henry). However, even though these three participants theorized their symptoms might be associated with an arrhythmia-related condition, each of them continued to theorize multiple other possibilities, and remained in the LDG.
Finally, there was some evidence that theorising an actual ‘issue’ with your heart could minimize the overall pre-diagnosis period. Study data found that fifty percent (n=3) of the EDG immediately assumed their symptoms were associated with a heart problem, versus only thirty percent (n=6) of the LDG.

4.4.2. Taking Shape - Influences Shaping the Evaluation Process

In addition to age and gender, four factors influenced the participants’ evaluation of their symptoms: expectations, symptom characteristics, inside knowledge, and knowledge gaps. These four influences provide the background necessary to understand how and why participants gravitated to specific theories to explain their symptoms.
4.4.2.1. Expectations

The first overarching theme that shaped the evaluation process is entitled expectations. Specifically, this theme explores how individual expectations shaped the evaluation process and the generation of theories. This theme has two subthemes comprising: 1) I’m too healthy to have heart disease; and 2) my family history and experience with illness shaped my beliefs.

4.4.2.1.1. I’m too healthy to have heart disease - I expect to be healthy.

The first factor which influenced participants overall evaluation process was the expectation of being ‘healthy’ and the perception that their lifestyle choices were conducive to a lower risk of ‘heart’ related illnesses. These ‘I’m too healthy for heart disease’ narratives created a disbelief in the idea that their symptoms could indicate cardiovascular disease. Surprise and confusion emerged, as participants dismissed, minimized, and pushed aside the idea of AF. Women, in particular, felt immune to cardiovascular risk, describing themselves as healthy and actively engaged in maintaining a healthy diet and exercise, as epitomised by Joyce’s comment: “Yeah. So, no, it was actually the last thing on my mind because I always kept a healthy heart. Ate really healthy”; and Lydia, “We didn’t know what it was because my entire life, I’ve been working out, you know, always, always.”

Likewise, Margret held minimal expectations of heart disease:

Actually, to be honest because I wasn’t even aware of Afib, I probably would have put it down to no, not me. Because I never smoked, don’t drink. I’m very healthy. I don’t eat a lot of junk food. Don’t do the deep-fried stuff. Every morning I either do stretching, or I do a small forty-five to an hour-long workout. I eat extremely healthy. I know that (Margret).

In addition to women’s lowered expectations of cardiovascular disease, based on their perceived level of health or fitness, was the influence of the media-portrayals of cardiovascular disease as being a man’s disease. Ellen minimized the significance of her symptoms as ‘no big deal,’ in part from the powerful messages she had seen in the drug commercials:

I just thought it’s not that big of a deal. Like I’ve never heard ever of like I said before the Eloquist [AF medication] thing. And they’re guys. They’re not women. On all of the
commercials on TV, it’s all men as a matter of fact. I don’t think there’s one woman on any commercial I’ve ever seen.

Although more women than men (five versus zero) indicated that they had no expectations of heart disease, several men were also unsure about what the symptoms meant, because of their perceived level of health and fitness. Ben described how he was shocked to learn of his AF, because he evaluated himself as healthy:

Yeah, yeah. Came as a total shock because I considered myself a moderate drinker, never smoked, never did drugs. You know, ate well, do smoothies every morning. I thought I was pretty fit and pretty healthy.

Finally, age was a significant factor in shaping participants’ expectations of developing heart disease. Younger participants held a lower expectation of heart disease than their older counterparts. Specifically, younger participants (six compared to three) considered themselves to be young and very healthy and at lower risk of cardiovascular disease (five in the younger group compared to none in the older group). Farah never anticipated a problem with her heart “Because I’ve always been healthy and strong and yeah”. Conversely, aging, disease, and illness raised expectations of heart disease among older participants, enhancing awareness and closer scrutiny of symptoms:

No, I thought it was heart because it’s been drilled into me that as you get older you can have heart problems. As you get older people talk about their health. And other people tell you what they have and what’s problem with them and what’s ailing them and so, therefore, you know, you think about more of yourself, too, you know. I could have a heart attack. I could have a stroke. I could have problems, you know, as I get older. And so, really, I just paid closer attention to what’s taking place in my body and especially the heart situation.

The increased awareness and attentiveness to their bodily symptoms did bring about more illness-related theories, in contrast to the ‘I am fine’ or ‘it is nothing’ narrative seen amongst the
younger group. However, the older group was equal to the younger group concerning the time spent theorising about their symptoms, before deciding to seek treatment.

4.4.2.1.2. My family history and illness experience shaped my expectations.

Family history was a second influence on participants’ evaluation of their symptoms. First, of six participants in the EDG, only two reported that family history was the impetus for an urgent evaluation of symptoms. These two participants recalled vivid memories of seeing a family member suffer or die from a cardiovascular event which dramatically impacted the evaluation of their ‘heart-related’ symptoms. For example, the memories of watching his father die from a massive heart attack, after bypass surgery, greatly influenced Neil’s approach to his health. Neil explained not wanting to be a burden to his family, or leaving them in a place of financial need. Therefore, when faced with his AF symptoms of heart racing and mild chest pressure, he evaluated his symptoms with great seriousness and developed a theory which related to cardiovascular illness. Fred’s expectations of the possibility of heart disease were also evident in his description, as he quickly evaluated his symptoms as being heart-related because of his family history:

There was my dad’s dad and his brothers. All three of them died from heart attacks. So, yeah, that being the case I never… When it happened to my dad when he passed away and all that I went and got my heart checked, you know. Just to be safe. And everything was fine. And I never had a problem since. So, when it [his heart] started doing it [chest pain and palpitations] I was right on top of it.

For those in the LDG, a family history of heart disease influenced their evaluation process in several different ways. First, three participants from the LDG recognized the symptoms as being ‘heart’ related, based upon their experiences with family members. However, even with this experience, they still expressed uncertainty about whether their symptoms would become a serious heart condition. For example, Farah recalls how her knowledge of her father’s heart attack caused uncertainty about whether her symptoms might also be indicative of a similar event:
“I thought it was my heart, that there was something wrong with my heart. That it might be a blockage or because my dad had heart trouble. And he had a bypass. And he gets that tachycardia and stuff. And so, I thought oh, I wonder if something like that. I didn’t really know”.

Likewise, Greg was also unsure about his symptoms, looking to his brother’s diagnosis of AF as a possible explanation for his symptoms: “I asked my brother about symptoms. I knew he was in Afib but I didn’t really realize what it was or anything about it. I thought well, could it be AF I’m experiencing”.

Seven participants in the LDG were much less swayed by their family history of heart disease, indicating their history did not influence their expectations or perceived risk for heart disease. Instead, these participants conceived alternative explanations for why they might be experiencing their symptoms. The experiences of Henry illustrate the ‘it will not happen to me’ approach to evaluating symptoms. Henry was very proactive in helping his mom evaluate her racing heart symptoms, however, when it came to his own health, he was much less inclined to view it as anything too serious. Rather, he indicated that his symptoms were ‘no big deal’ and were most likely attributable to an ‘athletic heartbeat.’ Likewise, Karen described how witnessing her father, and many other family members, suffer and die from cardiovascular disease weighed heavily on her as she evaluated her own symptoms. However, she also indicated that in the end, she was not too concerned about her symptoms because she assumed that the most likely cause of her symptoms was old age. Lastly, Helen, also in the LDG, learned from her mother-in-law’s experiences that you just have to carry on and not complain, because nothing else can be done about it:

Just thought it was something, it was going to happen in my life like it did with my mother-in-law. I mean, she went to the doctor for years trying to get help and never got it. And I thought it was all in her head. Well, then when I started getting it I thought I’m going to be
just like her. They didn’t do anything to help her and to me she didn’t look like there was anything wrong with her. Get up and carry on.

In contrast with those who had witnessed family members suffering from cardiovascular disease, sixteen participants described how their inexperience with any disease shaped their expectations of their new AF symptoms. Six of these participants described a cavalier approach to evaluating symptoms. Having always been relatively healthy, they tended to evaluate new symptoms through the lens of ‘not concerned, things always work out’ and they had low expectations of developing a serious medical condition. For example, Gillian’s inexperience of illness of only minor youthful ailments that quickly resolved without much thought or attention, led her to have minimal concerns about her symptoms. Her parents and grandparents, who had lived long and healthy lives, reinforced the lack of concern that she felt towards her AF symptoms. Further participants without illness experiences, also lacked a frame of reference for evaluating symptoms and were less astute in recognising symptoms when they did occur. Donna, who had never considered herself ‘sickly’ and always thought her health was ‘fine,’ evaluated the seriousness of her SOB only after it had become extreme over the course of a year.

4.4.2.2. Symptom characteristics

The type, severity, frequency, and duration of the symptoms were essential aspects of the overall symptom experience, and particularly relevant to how participants created theories to explain their symptom experience. Participants had several different ideas about what their symptoms might mean in terms of overall threat. Symptoms were labelled as either a non-threat of little concern, or a more threatening sign of something occurring within their body.

The variation in symptoms influenced participants in very different ways. First, concerning symptom severity, both mild and severe symptoms were as likely to be evaluated as significant as they were inconsequential. For example, despite experiencing severe palpitations that evoked somatic sensations (e.g., heart beating, chest moving) Neil (age fifty-eight) considered his symptoms as a
significant health threat, while Donna (age sixty-eight) had little concern and “didn’t think anything about it”. Mild symptoms similarly evoked different ideas about their symptoms. For example, Henry’s (age sixty-four) restless legs and irregular heartbeat were rated as mild and did not evoke concern while Edward (age sixty-eight) evaluated the “blood rushing back and forth” in his heart as abnormal and concerning.

Thirteen participants described how the variability in the frequency of their symptoms influenced their evaluation of whether their symptoms were concerning. First, symptoms which seemed to resolve and disappear for long periods of time were assessed as inconsequential, as seen in Ben’s experiences. He believed that the irregular tiredness and lack of motivation he experienced prior to exercising was a sign of ‘just being tired:’

For frequency [tiredness] it was rarely. But enough that I recall them but didn’t give me a lot of concern. You know, like, I should go to the gym today or I should hop on my bike or we should go for a walk or something. 50% of the time I would do it and never think twice about it and then the other times I would think why I am not motivated to get up and go to the gym.

Conversely, Len’s SOB during activity, such as climbing the stairs, and which occurred infrequently and randomly, signalled a more significant problem and that there was ‘something wrong’, beyond just being out of shape:

All I was thinking of was the lung. And then, you know some days I guess I felt okay and some days not…So, I’d run up the flight of stairs. And one day I made it. I was tired but I did it. The next day I was good until about the fifth or sixth floor and all of a sudden, I nearly collapsed… So, I knew there was something wrong.

The duration of the symptoms was another important aspect in the evaluation process. Symptoms which occurred over a very short duration tended to be evaluated as inconsequential. Ellen described how the duration of her symptoms influenced her evaluation: “No one ever told me it was a big deal or anything, you know. Like so what? It goes away, or I get busy doing something else and
don’t notice it” (p. 4). However, a change in the symptom pattern (such as the duration) often prompted evaluation of symptoms as concerning.

Women also had more variability in the type, frequency and duration of their symptoms, which influenced their evaluation processes. Women reported more often (fourteen times to five) that the variability in their symptoms made it difficult to evaluate what their symptoms meant or how they should be treated.

Lastly, of the fifteen participants (58% of all participants) who held the belief that their symptoms were nothing to be concerned about, ninety three percent (n=14) of them belonged to the LDG. In other words, the belief that their symptoms were benign, innocuous or of little concern was associated with a prolonged pre-diagnosis period. This lack of concern for the possible threat that their symptoms represented was equal among both age groups and genders. These beliefs were expressed in words, such as ‘it is no big deal,’ ‘not really concerned’ or ‘not much you can do about it.’ Reasons for the lack of concern varied. Some participants suggested that further assessment of their symptoms could wait until their next scheduled doctor’s appointment, which in some cases was months down the road. Others implied they did not give their symptoms ‘much thought,’ and were not bothered enough by them to assess them as related to a severe condition. Lastly, some participants normalized the occurrence of their symptoms by attributing them to age, too much exercise or caffeine, or suggested that irregular heartbeats frequently occurred in a vast majority of the population.

The remaining eleven (42%) participants believed their symptoms to be concerning and that the represented a credible threat to their overall health. These participants ‘knew something was wrong’ even though they did not always understand the extent of their symptoms. The majority (n=5 or 83%) of those in the EDG held the belief that their symptoms represented a credible threat to their health. Further beliefs that participants held regarding the nature of their symptoms are explored in the symptom theories theme.
4.4.2.3. *Inside knowledge - experience in health care.*

Another factor that influenced participants’ evaluation of their symptoms was experience with the healthcare system. Professional experience as a health care provider gave some participants the tools to further assess and evaluate their symptoms. In Fred’s case, his experience as a first aid attendant gave him the tools to evaluate his irregular pulse quickly, and the knowledge to understand that his pulse irregularity was something that needed to be evaluated by a physician. For others, their experience with healthcare influenced their overall approach to the evaluation of their symptoms with an intentionality and calmness. This is illustrated in Brenda’s comments, as her experiences as a nurse created a calm emotional state in response to her symptoms:

> And, you know, this started to feel better as I was sitting. Yeah. But anxiety, no, it’s not something I’m given to. You’re a nurse. How often do you get anxious? RW: Not very often. Brenda: No. You learn to control that. You just do. It’s part of who you are. You just don’t let the anxiety get there. We’re very Zen people.

Similarly, Karen who had also worked as a care aid talks about how she really evaluated her symptoms with calmness and did not get too worried about them:

> I don’t know. I just took it sort of in step I guess. I worked as a care aid for years and years. I saw all kinds of things. RW: And that you wouldn’t necessarily go to the hospital for everything that came up in your life. Karen: Rarely went to the hospital.

Finally, Gillian talked about how her role in health care influenced her symptom evaluation. She denied worrying about her symptoms and did not want to be one of those ‘patients’ who runs to the doctor for every minor ailment.

> And it sounds really bad. But there are some people that are like they just repeat. They’re always at the doctor. They always have some problem. And you tend to not take them seriously after a while, right. So, and that’s one reason I don’t go that often unless it’s something.
Three women and only one man in the study had experience in healthcare before their AF diagnosis. For the women, healthcare experience contributed to a prolonged evaluation period and the adoption of a wait and see approach to symptom management. Conversely, the only male with medical experience responded quickly to his symptoms.
4.4.2.4. *I didn’t know - knowledge gaps.*

During the pre-diagnosis period, nearly half of all the participants (n=12) described having limited knowledge to be able to evaluate their symptoms accurately. Without a pre-existing understanding of AF, many participants were left feeling perplexed about what their symptoms might indicate. Ellen conveys her perplexity, “Yeah. I had no idea. I don’t know. Once in a while, your heart would go crazy but I didn’t know it was a thing. I didn’t know”. Knowledge appeared to be an integral part of decision-making associated with an early or expedited diagnosis. Eleven of the twelve participants who identified having limited knowledge to assess their symptoms belonged to the LDG.

Gender differences were also evident in the amount of knowledge that participants possessed for the evaluation of their symptoms. More women reported complications associated with their inability to form an accurate conclusion regarding their symptoms (9 women versus 3 men). Additionally, a greater proportion of the women who reported a lack of knowledge, when compared to men, were part of the LDG (8 women versus 3 men). In particular, knowledge, or lack thereof, appeared to paralyze women’s decision-making abilities, as they reported feeling puzzled by their symptoms, which ultimately prolonged their evaluation period. For example, Ellen, who experienced symptoms for over nine months before her diagnosis, recalls how her doctor was shocked that she was unaware of her AF, “So, when the cardiologist came in he said, well, you have this thing called Afib, and he was shocked. He said, so you don’t, you didn’t know you had Afib. Like no. What is that?”

Ellen further described how her lack of AF knowledge influenced her inability to evaluate her symptoms, and ultimately prolonged her evaluation time. Margret’s story provides another example of how a lack of AF knowledge prolonged the evaluation period. Margret, who had dealt with palpitations for her entire adult life, indicated that she too had never heard of AF, assuming, instead, that her symptoms were the result of anxiety or a panic attack. Unawareness of what AF is not only prolonged Farah’s evaluation time, but it also evoked feelings of fear, once she finally learned the cause of all her symptoms: “My heart rate was so high and that was when they said it was atrial
fibrillation. And so, then I was scared. I said what is that? What does that mean?” (Farah). Lastly, Anne who experienced many years of AF symptoms (palpitations) which were unaccounted for, described how even with her work experience in healthcare, she did not know what AF was: “Even though I’d worked on the cardiac ward too for a few months. I didn’t clue in, you know. No, I had no idea what those terms meant really, you know”.

Men were far less explicit in describing how their lack of knowledge influenced the evaluation of symptoms. Only three men reported being completely unaware of AF before their diagnosis. Len’s quote provides an illustration of how he lacked the knowledge to evaluate his symptoms as being heart-related: “But somebody mentioned Afib just, you know, somebody at work. I didn’t know what Afib was”.

Each of the aforementioned examples illustrates how difficult it was for these twelve patients to evaluate their symptoms correctly, as being AF-related, given their reported low level of knowledge associated with the condition. Furthermore, the data suggests that AF knowledge differed among genders, and was associated with an extended pre-diagnoses period among the women.

4.4.3. Finding Support for their Theories

Without “definitive” evidence, participants struggled to form a plausible theory to explain their symptoms. Finding Support for their Theories’ described participants’ search for evidence to support their preliminary ideas (or tentative theories). Participants used four strategies for gathering evidence in piecing together (or forming) theories to account for their symptoms including: comparing themselves to norms (their baseline, others, norms for age and sex), using testing to determine their bodies subjective and/or objectives responses (monitoring BP, HR), eliminating possibilities, and reaching out to others with more ‘expertise’.

4.4.3.1. Comparing self with others.

Examining self in comparison to others was used to substantiate individual theories, and to determine whether the experienced symptoms were conceivably a ‘normal’ occurrence. Participants
used their own symptom norms, and those of their family, friends, and peers, including those of the same sex, as points of comparison. For example, Helen compared her palpitations to her mother-in-law [who experienced similar palpations] as a measure of what was normal or reasonable to expect: “Just thought it was something, it was going to happen in my life as it did with my mother-in-law” (Helen). Greg compared his symptoms to his brother, with AF, to support an AF-related theory for his symptoms:

And it wasn’t until near the last few weeks before I went into my GP, and I was thinking what I’m going to say or tell him. And then I was thinking what if I’ve got what this Afib or whatever. I didn’t even really know this fibrillation or whatever. Whatever my brother had, you know. And irregular, he called it more irregular heart rhythm. I didn’t even really call it atrial fibrillation or fibrillation. I just said irregular heart rhythm. I just said maybe I’ve got that.

For other participants, gender was employed as a point of comparison. Ellen compared her headaches based both on what was normal for her and for ‘women,’ in general,

Again, now looking back because I never had headaches before. And you know women always have headaches. I’m really lucky because I never really get a headache. In the last six months I’ve had more headaches than I’ve ever had in my life. Like dang, why am I getting a headache?

Clinton (age eighty) used a peer of a similar age in an attempt to substantiate whether his symptoms were normal:

Going to hole number six was quite a climb. I’d have to stop halfway up the hill. The guy I played with, he’s 80 years old, too, goes up there like there’s nothing to it. But they exercise every day”.

However, Clinton was not able to determine if his symptoms were normal or not, because the last statement, “they exercise every day,” suggests that age, as a comparator, did not provide an equal representation of what should be normal for his age group. Therefore, lastly, participants compared
their individual health with others less fortunate to evaluate the impact of their symptoms. Ben’s words illustrated how he compared himself with those at a homeless shelter to bring his own health into perspective: “But I always drive by the shelter and, you know, I always feel a lot better. So, that’s all I need to do is look at how other people are in relation to myself”.

4.4.3.2. Testing.

Testing was another prominent means that participants used to find support for their personal symptom theories. In the search to find further evidence to support their theories, participants tested themselves by: i) testing the limits and/or ii) self-monitoring symptoms. Participants described testing their theories for ongoing, new, and or unexpected symptoms.

Testing the limits involved participants actively testing themselves, looking for evidence as to why they were experiencing their symptoms. This form of ongoing testing involved pushing the body through physical exertion until symptoms appeared or disappeared. Len recounted how he tested his bodily limits to try and explain why he couldn’t catch his breath,

I worked on the fourteenth floor of a building. And, you know, I was testing myself. So, I’d run up the flight of stairs. And one day I made it. I was tired but I did it. The next day I was good until about the fifth or sixth floor and all of a sudden, I nearly collapsed like I felt I, somebody would have to call an ambulance because I, my chest was really hurting.

Several participants “tested” their symptoms through self-monitoring or by having someone else monitor them. Monitoring of participants’ symptoms, occurred manually and/or by machine (e.g., BP) and involved keeping a log of changes in physical parameters (e.g., BP, P), in some cases. Fred described his “testing” of his irregular heartbeat by manually checking his pulse,

It was just jumping around, rattling like, you know, beat. Then I’d test it. I used to be a first aid attendant so I tested it, and it would beat like six times and then stop. And then beat three times quickly and the one big beat and then it would just be all over the place.

Brenda, who experienced a sudden onset of nausea and dizziness [which initially she thought
was food poisoning] first tested to see if lying down would improve her symptoms and then tested further, by asking her roommate to listen to her heart with a stethoscope, to ascertain if her heart might be the cause of her symptoms.

Some participants were very strategic in their use of monitoring to support their theories of an arrhythmia. These participants described collecting “data” as evidence to convince their providers that their symptoms signalled a problem. For example, Anne, who had experienced difficulties in obtaining an AF diagnosis, monitored herself until she found an abnormal heart rate reading to explain her heart pounding and palpitations, and immediately took the new information to her doctor:

I had just gone through the drug store, took my pressure and I found that it was in like the high thirties, you know, 130s. And so, I thought that’s not good for me and at the same time I really felt my heart working again. And so, when I went into the office I said, ‘Can the nurse please take my blood pressure right now?’

Similarly, Len used monitoring over an extended timeframe to gather evidence in garnishing increased support and validation for his symptoms to convince his physician,

And so, then I started monitoring my heart faithfully three or four times a day. I got a cuff machine, blood pressure and pulse and. RW: Because you weren’t getting any answers with?
Len: Well, yeah because I just wanted to data, right. I kind of postponed it. But from February, March, and April for those well, for two-and-a-half of those months but for those three months I monitored it hard. And it would vary regularly in rhythm, nice pulse, nice blood pressure for four days and I was in Afib for two with little variance but, you know, give or take half a day or something. But it was very, it was regular. And I thought boy this is good information for my doctor.

4.4.3.3. Eliminating possibilities.

Eliminating possibilities was a strategy participant used in their search for a theory which fit their symptoms. In essence, they would begin a process of ‘brainstorming’ to see what would ‘stick’
or make the most sense. Gillian’s account of her AF experiences provided one example of how participants speculated and cycled through and eliminated theories during the evaluation period.

Gillian experienced symptoms for over three months before her diagnosis. Initially she speculated her symptoms might be anxiety, but as her symptoms progressed, this theory no longer made sense, and the possibility of a small stroke entered her mind:

Yeah. I just thought they were like anxiety or. At first, I thought what the heck is that. And then I went to sleep and woke up in the morning. It wasn’t there anymore… Well, I was kind of worried, I guess. Especially the whole fainting thing. Like what was that? Like am I having a mini stroke or something? But I wasn’t quite sure what that was. Didn’t know if that was actually from the atrial, from my heart. Or was that something completely different.”

Dan also worked through possible explanations for his symptoms, reassuring himself that symptoms of a heart attack would be different:

But for what it was it was just a matter of this fluttering here and, you know, nothing else. Normally if you’re having a heart attack you’re supposed to have all these symptoms, these pains. And stuff like that. Well, there was nothing there. So, I didn’t deem it to be something really, really serious or else I would have had some of these indications, right?

Clinton explained his cycle of theorising, as he imagined all the possible reasons as to why he was gaining all this weight [which was actually the symptoms of HF secondary to his AF]:

Well, the swelling I thought was, I was retaining water or fluid. And I don’t know why I would retain fluid. That I couldn’t understand because I didn’t drink a whole lot of water. I kept saying baby we’ve got to eat better, remember? I kept saying we’ve got to have less food because I’m gaining a little bit of weight. And of course, I’m just thinking it’s all in my tummy. And then so, then when I got up to 170, you know, my legs or my ankles were swollen so much. I thought, well, that’s something funny here. So, I thought, well, I, that I didn’t know. And then when I had that shortness of breath I coughed a few times and like
Paul said. But I, I had no idea what that could be. I didn’t think it was a heart attack because I never had any pain.

As might be expected, those in the EDG developed fewer theories for their symptoms than those in the LDG. However, similar to those in the LDG, the majority of the participants in the EDG were also unsure about what their symptoms meant. Nevertheless, and despite their uncertainty regarding the cause of their symptoms, participants in the EDG knew, with greater confidence, that there was something ‘wrong’ with their heart – a conclusion which created increased concern about their symptoms and may have been instrumental in their shortened evaluation period.

4.4.3.4. Reaching out - asking for help from friends and family.

Reaching out to others was another strategy participants used in an effort to gain more evidence or expert advice to support or refute their symptom theories. Participants were highly selective in who they reached out to, often turning to colleagues or family members who were health professionals, or other people with AF. Friends/family members, who were health professionals were viewed as possessing credibility as sources of expertise. For example, Gillian, a physiotherapist, first asked a colleague at work about her symptoms to gain his expert opinion about what her symptoms might suggest:

And so, I was having more episodes then. And then I had a few nights. What the heck? And I got up one night and I had one of my little fainting outs. And I thought oh, it’s probably a panic attack. So, that’s when I was, I talked to one of the respiratory therapists and said ‘oh, have you ever heard of these symptoms before’? ‘Oh, yeah. A little atrial fib. Atrial flutter,’ he says. ‘You know, women of a certain age.

The nonchalant way that her colleague explained that AF is ‘normal’ for ‘women of certain age’ seemed to make a lasting impact on Gillian’s theory creation, as evidenced in the following statement “So, I just thought, ah, it’ll go away”. Neil’s interview provided further evidence of the value participants found in reaching out to family/friends who were healthcare professionals. Neil
explains how he talked to his daughter about his health, valuing her understanding of his heart condition because she was training to become a registered nurse:

We [him and partner] do look things up [on the internet] to kind of get an idea. But, we rely more on our daughter now. Run things by her. Just because she seems to have a better understanding of what’s going on. She’s in it [in healthcare].

Lay persons were also consulted to validate participant theories, particularly when it was someone with AF. Cathy turned to a friend and neighbour with AF, after over a year of deliberating over her symptoms, when she began to theorize that she might have AF like her neighbour:

I didn’t notice a flutter at all. Like I had, I would say I had about six or more episodes of dizziness over a period of one year. And then all of a sudden, I started with this funny flutter in my chest. RW: What did you think about that? What were your thoughts? Cathy: I talked to my neighbour. She had Afib and she has a pacemaker. She said ‘Cathy, it sounds like you may have Afib’. Okay. So, I went to see my doctor and I said ‘I think I have Afib’. She checked my pulse and she said ‘I think you’re right. Good call’.

There were differences in the number of times men (n= 9) versus women (n=3) involved their partners in building, supporting or validating their symptom theories. Additionally, there were also differences in the numbers of older (n=9) versus younger (n= 3) participants who leaned on their partners for support, to develop their symptom theories. The following paragraphs explore both these age and gender differences.

Men talked to their spouses about their new AF symptoms, more than women did. Additionally, and following this ‘consultation’ with their spouses, more men described how their spouses urged them to take a more serious approach to their symptom evaluation. For example, Kevin (seventy-eight years old) talked about how he relied on his wife, who is also a nurse, to help him evaluate his symptoms. His theory was that the food he had eaten [radish in combination with wine], had caused his chest pressure and indigestion. However, he described his wife as “more skittish or
concerned than I would be” taking his symptoms more seriously, “You should never argue with a nurse. Especially if the nurse is your wife.”

Similarly, Monty (sixty-nine years old) talked about how his wife urged him to see his physician to further evaluate his symptoms,

I guess I talked to my wife about it [his symptoms]. She was the one that said you have to go to the doctor. You have to tell him about all the things you’ve got because he will actually look at you and see because there has to be something wrong.

However, he ignored her words, theorising that his symptoms were all associated with his weight, until he suffered from severe SOB, which limited his ability even walk across a flat parking lot. Isaac’s (eighty-five years old) interview provided a final example of the interaction between men and women following the onset of symptoms:

Well, I just woke up and I knew something was wrong so I sat on the edge of the bed. And I could feel it, feel my chest sort of rattling away. And so, I, you know, something was wrong. So, I woke my wife up and said I think we better get checked out (Isaac).

Conversely, only three women, all in the younger age group, described reaching out to their partners but only after months of saying nothing about the symptoms. When they did, however, unlike the response of the men’s spouses, the women were met with ambivalence and an overall lack of concern, often reinforcing their own ‘it’s nothing’ theories. Helen (sixty-seven years old) finally told her spouse about her symptoms when she could no longer keep up with him during their daily walks, because of SOB, only to have him reinforce her denial, “Well, I guess he was like me because it was his mom who had the same kind of thing [fatigue and SOB]. And he figured it was just nothing wrong. So, you just get up and deal with it”. Likewise, Farah (sixty-four years old) explains how her husband didn’t know what her “episodes” might mean and offered little support.
4.4.4. Disrupting Theories

‘Disrupting Theories’ represented participants’ altered evaluation of their symptoms, and re-theorising symptoms as more serious than they realized and required medical evaluation. Sixty-five percent (n=17) of the participants reported specific junctures in their symptom experience, which infused greater self-awareness and changed how they evaluated their symptoms. A disruption of their predominant or ongoing symptoms theories resulted primarily from changes in the characteristics of their symptoms. Participants described three common changes in their symptoms, which prompted them to re-evaluate their symptoms – symptom frequency, intensity, and exposure. Thirteen participants talked about how repeated exposure or frequency of the symptoms caused them to re-theorize their understanding of the symptoms: “And then, so, I think when I finally went in for it [to ED] to emerge it [palpitations] was happening quite often. It wasn’t just when I was. If I remember right it was happening when I was up or at night. It was just more so” (Edward). Likewise, for John, it was the increased frequency of symptoms during the night:

I sort of just left it. But when I was getting it more regular in bed when I was going to sleep I’d get up. And so, I knew there was something wrong. I’d wake up in the morning and I’d have this little bit of maybe sweating but not really heavy and my heart beating pretty hard. And then it would go fast and slow and fast and slow. Then I said I’ve got to go in to see the emergency. And that’s how we finally caught it [the AF diagnosis]. Got to be something haywire here.

Several other participants described how it was the severity of their symptoms and the context in which they occurred that caused them to re-evaluate their symptom theory(s). For example, Margret, who believed her symptoms were all anxiety-related for many years, explained how she began to question her theory when it no longer made sense:

I was washing my hair and suddenly my heart was beating a mile a minute. And I felt like I was going to pass out. So, I sat down on the edge of the tub and had to wait for a good five, ten minutes before my heart calmed itself down and got out of the tub and went to the doctor.
That’s when I figured, you know, something else has to be going on because it can’t be anxiety. There was nothing stressful. All I was doing was standing there washing my hair.

For some participants, it took a combination of many factors to bring about a change in their symptom theories. For example, Monty’s theory about his symptoms finally changed because of the severity of the symptoms, the context in which the symptoms occurred, and the expectations (as previously discussed) about when his SOB should occur. This progression of symptoms and changing context is exemplified in the following:

I mean, I probably had a couple of weeks or a couple of days of getting there and waking up in the middle of the night and going oh [as in that was strange] and then go back to sleep again.

Monty continued theorising about his symptoms for days, even trying to exercise to improve his symptoms which he considered to be weight-related:

Well, it was the last two or three days before I went into hospital. It was the point. And I said this is ridiculous because I was actually managing to lose a little bit of weight. And I was managing to do a little bit more exercise. And that actually wasn’t helping. If anything, it [his symptoms worse] was making things worse.

The breaking point for him was when his symptoms were becoming so severe that he couldn’t even walk across the parking lot without experiencing severe SOB:

You know, just suddenly. I found myself breathless in various situations. I had that situation where I came up here had to rest three times on the way to this door, you know. Now, I was looking at this and saying hey, wait a minute. This is a little bit more than being overweight and getting out of breath. There’s something serious going on here.

The development of different types of symptoms, in addition to their initial symptoms, commonly disrupted participant’s theories. For example, Cathy described how she had sporadic dizzy
spells for over a year; however, it was only when she also experienced a fluttering in her chest that she began to re-evaluate her symptoms:

I would say I had about six or more episodes of dizziness over a period of one year. And then all of a sudden, I started with this funny flutter in my chest… And that’s when I consulted with my neighbour.

Clinton began to re-theorize his long time palpitations, which he had previously attributed to weight gains and over-eating, when he began to experience shortness of breath for no apparent reason, suddenly realising that there was something serious happening with his health:

I went over to the drug store to pick something up and as I came out, I went into a bit of a cold sweat. And I didn’t know whether to go down on one knee or what. And then I eventually walked back. I was very weak. I sat down in the lobby there for about 10 minutes before I came up here. But that’s what triggered it was that walking back thing. And I said oh, we’ve got to do something. Something’s wrong here.

4.5. **Aim 3: Exploring AF Symptom Response.**

The third and final aim of this study was to identify and describe adults’ responses to their AF symptoms during the pre-diagnosis period, and to compare symptom responses based on age and gender. The response stage in the SEM is defined as all actions/activities that participants employed, in response to symptom occurrence, and initiated to deal with the symptom(s). The responses to AF symptoms were highly complex, convoluted, individualized, and conflated with both the perception and evaluation phases. Although each participant’s symptom experience was unique, there were common responses observed among all the participants. Responses were often influenced by the theories generated during the evaluation process. Participants had three major responses to their symptoms. These were: (1) a non-treatment response such as waiting, watching, and hoping their symptoms would self-resolve (n =20 or 77%); 2) self-treatment such as stopping, resting or laying down, coughing or deep breathing, and lifestyle changes (n=20 or 77%); and 3) health seeking.
As in the perception and evaluation sections of this chapter, the influence of age and gender, and the differences in responses amongst members of the EDG versus the LDG, is threaded throughout the entire response section.

4.5.1. Non-Treatment.

Not seeking treatment was a significant response for 77% (n=20) of the participants, who described this as a conscious and deliberate response to the perception and evaluation of their symptoms. Choosing to overlook, disregard or ignore their symptoms and to respond by not seeking treatment was pervasive among LDG participants- 90% (n=18), compared to only 33 % (n=2) of participants in the EDG. Responding with non-treatment was particularly prevalent among those who were symptomatic for more than one year, before their diagnosis (n=13). Additionally, seventy-five percent of the younger participants (n=9) versus fifty percent of the older age group (n= 7) reported employing ‘not seeking treatment’ as a response. Participants choice of non-treatment took one of two specific forms including 1) waiting, watching, hoping it will go away; and 2) I talked myself out of being sick. These non-treatment themes are now presented.

4.5.1.1. Waiting, watching, and hoping it will go away.

Many participants (n= 8) described a passive response of waiting, watching and hoping their symptoms would go away. A hopeful attitude that a non-treatment approach would lead to a resolution of their symptoms was seen in equal proportions among the LDG (n=6 or 30%) and the EDG (n=2 or 33%). The main difference between these two groups was the duration of the hopefulness. Hopefulness continued for a more extended period amongst those in the LDG, but was short-lived in the EDG, because of the unrelenting symptoms that initiated a quick response. Therefore, when the symptoms persisted, EDG participants abandoned hope that their symptoms would go away on their own and sought care.

Hopefulness that their symptoms would go away differed between the older and younger participants. Specifically, six younger participants compared to two older participants responded with
a wait, watch and hope approach. The younger participants indicated that ignoring minor aches, pains and injuries had helped them manage their symptoms, historically. These younger participants admitted that because they had never really experienced any major illness, when faced with the symptoms of AF, they continued to adopt their familiar pattern of ignoring symptoms: “Well, I think it was more that my youthful health-care plan, if I ignored it, they (symptoms) would go away” (Gillian age sixty). Neil (age fifty-eight) also demonstrated the younger participants’ response of ignoring symptoms: “Most things, you know, you ignore it, and it goes away. Passive and, you know, just ignore it. Maybe it’ll go away”. Additionally, four participants, from the younger group, were hopeful their symptoms would self-resolve, based on the symptom theory of stress in their lives, a phenomenon not observed in the two older participants.

   And in the back of [my] mind, I was still hoping it (AF symptoms) would all just go away.
   Hoping this was all just stress related. So, I didn’t necessarily. I didn’t make an appointment right away with my family doctor. I was hoping it’d go away. (Len age fifty-eight).

4.5.1.2. Talking themselves out of being sick.

Talking themselves out of being sick was another non-treatment approach used by participants. In total, one EDG and five LDG reported that they delayed seeking treatment because they had more pressing priorities, which superseded the need to seek treatment for the symptoms they were experiencing. For example, Gillian said nothing to avoid spoiling or cancelling an upcoming vacation, or possibly receiving a diagnosis which could increase her travel insurance:

   So, I didn’t actually want to go to a doctor before I left on my trip because of my travel insurance, right. So, I just thought, ah, it’ll go away. But then when I flew to Buenos Aires I had a lot (of symptoms) right at the beginning of the trip. I think it was, like we went from February here to thirty degrees and humid there. Jet lag and, you know, all that stuff. And it was, it really kind of screwed up my trip to be honest because I just felt so incapacitated.
   Although both men and women described ‘not having time’ to be sick their circumstances varied. Overall, more men talked themselves out of being sick because of their need to continue with
their active lifestyles,

But I said I still swim every day. I walk or run every day, do yoga at night for, you know, half an hour. We do yoga classes usually twice a week. We’ve been pretty busy now. And I think we just caught up with things. I didn’t have time to get sick. And you’re sort of in denial, you know (Greg).

On the other hand, women described talking themselves out of being sick more often, and using denial because of their many caregiving, family and work obligations:

Because then you just don’t have time. Like, I don’t have time for this. Taking care of his parents and doing stuff for my husband. I’m doing the job. What the hell? I don’t have time. Having a cold, no, don’t have time for that. Don’t get sick. Don’t get the flu. There’s so much stuff to do all the time. Yeah, I just don’t have time for it. And you just talk yourself out of things, too, I think because you don’t have the time. Like well, I can’t be sick (Ellen).

More participants in the older age group (four compared to two) reported talking themselves out of being sick based upon too many work, travel, sporting and family obligations.

In summary, all of these participants chose not to seek immediate medical treatment based on the belief that their symptoms were inconsequential, fleeting, and insignificant, and would hopefully resolve themselves. In the case of the participants in LDG, this ‘hopeful’ belief and the ability to ‘talk themselves out of being sick’ contributed to their prolonged pre-diagnostic period.

4.5.2. Self-Treatment.

Once participants became aware of and had evaluated their symptoms, 77% (n= 20) reported responding first with self-treatment; 70% from the LDG (n=14) and 50% (n=3) from the EDG. Self-treatment is a group of responses that describes the participant’s independent, self-initiated actions, prior to seeking care from their HCP. Examples of some of the self-treatment approaches, employed by participants, included stopping, resting or lying down, deep breathing and coughing, and lifestyle changes. In many cases, if the self-treatment was successful and the symptom stopped or went away,
the chosen treatment was deemed effective.

4.5.2.1. **Stop, rest, or lay down.**

Ten participants, eight of whom were women, reported responding to their symptoms by stopping activities, resting or lying down and waiting for the symptom(s) to pass. All ten participants, who responded in this way were in the LDG. Participants were involved in a variety of activities when their symptoms occurred, such as eating lunch, walking, running, sleeping or showering. They were often forced to rest, because of severe/intense symptoms such as SOB, light-headedness or dizziness. For example, Cathy described resting in response to severe light-headedness, while skiing:

Like almost fainting. That bad like when I was skiing I just said to my girlfriend, oh, something’s wrong, you know. I said I just have to fall down. So, I fell down and just rested for a few minutes and I was pretty good. It passed, you know.

John and Clinton were the only men who reported needing to rest immediately, by either sitting or lying down in response to their symptoms. John described needing to rest because of the onset of AF symptoms during exercise:

Exercise bike and so, yeah, I would get really, really, I’d get sweaty and heavy heartbeat and feel nauseated. And so, I would just lie down on the couch right there. And do that for maybe five minutes, ten minutes and I’d feel better. I’d get up and I’d feel much better. I’d get on my bike and pedal. It seemed to be gone. So, it was, I couldn’t ever diagnose what it was.

4.5.2.2. **Coughing or deep breathing.**

Three men and one woman, all in the LDG, reported responding to their AF symptoms with deep breathing or coughing. The three men described flutter or palpitations in their chest, to which they would respond by taking big breaths or coughing until the symptoms passed. John explains how this technique worked for him:

I’ll get a little attack say once every two, three weeks but I can control it with breathing, so. I don’t know. Medication I don’t take that very often because the breathing seems to have faster results than the medication. I take big breaths in through my nostrils and breath out
slowly through my mouth. And I do that anywhere from five to ten times. And it’s gone.

Similarly, Clinton used coughing to correct his symptoms: “you just go (cough, cough) and take some deep breaths in between. And your heart will regulate and that’s what I would do. I did that for two or three years”. Farah was the only woman who reported responding with deep breathing, combining with rest, following the onset of AF symptoms:

Like the other day I was vacuuming and making beds and pushing things around and moving things and going up and down the stairs and then that was when I felt that. I just went and laid down for a bit. Lay down and deep breathing. It got better”.

4.5.2.3. **Lifestyle changes.**

Sixty five percent of participants (n=17) attempted some form of lifestyle change in response to their symptoms, during the pre-diagnostic period. Lifestyle changes included modifying activities, changing jobs, changing diet, reducing or quitting alcohol, and adopting relaxation techniques. Each of these changes will be discussed, briefly, in the following section.

4.5.2.3.1. **Modifying activity.**

Thirteen participants indicated that prior to their diagnosis, their symptoms led them to modify their physical activity – increasing, decreasing, or stopping activity all together. Specifically, nine women and four men restricted their activities such as walking, hiking or running. Self-imposed activity limitations were described as anticipatory in nature, as participants attempted to avoid triggering their symptoms. For example, Gillian, who experienced random occurrences of severe dizziness and fainting, limited her volume of activities such as hiking or skiing to avoid triggering symptoms (she worried about extreme symptoms in secluded areas). Although women (n=4) tended to restrict their activities, two men in the study modified their sporting activities rather than avoided them all together. For example, Monty described how he had adapted his golfing: “So, to start with I found it was getting more and more difficult to walk around the golf course, for instance. And so, I started taking carts”. Twice as many participants in the older age group (n=4 ≥ 68) compared to the
younger group (n=2 ≤ 67) described the negative impact of their AF symptoms on their sporting activities in the pre-diagnosis period.

In contrast to those who decreased their activity, were those (n=4) who increased their activity once they began to experience AF symptoms. Ellen, Margret, Neil and Monty all described exercising more when they became symptomatic, attributing the symptoms to being overweight. Ellen depicts how she responded:

Just exercising more and, you know, I’ve been trying to be better with my food and going back to cleaning in the morning. But now, I’ve lost about fifteen pounds so far. So, yeah. I still have twenty-five to go.

4.5.2.3.2. Changing jobs.

Four participants, three of whom were in the younger age group (≤ 67), talked about how they changed jobs or quit work, because of their ongoing pre-diagnostic symptoms. Additionally, all of the participants who changed jobs, as a form of self-treatment, were in the LDG. This response was associated with theorising stress as the precipitant of their symptoms, and they believed that removing the stressor would diminish their symptoms. Farah’s (age sixty-four) experiences illustrate how the stress of one job was affecting her heart:

I think it was because I was quite stressed at work for a period. And I think it started getting worse then because I can remember saying to my people I worked with oh, I’m feeling really stressed. My heart’s funny and, you know. I’m having a heart attack. But I’m not in that job anymore so. I changed jobs. It’s better now.

4.5.2.3.3. Dietary changes.

In the hopes of reducing or preventing their pre-diagnostic symptoms, seven participants altered their diet or alcohol intake. There was a notable difference among the two age groups when it came to dietary changes, with thirty-three percent (n=4) of the younger age group (≤ 67) attempting changes in their diet in response to their symptoms versus only seven percent (n=1) of the older age
group (≥68). Edward (age 68), Farah (age 64), Joyce (age 63) and Len (age 58) reported reducing or quitting coffee or tea drinking altogether, while Neil (age 58) and Ben (age 59) reported trying to eat healthier and reduce their alcohol intake.

4.5.2.4. Relaxation.

Three participants, two women and one man, all in the younger age group (≤ 67), reported that they started practicing relaxation techniques to minimize their symptoms. These relaxation techniques included activities such as deep breathing, relaxing, listening to music, colouring, exercise and mindfulness activities such as yoga. Farah (age sixty-four) described how she practiced relaxation in response to her symptoms during the pre-diagnosis period:

“I just take more time to sit down and relax rather than just running around all the time and doing things for everybody. I just take time for myself and I don’t know, I put nice music on or something. Or I’ve got some of these adult colouring books that’s pretty relaxing”.

4.5.3. Health Care Seeking

Often the final step in the symptom experience involved participants responding to their AF symptoms by health care seeking from their HCP. However, if participants did not receive a definitive AF diagnosis, the pre-diagnosis period continued. Eventually, all but one of the study participants responded to their symptoms by seeking health care. The exception was Joyce, whose fainting in a public place, forced ambulance services that precluded her actively seeking health care.

The twenty participants in the LDG reported several distinctive reasons for finally seeking health care. Despite adapting non-health seeking responses which had previously been effective, all participants eventually arrived at treatment seeking as a response. Four participants turned to their HCP when they realized their usual way of treating their symptoms was becoming less effective. For example, when Farah’s usual wait-and-see approach to symptoms, which included a weekend of resting and waiting for her palpitations to dissipate, no longer worked, she decided to go to the hospital. Two participants described “putting off” health care seeking for many months because they
did not want to disrupt their travel plans. It was not until they were near a hospital, while their symptoms were occurring, that they decided to seek treatment from an HCP. Lastly, four participants in the LDG reported not using their HCP until they had a regularly scheduled doctor’s appointment. In other words, these participants waited until they had another reason for a check-up, to report their symptoms to their HCP. Greg was an extreme example of this type of response; he endured weakness, SOB and activity intolerance for nine months until he had his regularly scheduled doctor’s appointment.

Participants relied on their past experiences with illness to help formulate their response to the AF symptoms. Treatment-seeking patterns, formed throughout their lives, were described as influential in their decisions to seek (or not seek) care from their HCP. Thus, participants did not seek care based solely on the severity, frequency or nature of their symptoms. Instead, their decisions were based upon an array of influences, such as their tendency to initiate self-treatment strategies or to wait and watch their symptoms before treatment seeking. Also influential was the support of family, friends and HCP. These factors are explored in the following paragraphs.

Many participants (n=13) were reluctant to seek care for their health but the firm/stern urging and insistence of partners, loved ones and friends often precipitated a health-seeking response. Specifically, eleven participants within the LDG indicated that family or friends played a significant role in their response compared to only two participants in the EDG. These participants were often willing to wait out the symptoms, but the intensity, persistence or novelty of symptoms, alarmed family members. For example, when John’s heartbeat fluttering persisted over time, and gradually became worse, his wife convinced him to seek treatment: “But this fluttering part didn’t seem right to me. So, that’s my wife says better get in.” Ellen, who seldom complained about her health, elicited her husband’s take-charge-action in response to her chest pain, “I said you know what, something is bizarre. I think we should just get it checked out. He said get in the car right now” (Ellen). Without the insistence of her roommate and son, Brenda would have waited longer for her symptoms (racing heart, light-headedness and GI symptoms) to pass before seeking help: “So, she (roommate) starts
freaking out and her and my son insist that I go to the hospital which was probably the wise choice at the time” (Brenda). Although he initially ignored her, Monty described his wife as his biggest influence for seeking treatment,

The biggest treatment, well, the biggest reason to for seeking treatment was being nagged out by the wife in reality. But that was to do with breathing at night. She said I wake up. I realize you’ve stopped breathing. And now I’m lying here waiting to see if you’re going to start breathing again or do I have to kick you or something, you know. And she said that was happening at least two or three times a night. You’ve got to do something about it (Monty).

Despite urging from loved ones, participants did not always seek care immediately, such as Henry, who was encouraged to get checked out but, unable to get an appointment, and decided to wait for his regularly scheduled appointment.

Participants’ (n=6) past responses to symptoms influenced their current responses to their AF symptoms. Specifically, these six participants indicated that their childhood experiences strongly influenced their health seeking patterns and behaviours. Four women and two men, all within the LDG, described a pattern of not going to the hospital for treatment, or infrequently accessing their HCP, because of the patterns formed during their childhood. Four younger (≤ 67) participants compared to only two older (≥68) participants admitted to avoiding interaction with their HCP, unless it was something very serious. Gillian (sixty years old) elaborated how childhood patterns shaped her treatment seeking behaviour in adulthood:

I mean, we were always brought up very…. Well my parents aren’t British but, you know, the whole Protestant work ethic. You hurt yourself, well, get over it. You’re good. You’re bleeding. Here’s a Band-Aid. We never went to the doctor as kids for. Like I know lots of people that take their kids to the doctor all the time. I’m like what. Oh, we were brought up kind of very, you know, if you fall down. Get up. Get up get going (Gillian).
Gillian also described her continuing childhood pattern of ignoring symptoms in responding to her present symptoms: “If I ignored it would go away. Hurt yourself. Go to bed, wake up in the morning. It’s gone, right.”

Finally, when isolating the response of those in the EDG (four men and two women), several different reasons for their expedited health care seeking responses were evident. First, one woman and one man reported feeling fearful and worried about their heart-related symptoms (chest pain), because of their family history, or because of their own previous experiences with cardiovascular disease. This fear precipitated early treatment seeking. Next, three participants, all of whom were men, had never before experienced any heart related symptoms, such as a racing heart or palpitations, and were concerned about what their symptoms might indicate. Experiencing symptoms at night tended to prompt an early response. The last remaining participant within the EDG did not make the decision to seek care as an individual, instead, and as described above, she was taken to the ER by ambulance following her collapsing to the ground in a public place.

4.5.3.1. Repeat health care seeking.

Over half of the study participants indicated that repeated health care seeking was needed in order to obtain an official diagnosis. The difficulty in obtaining a definitive diagnostic test for AF differed by age and gender, amongst the study participants. Seven of the thirteen women interviewed indicated that they faced challenges in obtaining a diagnosis because of normal test results, compared to only three of the men. Additionally, five of these seven women were in the younger age group.

Seventy percent (n=14) of the participants in LDG reported that they sought help from their HCP, following the onset of symptoms, but were unable to get any definitive answers or treatment for their symptoms. These delays prolonged the pre-diagnosis period. Eleven participants in the LDG who had repeated health care-seeking visits to their physician, described hearing the words ‘you’re fine’, having no obvious signs of any illness following their diagnostic testing (e.g., manual pulse check, ECG and Echo Cardiogram). Anne’s words illustrated the experiences of many of the participants: “You know, sometimes a doctor tells you you’re fine you can actually be fine”. For these
eleven, being told ‘you’re fine’ had a profound effect on their responses and their pre-diagnosis time frame

For some, hearing the words ‘you’re fine’ provided complete reassurance and for others a nagging reassurance. However, participants varied in how their HCP’s reassurance influenced their overall evaluation and future response to their symptoms. For six participants, hearing ‘you’re fine’ was a total relief, and minimized concern, worry or anxiety. This relief reinforced the insignificance of their symptoms and prompted them to enter a period of rest and contentment, ignoring or self-treating their symptoms. Brenda described how the words ‘you’re fine’ affected her: “It eased my mind; I totally put it on the back burner, shelved it, filed it, and never looked at it again” (Brenda). Conversely, the remaining five participants either remained uneasy about their symptoms, despite the reassurance, or were hesitant to seek follow up care because of their concerns about being a burden. For example, Len was told he was fine, but he knew something was not right. Therefore, he continued searching for an explanation for his symptoms for a period of six months before he was able to convince his HCP to give him a standing ECG order, which revealed AF. Lastly, the experience of receiving a ‘you’re fine’ from their HCP, led some participants, for example Helen, to feel like a burden, and hesitant to seek further health care. Helen was told that she was ‘fine’ and she therefore avoided further health seeking for her symptoms, in order to avoid troubling her physician with her symptoms: “Because that’s what it seems like is a bother. There’s really nothing wrong and they’ve told me nothing’s wrong. Then why would I trouble anyone”.

The repetitive visits to their HCP only to hear the words ‘you’re fine’ created some frustration for many of the participants. Both men and women described feeling frustration because of inadequate diagnostic testing and follow-ups, not feeling heard, not being taken seriously, or feeling too rushed during their office visits for their concerns to be addressed or to be properly assessed. For example, Greg lamented, “Nobody took my pulse” and Kevin said, of his GP, “Like he never seems to spend any time with what I call the diagnostic type things. You know, he’s very quick to put you
on a medication”. Anne was so frustrated that she went so far as to blame her physician for her condition:

And so, I really accused her of my atrial fibrillation. I said, ‘This is all your fault. You’ve ignored it and you knew. And I told you several times.’ And she said to me, ‘But you haven’t told me recently, have you?’ And I thought what’s the point if you’re calling me paranoid.

Having to convince an HCP that their symptoms should be taken seriously was frustrating for participants, such as Len, who described making multiple visits to his physician without diagnosis or any follow-up testing:

But so, then I made an appointment with my family doctor. And again, he said we did everything for you like he was a little annoyed. I don’t know what else we can do, you know. And I told him okay next time, you know, I’ll go to emergency when I’m out [of rhythm] just so I can prove it.

Although men expressed considerable frustration at the lack of diagnostic testing, one participant was struck by the gender inequality in diagnostic testing between herself and her husband.

Yeah and it’s always, it’s always kind of amazing to me. My husband, it’s just interesting. Like he’ll come home and oh, they’re doing this test. They’re doing that test. They’re asking him all this. It’s like wow. It’s funny that. I mean I’ve asked him do you go in there and just say that you feel terrible. How come you’re getting all this? And I remember thinking when like even then why didn’t, why don’t they give me an EKG. Like we’re both the same age. Why are you getting one and I’m not? And my husband is not like unhealthy. He’s just a guy (Ellen).
Chapter 5: Discussion

5.1. Introduction

The symptom experience of the participants in the current study was highly variable and complex and involved the dynamic interaction of perception, evaluation, and response. This is one of the first studies to disentangle the individual components of the pre-diagnostic AF symptom experience in order to understand their unique contributions.

The symptom experience included perception, where the noticing and awareness of symptoms was evoked through bodily senses – seeing, feeling and hearing. Some symptoms were perceived to be vague and almost incomprehensible, while others commanded attention; announcing their arrival with extreme dizziness, fainting, SOB or chest pain. The second aspect that was central to the symptom experience was evaluation, including the processes of speculating, testing and forming theories about the symptoms’ cause(s) and treatability. Each aspect of evaluation was influenced by the participants’ expectations, such as being healthy or having a perceived lack of risk for heart disease. The participants found support for their theories in various ways, such as testing (pushing their body through physical exertion), comparing their health to that of others, eliminating possibilities, and reaching out to family and friends. Lastly, the symptom experience entailed participants’ responses to their symptoms during the pre-diagnosis period. Some common responses, prior to health care seeking, included non-treatment approaches, such as waiting, watching, and hoping their symptoms would go away; and attempting self-treatment options, such as changing diet or exercising.

The participants’ perception, evaluation, and response to AF symptoms were influenced by many factors, including age, gender, sex, previous illness experience, education and the context in which the symptoms were experienced. The nature and timing of their symptoms varied for the majority of the study participants, creating challenges in the perception, evaluation and response to obtain a timely diagnosis. The following section will explore the various ways in which this study
advances the current understanding of the symptom experience and follow with a discussion of the influence of age, gender, and early or late diagnosis on the symptom experience.

5.2. The Symptom Experience in AF

The Symptom Experience Model (SEM), as applied to AF, provided a framework to explore the pre-diagnosis period. Despite three distinct processes characterising the pre-diagnosis symptom experience often these three stages were interconnected. Perception, evaluation and response rarely occurred in a linear fashion, in patients’ experiences of their symptoms; rather happened cyclically and often overlapped. For example, it was not uncommon for a participant’s evaluation to influence their response and thereafter (alter) their perceptions. Additionally, participants whose response did not effectively alleviate or explain their symptom(s) would return to the process to re-evaluate them. At times participants characterized the three processes as happening simultaneously and fluidly.

One of the primary findings of this study was the overall time participants took to cycle through the perception, evaluation and response phases of the AF symptom experience. Seventy-seven percent (n=20) of the study’s participants experienced a time frame, greater than forty-eight hours from noticing their first symptoms until treatment. More importantly, were the 54 % (n=14), who experienced a time period of one year or greater. Previous studies have shown that protracted timeframes in untreated AF that went beyond periods ranging from as little as five hours (Glotzer et al., 2009) to twenty-four hours (Van Gelder et al., 2017), conferred an estimated five-fold increase in the risk of stroke (Manning & Singer, 2018). Furthermore, patients with AF have a two-fold risk for dementia, a three-fold risk for HF, and an overall increase in the risk of mortality ranging between forty to ninety percent (Benjamin et al. 2009; Camm et al. 2012; January et al. 2014). The findings of this study begin to address the gap in understanding why patients with AF symptoms may experience prolonged delays in health care seeking and diagnosis.

One of this study’s key findings during the perceptual period, was participants’ experiences of partial awareness, of sensing something ‘but nothing really’. In this period, participants
experienced vague symptoms outside of their immediate awareness, which were not fully perceived until they reflected back - days, weeks or even several years into the pre-diagnosis period. Wyke and associates (2013) elaborated the process of developing symptom awareness, suggesting that certain aspects of symptom perception happen at an ‘unconscious’ level and may not be fully realized, until viewed retrospectively. This was true of participants in the current study who considered themselves asymptomatic in the pre-diagnostic period, but who reported having experienced a range of symptoms when they re-examined this time period retrospectively. Similarly, previous studies have reported an asymptomatic, pre-diagnosis period that may not have been symptom free, but which was characterized by subliminal symptoms (Koldjeski et al. 2004).

This pre-perceptual/unconscious awareness is difficult to access using models of symptom experience. The SEM in AF, is one of the few models that draws attention to perception within the symptom experience. Other models, including the SMM model (the basis for the SEM in AF) only address events that happen after the point in time when full awareness or recognition of the symptoms occurs (Koldjeski, Kirkpatrick, Everett, Brown, and Swanson, 2004). It is important that this pre-perception period be considered in models describing the symptom experience, as the development of awareness often occurs over time, as bits of information are acquired (Koldjeski et al. 2004). Activity and rest were found to heighten pre-clinical symptom awareness (e.g., palpitations, heart fluttering, skipping or jumping), in almost three-quarters of the participants (n=17) and may help to illuminate this critically important period of the symptom experience.

Symptom evaluation was also challenging for participants, and they found it difficult to determine whether their symptoms warranted treatment from a HCP. The self-limiting/intermittent nature of their symptoms, as well as the complexity associated with multiple and interacting symptoms, challenged participants in the evaluation process, and was associated with protracted health care seeking time frames. Other studies have examined the role of intermittent symptoms in prolonging the evaluation process. Several, specific to AF and cardiac populations (Devon et al., 2010; Hwang & Jeong, 2012; McCabe et al., 2016b; O'Donnell et al., 2014), showed that sporadic
symptoms created a false sense of security that symptoms were insignificant. Evans and associates (2014) found that self-limiting, or symptoms that come and go, gave patients with cancer ‘false hope’ that their symptoms were not concerning and, consequently, did not need the formal response of health care seeking. Leventhal and associate’s (1992) Common Sense Model of Self-Regulation is one of the few symptom models to address the temporal aspects of symptoms, and whether they are intermittent or chronic in nature. They note that temporal features are one aspect of a feedback loop that assists individuals in appraising and evaluating symptoms in order to respond to, and cope with them. Similarly, in the current study, the participants’ evaluation of temporal symptoms validated their theory that there was ‘nothing to be concerned about’, and reinforced their decision to ‘wait and watch.’

Lastly, study findings indicated participants’ use of several cognitive processes to evaluate their symptoms. Participants engaged in advanced and complex cognitive processes in seeking to explain their symptoms. Speculating, forming theories, and finding evidence to support (or refute) their theories (e.g., testing, symptom comparison with others) are consistent with higher order thinking (Bloom, 1956). It was not unusual for this significant cognitive processing to extend over time as participants generated and cycled multiple theories, until a reasonable explanation for symptom causation was obtained. Cognitive processes have been described previously in the literature in conjunction with illness behaviour (Leventhal et al., 1992) and specific to symptoms and health seeking in patients with cancer (Petersen et al., 2011; Koldjeski et al., 2004) but not to the depth and breadth as current findings. For example, cognitive attention to symptom attributes (e.g., location, timeline, extent, and cause) (Leventhal and associates, 1992), the use of comparisons to evaluate symptoms (Petersen et al., 2011), and the processing of symptom information (forming labels appraising threats, and considering possible outcomes) (Koldjeski et al., 2004) have been described but a broad and inclusive approach to detailing the various ways in which individuals cognitively evaluate their symptoms has been lacking.
5.3. Age and the Symptom Experience

In the present study, symptom perception, evaluation, and response differed between younger and older AF patients. Compared to older participants (≥ 68), younger participants (≤ 67) reported more severe and frequent symptoms, such as chest pain and dizziness. However, younger study participants also perceived more frequent weakness, lethargy, and fatigue, non-specific symptoms that older adults typically experience (Reynolds et al., 2006). Reynolds found that older adults with AF (≥ 65) were more likely to experience dyspnea (p = 0.02) and fatigue (p = 0.03), whereas their younger counterparts (≤ 64) were more likely to experience dizziness (p = 0.05) and palpitations (p < 0.01). Additionally, older adults with AF are often less symptomatic than non-seniors, and face more daily variation in their symptoms’ intensity, duration and frequency (Hickey et al., 2013). The decreased severity of specific symptoms in the older population has been explained by the differences in activity between younger and older individuals. Reynolds et al. (2006) suggested that younger, more active patients may find AF significantly more disruptive than older patients, particularly those older adults who were prone to additional health problems. Younger participants in the current study similarly experienced symptoms that disrupted their work to the point of having to change jobs. Lastly, older adults have lower expectations for health; they minimize the impact of illness and evaluate the overall severity of their symptoms, based upon the impact those symptoms have on their ability to perform the activities of daily living (Elias & Lowton, 2014; Garimella et al., 2015). Regardless of the reason, the current findings add support to the existing literature, wherein older adults reported less severe and less frequent AF symptoms than their younger counterparts.

Older and younger participants differed in their theorising of symptoms as ‘age-related’. Older participants attributed their symptoms to aging and the natural course of their ‘bodies breaking down,’ which contributed to their overall lack of concern about their symptoms, compared to the younger participants. Several other studies have also described differences in the acceptance and evaluation of symptoms, by age (Chew-Graham et al., 2012; Gjørup et al., 1987; Lefler & Bondy,
Furthermore, older adults, who experienced vague symptoms, such as tiredness, lethargy, and a depressed mood, more often associated these symptoms with the aging process (Elias & Lowton, 2014). In their study, specific to arrhythmias, Dracup and Moser (1997) found that older patients had trouble differentiating their irregular pulse from overlapping symptom(s) of another chronic illness. Furthermore, they reported that older adults with AF often suffered from ‘vague’ symptoms and were more likely to attribute those symptoms to aging, when compared with their younger counterparts. Therefore, the present study’s findings further validated the extant literature concerning the experience of older participants with AF, and identified some of the challenges that older adults had in separating their AF symptoms from ‘normal’ aging during the pre-diagnosis period.

During the pre-diagnosis period, this study found differences in symptom response between younger and older participants. Younger participants (≤ 67) tended to choose more non-treatment approaches to dealing with their symptoms than their older counterparts did. Hopeful that their symptoms would simply go away, many younger participants adopted a wait and watch approach that they had used historically to deal with minor illnesses (e.g., colds, bumps, and bruises). This might reflect the younger participants’ more limited experience with illness and coping. However, it is more likely, and consistent with symptom theory (SEM, Leventhal), that their avoidant behaviour reflected the mental schemas they formed in childhood, in response to minor symptoms that had persisted over time and that were not challenged. O’Neill & Morrow (2001) found that older adults were more likely to confront their chronic illness with active coping, than younger adults. However, even though it has been well documented that older adults perceive, evaluate and respond to symptoms differently than younger adults (Hickey et al., 2013), the present study is the first specific AF study, to report that younger people may be more likely to ignore or internalize their symptoms rather than share what they are experiencing with others.

Younger participants perceived greater difficulty in obtaining adequate diagnostic testing. They experienced repeated normal diagnostic results following symptomatic episodes. However,
despite these challenges, there were no differences in the time from the first reported symptoms until diagnosis, between the younger and older age groups. Nonetheless, this study did highlight the younger participants’ perception of being disadvantaged due to the difficulty in obtaining diagnostic testing for their symptoms. It also demonstrated that they had difficulty in obtaining a diagnosis from their HCP, possibly because of their (younger) age. Another possible explanation is the 1% prevalence of AF in younger adults may contribute to physicians’ being less vigilant when assessing younger patients (Sankaranarayanan et al., 2012).

The one other study that has explored the decision-making process in the pre-diagnosis period of AF did not find an association between age and the pre-diagnosis time frame (McCabe et al., 2016a). However, the existing body of cardiac literature concerning MI/ACS patients does indicate that older adults prolong treatment seeking, compared to their younger counterparts; although there is no indication that their lengthened pre-diagnosis time is associated with difficulty in obtaining adequate diagnostic testing (Moser et al., 2006). Therefore, the present study offered a new insight into the experience of younger participants within the pre-diagnosis period of AF and, specifically, the challenges that younger adults encounter in obtaining a definitive diagnosis, when presenting with the vague, non-specific symptoms often associated with AF.

5.4. Gender and the Symptom Experience

There were some clear differences between men and women in the variability of symptoms (perception), their awareness and familiarity with AF symptoms, their theorising (evaluation), and responses. Each of these differences will be explored in detail in the following section.

5.4.1. Variations in Symptoms

One of the key differences noted between men’s and women’s experiences of their AF symptoms prior to diagnosis, was that women reported a wider range of, and more severe, symptoms. The severity with which women experienced their symptoms was evident, not only in their reported symptoms and SCL scores, but also in the language they used to describe their symptoms. Women
used strong descriptive language such as ‘pounding’ or ‘heavy’ to describe the feeling of their heartbeat, whereas men were more likely to use words such as ‘racing’ or ‘palpitations’. The greater severity and range of symptoms is also evident in the extant literature, which describes how women experience more palpitations and skipped heart beats (Dagres et al., 2007; McCabe et al., 2016, 2017; Potpara et al., 2012); more fatigue (Potpara et al., 2012); chest pain (Dagres et al., 2007; Potpara et al., 2012); and dyspnea (Dagres et al., 2007).

The existing literature provides evidence of several biological/sex differences between men and women, which may partly account for the increased severity and frequency with which women experienced pre-diagnosis symptoms. For example, women have a higher prevalence of thyroid dysfunction and hormone fluctuations, when compared with men (e.g., post-menopausal women) (Blum et al., 2017). Thyroid dysfunction can lead to symptoms such as palpitations, SOB and angina, and the development of AF and heart failure. Similarly, the hormone fluctuations which occur during menopause can also precipitate palpitations. Women also have an increased resting and maximum pulse rate, which can lead to even higher rates during arrhythmic events (Blum et al., 2017). Therefore, women with AF are more susceptible to reaching rates where the heart can no longer effectively pump blood, because of a shortened diastolic filling period. Women also have decreased vagal tone, which limits their ability to constrict blood vessels during periods of hypotension; this, in addition to the decreased cardiac output associated with the rapid heart rate, may further exacerbate their symptoms. Consistent with these findings from the literature, the present study found that only female participants experienced GI symptoms. It is well documented that a sudden drop in blood pressure, in association with a cardiovascular condition such as AF, can precipitate the onset of GI symptoms such as nausea and vomiting (Fuller, Alemu, Harper & Feldman, 2009). Therefore, these GI symptoms probably represented a drastic change in cardiac output and provide further evidence of the increased severity with which women experience symptoms in the pre-diagnosis period of AF.

Research that has explored gender and the perception of symptoms offered some additional insights into why women experienced a wider range of, and more severe, symptoms in the present
study. According to O’Neill and Morrow (2001), women are taught (or socialized) to be more attuned to their bodily symptoms than men. Additionally, the increased symptom severity in women is often a reflection of the socio-cultural values, which make it more acceptable for women to feel and express their body symptoms (O’Neill et al., 2001). However, it is interesting that even though women reported greater severity of symptoms within the SCL and throughout the interviews, they also tended to justify their decisions to forgo treatment seeking because of other more pressing priorities. Clarke and Bennett (2013) argued that many women are viewed as the gatekeepers of the family, attending to the needs of others at the expense of their own health. Thus, women underestimate, or even ignore, their symptoms, as it is the ‘right’ or appropriate thing to do as a woman, or caregiver, within the household (Clarke & Bennett, 2013). Lastly, reflecting cultural, and generational discourses about appropriate responses to illness, Sinding and Wiernikowski (2008) found that women more than men, choose to not dwell on their physical problems, but instead keep busy and maintain a positive outlook irrespective of their bodily suffering.

It is probable that, in this study, the protracted health care seeking time reflected cultural gender norms. Irrespective of the reason for prolonging health care seeking, the present findings suggest that women’s symptom experiences in the pre-diagnosis period are characterized by more severe and a wider range of total symptoms.

5.4.2. Knowledge Expectations and Risk Perceptions

The present study provided evidence that an individual’s knowledge of AF may influence their perceptions of their symptoms, the associated theories they form and the subsequent response(s). Women, in particular, were deficient in knowledge to evaluate their symptoms, with nearly three times as many women as men stating that they were unfamiliar with AF before their diagnosis. This disparity in AF knowledge intersected with their expectations of being healthy and their overall risk perceptions. Women described not having a basis of information with which they could accurately evaluate their symptoms. Therefore, many women presumed their symptoms were of ‘little concern’
or ‘nothing to worry about’, and subsequently evaluated them as having a low priority or risk to their health. Additionally, knowledge appeared to be an integral part of the decision making associated with an early or expedited diagnosis. Eleven of the twelve participants, who identified themselves as having limited knowledge to be able to assess their symptoms belonged to the LDG; of these eleven participants, eight of them were women. In another study (Moser et al., 2006), women continued to hold onto the mistaken belief that cardiac symptoms and events primarily affect men; this belief may have led to a decrease in their motivation to acquire knowledge and awareness of cardiac symptoms. Lastly, existing literature corroborates the findings from the present study, suggesting that a lack of knowledge or awareness about AF and its symptoms may lead to misattribution/misinterpretation of AF symptoms (McCabe et al., 2015, 2016a; Thrysoee et al., 2017).

Although women described inadequate knowledge to be able to evaluate their AF symptoms, they had higher educational levels compared to men. Women reported more challenges in evaluating their AF symptoms as a threat that required further evaluation from a HCP. This suggests that education alone may not influence participants’ understanding of AF, but rather decision making relies on a host of other factors, such as the nature of the symptoms, age, gender cultural norms and self-determination of cardiac risk. In contrast to the present study, two studies (Frewen et al., 2013; Goli et al., 2012) found a positive association between knowledge of AF and the accurate evaluation of AF symptoms. Specifically, these researchers found that individuals with lower levels of education were less likely to be aware of their symptoms, were less likely to rate their symptoms as serious or related to their heart, and this resulted in less effective coping responses. Furthermore, a recent study (n=6324), found that AF awareness worldwide differed by gender, with women more aware (52%) than men (43%) (Wendelboe et al., 2018). These studies further support the argument that AF health care seeking is a complex process, and education or knowledge alone may not lead to early health care seeking.

Among the challenges that women faced in evaluating their symptoms, the present study found that more women than men experienced symptoms from pre-existing conditions which
complicated their evaluation process. These comorbid symptoms, which often occurred in parallel with their AF symptoms, appeared to alter their overall expectations. Expectations were defined as the belief(s) pertaining to that which is most likely or expected to happen (Dolovich et al., 2008), and were evident in the theories they created to account for their symptom(s). More often than men, women in the current study expected their symptoms were part of a pre-existing condition (six women versus two men), rather than an indication of any new illness. Therefore, because these participants expected that their symptoms would react to the usual treatments, they responded with treatments which had been previously effective, such as increasing their breathing medications, exercising or changing their diet. Evidence has shown that women with cardiovascular symptoms often experience atypical symptoms that are attributed to other comorbid conditions that can confound symptom evaluation (Gallagher et al., 2010) and which can contribute to the generation of alternative theories to explain their symptoms. Additionally, other studies, although not gender specific, also describe the influence of previous illness experience on AF symptom evaluation (McCabe et al., 2011; McCabe et al., 2015). Previous experience with a non-serious condition increased the likelihood of an individual’s attributing their AF symptoms to other non-threatening causes (McCabe et al., 2015). Consequently, these expectations associated with their previous illness experience may have extended the periods of self-treatment, or waiting and watching, and protracted the pre-diagnosis time frame.

Lastly, perceived risk was another important evaluative component where gender differences were observed. Thirty-eight percent of the younger women in the current study described feeling immune to cardiovascular illness, while men unanimously saw themselves as having at least some cardiovascular risk factors. These younger women considered themselves very healthy and worked hard to maintain their health, never considering the possibility of illness and assuming that cardiac disease was unlikely to occur in younger women. Similar findings have been reported in MI research (Davis et al., 2013; Leifheit-Limson et al., 2015). Following a study of mass media campaigns and education, women were more likely to experience MI symptoms that did not match their perceived
low risk for heart disease, when compared to men. Women’s lowered expectations of cardiovascular disease are thought to be deeply rooted in the genderization of heart disease as primarily a man’s disease (Emslie & Hunt, 2009; King & Arthur, 2003).

5.4.3. Lean on Me - Men’s Reliance on Women during the Pre-diagnosis period

Women and men differed in their reliance on partners for symptom evaluation/response. Men showed a greater tendency to rely on their partners, following symptom onset, while women concealed their symptoms from their partners. Even when women reached out to their partners they were met with ambivalence and an overall lack of concern. Men’s lack of concern towards their partners’ symptoms may reflect their own masculine views on health; which include enduring through symptoms, being stoic and self-sufficient, and viewing health seeking as ‘weakness’ (Emslie & Hunt, 2009; White, 1999; White & Johnson, 2000). Furthermore, it is possible that men perceived a lower likelihood of women experiencing MI or AF or any other heart related illness. In contrast more men described their spouses as actively urging a serious approach to their symptoms, again reflecting the nurturing gender role of women and the expectation that men are more likely to have heart disease.

The influence of partners on men’s health seeking in this study runs counter to men’s socialization to a masculine identity. Men have been socialized to be in control, physically able and self-sufficient; to not live a ‘healthy’ lifestyle is a way to be ‘masculine’ (Bottorff, Oliffe, Robinson, & Carey, 2011; Emslie & Hunt, 2009) as is displaying courage and endurance in the face of illness (Alcaras & Roper, 2006). In the current study, the inconsistency in following this tendency, of the ‘masculine’ man’s being self-sufficient, and their showing dependence on their female partners for health care seeking may be explained in a number of ways. It may reflect women’s traditional health gatekeeping role, wherein wives attend to family health and are more active in urging or directing their husbands to seek treatment (Bottorff et al., 2011, Clarke & Bennett, 2013). King and Arthur (2003) called this tendency in women to support their family above their own health needs, ‘othering’, and suggested that some women may value the health or well-being of others over their
own. It may also represent men’s shifting responsibility for initiating health care seeking to assuage guilt; thus, maintaining their ‘non-healthy’ lifestyle as a way to be ‘masculine’ while allowing their partners to decide on the needed treatment (Emslie & Hunt, 2009; Schoenberg et al., 2003). Finally, a gender-based theory regarding lay person consultation provides another possible explanation for why men turned to their partners more readily than women did (Schoenberg et al., 2003). Men often have a smaller support network outside of the family and, therefore, turn to their spouse following the onset of illness - whereas women routinely consult other friends or a wider support network, rather than their own husbands, in the face of illness (King & Arthur, 2003; Schoenberg et al., 2003).

Similar findings have been shown in other cardiac literature, demonstrating the reliance that some men have on their partners during the evaluation of, and response to, their symptoms (Noureddine et al., 2010; O’Brien et al., 2005). Men’s reliance on women, to aid in their evaluation and response, is indeed an important finding and suggests that men’s consultations with their partners may influence early health care seeking following the onset of perceptible AF symptoms.

5.5. EDG versus LDG

The study’s findings revealed that patients with AF assumed two patterns of time to AF diagnosis: early and late, the early associated with a quick, timely diagnosis (EDG) in less than forty-eight hours after the onset of first symptoms while the late were those who experienced periods of greater than forty-eight hours (LDG). The time to diagnosis was associated with differences in symptom perceptions, evaluations and responses.

5.5.1. Different Perceptions

Beginning with perception, the EDG and the LDG differed in the type and severity of symptoms they perceived in the pre-diagnosis period. As expected, those in the LDG described experiencing symptoms which were not readily perceptible. After looking at this time period retrospectively, the study’s participants described a gradual onset of ‘vague’ symptoms or atypical cardiac symptoms, such as nausea, vomiting and diarrhea, activity intolerance, oedema and
headaches. Additionally, the LDG self-reported more non-specific symptoms, on the SCL, such as tiredness, SOB, difficulty in catching breath with exertion, and difficulty sleeping. These vague or non-specific symptoms proved to be challenging for those in the LDG to perceive, readily, as a serious symptom warranting an urgent evaluation and a health seeking response. Similarly, McCabe and associates (2016a) found that symptoms, such as fatigue, dyspnea and a rapid heartbeat were associated with a delayed diagnosis.

Consistent with previous AF research, early treatment seeking was influenced by symptom characteristics (McCabe et al., 2016a; 2016b). Symptoms that negatively influenced overall cognitive ability to perform work (e.g., lack of mental sharpness, attentiveness or concentration), were more prevalent in the EDG, suggesting a relationship between cognitive symptoms and early treatment seeking. The presence of cognitive symptoms during periods of AF has been previously documented, although the exact mechanisms remain unknown (Elias & Lowton, 2014; Gross & Stern, 2013). The heightened societal attention given to cognitive impairment may have contributed to participants in the EDGs perceiving their symptoms as a greater health threat and influenced their care seeking (Hsia et al., 2011). Conversely, those in the LDG experienced vague symptoms, which were perceived as more benign and did not evoke the same response. Timing of the symptoms and the surrounding circumstances appeared to enhance symptom perception. More participants in the EDG reported night awakenings and interruptions. As previously noted, participants described more awareness and urgency in their evaluation of, and response to, symptoms that occurred during rest. Therefore, the current study highlights the importance of activity level - namely rest on the ability of individuals to recognize and become aware of their symptoms as an indicator of disease or dysfunction in their body.
5.5.2. Aspects of Evaluation in an Early or Late Diagnosis

Several aspects of the evaluation process may have influenced the time from first symptoms until diagnosis. One of the most significant reasons that emerged for prolonging the evaluation period and deferring health care seeking was the extent to which participants theorized that their symptoms were associated with other non-illness or comorbid conditions. It was common for participants in the LDG to hold firmly to their theories. Substantially more participants (thirteen compared to one) in the LDG theorized that their symptoms were a normal process of aging (e.g., declining energy and exercise intolerance) were related to other non-illness conditions such as stress (nine compared to none) or to a theory of ‘nothing,’ which was devoid of any illness or real explanation (fourteen compared to one). For those in the LDG, theorising that their AF symptoms were related to other conditions clearly lengthened the evaluation and pre-diagnosis time frame. These findings are consistent with the existing literature, which indicates that during the evaluation period, AF patients commonly attribute their symptoms to: stress (Deaton et al., 2003; McCabe, 2009; McCabe et al., 2011, McCabe et al., 2015); age (Deaton et al., 2003, McCabe, 2009; McCabe et al., 2011; Verma et al., 2014); comorbid conditions (Deaton et al., 2003; McCabe et al., 2011; McCabe et al., 2015; McCabe et al., 2017); diet (McCabe et al., 2011); and physical deconditioning (McCabe et al., 2015).

The second factor which appeared to influence the overall pre-diagnosis time was whether individuals evaluated or judged their symptoms as concerning or not. For example, the evaluation of symptoms as benign, innocuous or of little concern, was much more prevalent among those in the LDG (n=14) versus those in the EDG (n=1). This apathy or lack of concern about their symptoms may have reflected the intermittency of their AF symptoms. This symptom pattern might have given participants the false hope that their symptoms were inconsequential and ‘nothing to be concerned about’, thus reinforcing a ‘wait and watch’ response (Evans et al., 2014). Unrealistic optimism (Sheperd, Klein, Waters & Weinstein, 2013), or an individual’s bias towards favourable outcomes, or the notion that the future will be better than that which is possible (Sheperd et al., 2013) may also
have played a role. Such optimism may have reduced the perceived threat of harm and promoted increased comfort with a non-treatment or a “wait and see” approach.

An overall lack of concern of the LDG towards their symptoms and a generalized sense of apathy endured, despite symptoms which participants described as being heart-related. This finding is contrary to the priority Western society gives to cardiac symptoms (Ratner et al., 2006). McCabe and associates (2016b) explored the pre-diagnostic evaluation of symptoms and found that 46 % of patients (n=60) evaluated their symptoms as serious, 31 % were unsure about the serious health threat, 16% were unconcerned, and 7% saw them as life-threatening. Likewise, research into patients suffering from MIs has found a wide range of evaluations associated with cardiovascular symptoms, from those who were very concerned, to those who assessed their symptoms as a non-threat (DeVon et al., 2010, Hwang & Jeong, 2012; King & McGuire, 2007; O’Donnell et al., 2014). Together, these findings suggest that individuals frequently assess their cardiovascular symptoms, including those associated with AF, as minimally concerning, and this lack of concern is associated with a prolonged pre-diagnosis time period.

Another important component which appeared to influence the total pre-diagnosis time, was the participants’ past experiences with illness and their views on health. First, and particularly for participants in the LDG, experience with comorbid conditions confounded their ability to differentiate the symptoms of AF, from their previously experienced symptoms. More specifically, experience with generalized illnesses, such as COPD or hypertension was more prevalent in the LDG, whereas those in the EDG had more experience with previous cardiovascular illnesses, such as MI. For this reason, it appears likely that personal experience with cardiac disease precipitated a more serious evaluation and led to expedited treatment seeking. Surprisingly, in the LDG, an awareness of a family history of cardiovascular disease did not translate into more concerned judgments during the evaluation period. To date, there has been limited research that addresses individual decision-making following the onset of AF symptoms, or how illness experience influences evaluation. However, some older studies, on MI patients, demonstrated mixed results with some reporting a relationship
between previous illness experience with a MI and the severity with which subsequent symptoms were rated, and an overall reduced time between the symptoms’ onset and treatment seeking (Jemmott, Ditto, & Croyle, 1988; Petrie & Weinman, 1997). Conversely, other studies have reported that previous illness experience had little to no effect on the overall symptom evaluation, and may even have led to a longer evaluation time (Moser et al., 2006). Although not a direct relationship, the current study suggested that personal experience with cardiovascular disease promotes early treatment seeking (< forty-eight hours), whereas chronic health conditions, vague non-specific symptoms and intermittent symptoms can prolong health care seeking.

Lastly, findings from the current study corroborated existing symptom research (Evans, Chapple, Salisbury, Corrie, & Ziebland, 2014), which suggested several possible events or factors which could disrupt the usual apathetic response to AF symptom, and which were observed mainly in the LDG, leading to health care seeking. For example, participants in the current study reported that repeated exposure to, or increased frequency of the symptoms, as well as the severity and context in which the symptoms occurred propelled them towards health care seeking. Furthermore, different types of symptoms in addition to their initial symptoms also promoted health care seeking. Similarly, Evans and associates reported that avoidance behaviour was likely to be broken when a pattern of symptoms became apparent, when there was an increased frequency in symptom episodes, a change in the nature of symptoms, or the occurrence of additional symptom(s). For this reason, findings from the present study advance the knowledge concerning the factors which can disrupt the pattern of avoidance, as it concerns health care seeking in AF.

5.5.3. The Spectrum of Responses among those in the EDG versus the LDG

Another remarkable difference between the EDG and the LDG was the tendency of LDG participants to respond to their symptoms by choosing non-treatment, for periods ranging from two weeks to several years prior to their diagnosis. Nearly all of the participants (n=18, or 90%) in the LDG described employing a non-treatment approach (such as waiting and watching, or hoping their
symptoms would go away), for various lengths of time prior to health seeking, compared to only one third (n=2) of those in the EDG. The LDG’s propensity to respond by essentially ignoring their symptoms, in the pre-diagnosis period, mirrored the earlier work of McCabe and associates (2016a). McCabe found that 91% of participants in their ‘delay’ group responded by waiting, watching and hoping their symptoms would self-resolve, compared to only 9% of the ‘non-delay’ group. Deaton et al. (2003) also reported that non-treatment was common among AF patients, although their study was not specific to the pre-diagnosis period. Several ACS/MI studies have also observed patients’ use of non-treatment approaches, wherein individuals avoided seeking treatment and perceived their symptoms were not serious enough, or they decided to wait and see what happened (Moser et al., 2006).

A second notable aspect of the late group was their pattern of self-treatment, prior to obtaining a diagnosis from their HCP. Some of these self-treatments were very minimal, such as deep breathing and coughing, whereas other treatments involved significant life style modifications, such as changing jobs and limiting daily activities, in order to minimize the effect of their symptoms on their QOL. One of the most profound differences, between the EDG and the LDG, was the number of participants in the LDG who described simply stopping, resting or lying down when they experienced symptoms (twelve compared to none). Conversely, those in the EDG described almost no self-treatments, prior to their diagnosis. Gender also intersected with the treatment choices of those in the LDG, with more women implementing self-treatment strategies, such as lying down and resting. In fact, the need to ‘lie down’ in response to their symptoms was another indicator of the severity of the AF symptoms that the women experienced. Consequently, on average, women experienced a longer total pre-diagnosis time, with 77% of women experiencing a one-year or greater pre-diagnosis time, in comparison to only 38% of the men.

It remains unclear why so many participants of the study chose self-treatment, in spite of their often-significant cardiac symptoms. Furthermore, it is unclear why more women continued with self-treatment activities, and endured a longer pre-diagnostic time, despite their severe symptoms, such as
dizziness and syncope. Data from a meta-analysis that explored the symptom experiences of women with illness offer some insights into this (O’Neill & Morrow, 2001). O’Neill & Morrow (2001) found that women responded to frightening symptoms, such as chest pain, with more avoidance-type coping strategies. Additionally, the extant literature on ACS patients found that the factors behind women’s propensity to initiate self-treatment activities were two-fold: first they felt it was a way to maintain control and, second, it stemmed from a perception of the low risks associated with cardiovascular disease among women (Dempsey, Dracup & Moser, 1995). No previous study has reported on gender differences in the self-management of AF symptoms prior to diagnosis. That said, the current findings are in line with other studies where participants who engaged in self-management strategies also experienced a longer pre-diagnosis time period (McCabe et al., 2016a).

The final response explored was health care seeking. The importance of early treatment seeking and early AF diagnosis cannot be overstated, given the severe risk of stroke and heart failure, and in addition, the many other serious health outcomes, such as dementia, emboli and decreased quality of life (Benjamin et al. 2009; Camm et al. 2012; January et al. 2014; Manning & Singer, 2018). Participants in the current study argued that they were not solely responsible for the extended pre-diagnosis period, and that some of the responsibility lay with the HCP. A remarkable seventy percent of the LDG reported that they sought care from HCPs following the onset of their symptoms; but, initially, they were unable to obtain definitive answers and/or treatment for their symptoms. Primary care physicians often dismissed AF symptoms, a trend observed in other recent AF literature (McCabe et al., 2015; McCabe et al., 2016a; Withers et al., 2015). Furthermore, the existing literature describes how women with AF received less aggressive treatment in terms of rate control and symptom management, even though on average, they suffered more severe and more frequent symptoms (Tsadok et al., 2015; Blum et al., 2017; Piccini et al., 2016; Schnabel et al., 2017). The present study found that more women, than men, experienced HCP dismissal of their symptoms. They were met with statements such as ‘You’re fine’ or ‘Don’t worry about it’ when they sought treatment for their symptoms. Despite having reported more frequent and more severe symptoms than
men, a large percentage of the women felt they were dismissed when they brought their symptoms forward. Gender inequity has been previously documented, in relation to post-diagnosis AF care, with women reporting a lower QOL and more severe symptoms, whilst being undertreated in terms of rate control, anticoagulation and electro-cardioversion (Blum et al., 2017; Potpara et al., 2012; Yarnoz & Curtis, 2008). Another study explored the experiences of women, in the pre-diagnosis period and found similar results. Deaton and associates (2003) found that all of the women in their study (n=3) reported that they were not taken seriously by their HCP; but, instead, their symptoms were dismissed and/or attributed to either menopause or stress.

In summary, the current study highlighted three important points regarding the responses of the participants in the EDG versus those in the LDG. First, the findings suggest that women with AF symptoms engage in self-management to a greater degree than men do, even while experiencing more severe symptoms. Secondly, there is a possibility that the difference in pre-diagnostic times may, in part, be associated with women’s propensity to engage in self-treatment strategies, in lieu of health care seeking. Third, the current research suggests that those who engage in self-treatment strategies, prior to health care seeking, experience longer pre-diagnosis times.
Chapter 6: Implications, Limitations and Conclusions

How individuals perceive, evaluate and respond to their symptoms in the pre-diagnosis period of AF is an immensely complex process, with multiple interconnecting factors. In the current study, age, gender, sex, previous illness experience, education and context influenced every aspect of the symptom experience. Most importantly, the current study identified significant gaps in participants’ awareness of their AF symptoms, as well as their ability to evaluate and respond to their symptoms in a timely manner. Gender and age differences in the symptom experience, as well as the under-reporting of symptoms and an extended pre-diagnosis period, all have implications for practice, education, and research. Each of these implications will be discussed in the following paragraphs.

6.1. Implications for Practice

The findings suggest a number of implications for practice. First, there is a need for more effective screening and early detection of AF or AF symptoms, especially given the numbers of individuals who experienced symptoms for protracted periods. Second, there are implications for how clinicians approach the health assessments they make of older adults and women; those most at risk of having a protracted AF pre-diagnosis time frame. Each of these practice implications is now discussed.

Several ongoing screening strategies are being implemented for the general public, in order to identify those patients who are living with untreated AF (Freedman et al., 2017; Taggar & Coleman, 2016). They include random pulse checks in the clinic/community or electronic screening, using hand-held devices (Freedman et al., 2017). Although these initiatives have shown promising results in detecting new cases of AF, larger national level randomized trials are needed, prior to implementing concerted screening efforts (Freedman et al., 2017). Furthermore, these screening strategies may be ineffective at detecting AF in patients with symptoms and pulse or heart rhythm abnormalities that are sporadic, unpredictable and often infrequent. Consequently, relying solely on the current screening
approaches may still delay diagnosis and treatment, subjecting patients with AF to a greater risk of negative health outcomes.

Second, there are practice implications for health assessments in a clinical setting. Using a generic approach to symptom assessment may lead HCPs to dismiss the significance of symptoms prematurely, for men and women across the age spectrum. Normally, HCPs assess symptoms according to typical characteristics, such as frequency, intensity, and duration. However, the highly individualized variations in symptom patterns according to age and gender, observed in the current study, point to a need for gender and age-specific symptom assessments.

The results of the present study suggest that integrating several screening and health assessments into current practice, may increase the likelihood that individuals living with untreated AF will receive a timelier diagnosis. First, given the diagnostic challenges presented by paroxysmal AF (intermittent AF), it may be advantageous to teach patients how to assess their own pulse using a manual radial technique. This practice may increase the likelihood of individuals detecting and reporting pulse irregularities to their HCP. Second, as many older adults have access to automatic blood pressure machines for home monitoring, or frequently access blood pressure machines in pharmacies, more could be done to educate patients on the importance of reporting resting heart rates that are irregular, or greater than 100 beats per minute. Third, the current findings suggest several ways in which health assessments could be more effective at detecting new cases of AF. In addition to pulse checks, health assessments for those at risk of AF could include key questions, which improve patients’ own symptom recognition. For example, specific questions which target situations of heightened symptom awareness, such as at rest or during activity, could be routinely included in assessments, particularly for older adults. Examples of these types of specific questions might include, “Do you feel your heart racing, pounding or jumping at rest, during periods of stillness (e.g., while falling asleep)?”, and “Do you notice any changes in your ability to catch your breath during activity (e.g., walking or running)?” Drawing attention to specific points in time of heightened symptom awareness may help patients recognize that their symptoms are not ‘normal’. This in turn
could lead to patients reporting these experiences, and the HCP initiating further testing to determine if AF is the cause. Fourth, health assessments could also target how awareness of symptoms is evoked through bodily senses such as seeing, feeling or hearing. Asking questions in relation to these senses, such as have you heard or seen your heart pounding, could increase the recall of symptoms which might otherwise go unnoticed.

Another important finding, which has implications for practice, was the individualized theories that participants devised to minimize the importance of their symptoms during the evaluation. Practitioners who are cognizant of some of these common theories, such as ‘it is nothing really’, or ‘I’m just getting older,’ ‘I must be stressed or anxious,’ or ‘it is just my chronic health challenges’, could recognize and respond appropriately. For example, during a health assessment, if the patient indicates they have experienced/are experiencing symptoms which they associate with the aforementioned theories, an astute health care provider could initiate more probing questions or a more in-depth health assessment, to investigate the symptoms further.

The current findings suggest that health assessments and screening efforts might be ‘tailored’ for men and for women. First, women experienced greater variability in the nature and type of symptoms, such as GI symptoms (sudden onset of nausea vomiting), respiratory-based symptoms, or generalized fatigue. Women also used different language to describe their dysrhythmias, such as pounding and heavy, whereas men more often described their pulse as racing or said they had palpitations. For these reasons, screening practices could reflect gender differences, by adapting screening questions and or assessment tools to include the different language that men and women use to describe their symptoms. Additionally, screening tools should be more inclusive of the varied symptoms that men and women experienced in the pre-diagnosis period. A more in-depth discussion of possible adaptations to screening tools will follow in the section on implications for research.

Another important gender-specific implication is the need for clinicians to pay serious attention to women’s symptoms, in light of their greater tendency to keep symptoms to themselves, as
well as women’s non-recognition of the significance of their symptoms. Informed vigilance, from HCPs, could expedite the early detection of AF when women present with symptoms.

Lastly, assessments should account for the differences observed between older and younger adults. The tendency of older adults to understate (or underestimate) the severity of their AF symptoms and their failure to report subtle or infrequent symptoms, such as SOB, fatigue or activity intolerance, underscored the importance of vigilant assessments within this population group.

The study found a far too common occurrence of patients, who recognized their symptoms and sought health care, but were turned away. Two thirds of the participants in the LDG experienced some form of health care provider delay. The study participants’ struggles to gain support from their physicians, when presenting with symptoms other than pulse irregularity, had a profound impact on the timing of their diagnosis. Health care providers play a vital role in reducing overall pre-diagnostic time. Despite the challenge of confirming AF on an ECG tracing, healthcare practitioners still need to investigate their patients’ reported symptoms thoroughly, through diagnostic testing. Patients who choose to report their symptoms are currently the minority among patients and, therefore, should be taken seriously.

The results of this study point to the importance of developing an HCP checklist for use during health exams and screening, which could guide practitioners towards a more direct or straightforward line of questioning. This in turn may help them identify patients, potentially presenting with AF, who might otherwise go undetected. The incorporation of gender and sex differences in the list of questions would be an important consideration, in the development of this assessment tool.

6.2. Implications for Education

Unlike other cardiovascular conditions, such as myocardial infarction, atrial fibrillation has had limited public/media attention. Without media and professional messages, AF awareness remains largely unknown. Specifically, a recent study (n=6324), found that AF awareness worldwide
remained low at 48%, whereas awareness in Canada was even more alarming at 25% (Wendelboe et al., 2018). Conversely, MI awareness was significantly higher worldwide (74%) and in Canada (78%). The public may lack the required information to evaluate and respond to AF symptoms appropriately (McCabe et al., 2016a). For example, nearly half of the study’s participants (n=12) indicated they had insufficient knowledge of AF to be able to evaluate their symptoms accurately. Existing evidence suggests that, in itself, blanket education of the general public is not effective at reducing treatment seeking time frames in the MI population (Caldwell & Miaskowski, 2000). The current study found that prolonged health seeking often reflected a patient’s misinformation about AF symptoms and treatment. Areas of misinformation included a lack of the perceived risk of negative health consequences, a blunted sense of urgency in responding to AF symptoms, and a tendency to engage in prolonged self-treatment; all of which have implications for education. Thus, specific education which addresses these areas of misinformation, could target seniors and other at-risk patients (history of hypertension, heart failure, coronary artery and valvular heart disease, sleep apnea, obesity, thyroid problems and alcohol abuse) in various locations; such as, community-based cardiac rehab programs, HF clinics, AF clinics, doctors’ offices, senior centres, and pharmacies.

There are several different foci where the education offered to those at risk for developing AF could be enhanced. The education should highlight the many and varied potential symptoms of AF. It should also stress that AF symptoms may not resemble the classic symptoms of a heart attack or a stroke, but nonetheless require urgent treatment seeking to mitigate any serious, negative health outcomes (i.e. stroke, HF). Furthermore, education should emphasize that, even though AF is a heart rhythm disorder, it may occur in the absence of arrhythmic symptoms, such as skipping or racing heartbeats or palpitations, and that other symptoms, such as dyspnoea and/or fatigue, may be the primary presenting symptoms. Additionally, it should be clear that in the absence of any perceived symptoms, the risks associated with untreated AF remain (Chen-Scarabelli, Scarabelli, Ellenbogen, & Halperin, 2015).
Second, AF education should stress the highly irregular pattern with which the symptoms of AF often occur, and confirm the risks associated with all types of AF, whether it is paroxysmal (intermittent), persistent or permanent. AF education should address the risks of self-treatment, a pattern of AF symptom response that was observed in the current study. The elusive nature of AF’s symptoms, and the symptoms’ resolution with strategies, such as deep breathing or rest, often reinforced this pattern of self-treatment. Furthermore, it should be stressed that, based on the current findings, many individuals with AF theorize their symptoms to alternative explanations, such as aging, fitness levels, diet, comorbid conditions and stress. Therefore, patients with symptoms of AF should be encouraged to confirm their individual theories with their HCP, and not to ‘treat’ themselves, without discussing their symptoms with their HCP.

Education should be tailored to address the age differences in the symptom experience. Younger participants were more concerned about, and perceived greater risk for, cardiovascular disease than their older adult counterparts. An important area of emphasis is dispelling age-related myths. The education of younger adults (≤ 67) should be aimed at dispelling myths such as heart disease occurs only with advanced age (Leifheit-Limson et al., 2015), and that symptoms such as breathlessness on exertion or a pounding heart are not normal and could be indicative of AF. Similarly, older adult participants (≥ 68), who recognized their greater risk of heart disease because of aging, still stand to benefit from education that differentiates the normal changes of aging from the symptoms signifying AF, which warrant help seeking.

Finally, a tailored approach to patient education should also focus on the gender components of AF symptom evaluation. Gender specific education should highlight the respective symptom patterns that are specific to men and women, such as women’s experiencing a wider range of symptoms (e.g., GI, respiratory) that are more severe. Second, gender specific education should stress that women more often present with multiple or clustered symptoms, associated with a complex health history (more comorbid conditions). Third, women’s tendency towards more intermittent
symptoms, misleads them into evaluating their symptoms as ‘non-serious’ in nature, which increases their risk of serious consequences (e.g., stroke) from failing to seek care. The present study also identified that women were more independent in their decision making; not discussing their symptoms with their partner, and putting the needs of their family first. Patient education, tailored to women, could iterate that the societal constructs, which position women as the caregivers to others within their family and social circles, should not come at the expense of their own health. More education is needed, across all age groups, about the socialization of gender roles and the impacts of these roles on the maintenance of one’s own health.

It is important that education emphasize, at a broad level, the spectrum of potential symptoms, as well as the intermittency and severity with which these symptoms may occur. Furthermore, education should highlight the complexity of the symptoms experienced across all ages and both sexes. Education must focus on the risks that both men and women face, in relation to developing AF, to assist both men and women in assessing the symptoms of AF with a higher degree of urgency.

6.3. Implications for Research

This study, which was exploratory in nature, provided a starting point from whence future research can be developed, to understand this critical time period in the AF trajectory. There is very little available research concerning the pre-diagnosis period of AF. This research is important as it may serve to facilitate the early identification of AF symptom(s), and lead to the formulation of appropriate strategies to increase awareness of AF symptoms and treatment.

The current study illuminates the tremendous impact that gender and age had on individuals’ perception of, and evaluation and response to their symptoms; however, many unanswered questions remain, which could drive future research. For example, findings from the current study were unclear about the reasons for women’s tendency to continue with self-treatment activities, despite the severity of their symptoms, and the prolongation of their pre-diagnostic time. Further gendered research could
explore this question, identifying the role of avoidance-type coping strategies among women compared to men in the pre-diagnosis period of AF. This research could be used as a basis for supporting women to seek assistance from their HCP, rather than relying on self-treatment. Additionally, research could further investigate how and why AF knowledge differed between men and women in the current study; to ascertain the relationship between knowledge and health care seeking. Furthermore, future inquiry should seek to understand the relationship between gender, culture norms, and health literacy. For example, it was unclear whether women’s inability, or unwillingness, to access health care information for themselves stemmed from the practice of caring for others before themselves, or whether it reflected an actual knowledge deficit. Lastly, the current study identified that women felt more immune to developing AF than men did. This lack of perceived risk in women may have had profound effects on the timeframes of health care seeking, and therefore warrants further investigation.

Men’s reliance on women during the evaluation and response to symptoms is an important finding which could be the basis of future research. An understanding of the reasons for partner-to-partner gender differences related to confiding personal information about their symptoms, is incredibly important and the knowledge could aid in the development of gender-focused interventions to promote early health care seeking. It is vitally important to research gender sensitive ways to support men and women to seek timely care, especially given the evidence of the current literature’s lack of effective guiding strategies to address this need.

Another interesting finding which has implications for future research is the importance of viewing symptoms retrospectively, whereby individuals identify more symptoms that may otherwise have gone unnoticed. It would be advantageous to explore the differences in perceived symptoms within a retrospective and a prospective pre-diagnosis period. A study of this nature would help to clarify how much of participants’ pre-diagnosis symptom experiences were subject to recall biases, whether or not subtle symptoms were perceived more readily retrospectively given the extended time for reflection, and how evaluations of symptoms differed between these two groups.
The perception that HCPs minimized, disregarded or overlooked AF symptoms was highly distressing for patients, and was one which contributed to diagnostic delays with serious repercussions. In order to gain a more balanced view of the issues surrounding HCP delays, further research needs to explore the experiences of HCPs in managing the symptom experiences of men and women with AF. Because this study was qualitative in nature with a relatively homogenous sample, additional studies are needed with more diverse samples, to: 1) explore just how widespread the issue of healthcare provider delays are from the patient’s perspective; 2) discover the barriers HCPs face in diagnosing AF; and 3) identify strategies to minimize delays associated with HCPs. Most importantly, the current research identified that many of the women in the study felt marginalized and disregarded by their HCP during treatment seeking. Future research should investigate gender inequity in the treatment of AF and identify strategies to minimize it within the setting of the HCP’s practice.

Existing AF symptom assessment tools do not differentiate patients based on gender. For example, the symptom checklist used in this study was a generic tool, and did not consider GI symptoms or the different language that men and women use to describe pulse irregularity. Therefore, future research should focus on identifying a gendered, sensitive symptom checklist for investigating symptoms of AF.

Although the SEM provided a framework to explore how participants made sense of their symptoms during the pre-diagnosis period, it was also deficient in several areas. Sex rather than gender, was included in the SEM in AF as a demographic factor which may influence the core concepts of the model. However, the current findings suggested that gender, rather than a person’s ‘sex’, can influence the overall symptom experience, including their interpretation of risk associated with cardiovascular disease, formation of individual symptoms theories, expectations, and the overall type and nature of the symptoms experienced. Lastly, one of the major critiques of the earlier versions of the SEM, was its inability to account for the cognitive process involved, particularly in the evaluation of symptoms (Biddle et al, 2007). Extant literature corroborated the findings from the
current study, whereby individuals used complex cognitive processes such as speculating, theorising and comparing during the pre-diagnosis symptom experience (Koldjeski et al., 2004; Leventhal et al., 1992; Petersen et al., 2011). Subsequent adaptation of SEM through the integration of mental schemas (Bruno, 2013) strengthened the cognitive aspect of the model. However, the findings from the present research suggest that further elaboration as to ‘how’ participants evaluated their symptoms is needed. These deficiencies should be the focus of future research in order to create a more inclusive model for capturing the pre-diagnosis period of AF.

Finally, the current study was not able to stratify its sample into smaller subgroups because of the limited number of participants. Therefore, understanding the differences between smaller subsets of age groups remains a fruitful area for future research. Other studies, comprising more diverse samples, are needed to investigate further the influence of gender and age on the perception and evaluation of, and response to AF. The results of such studies could further support strategies to implement effective teaching, targeted at correcting the misconceptions or gaps in patients’ understandings, and tailored to how participants evaluate and respond to their symptoms.

6.4. Limitations

There were several limitations to this research. First, the sample lacked ethnic and cultural diversity, with all of the participants being Caucasian and residents of Western Canada, and very few (n=1) participants lived in rural areas. Second, due to the sample size, stratification of the age groups into four subsets was not possible, which limited the study’s ability to detect more subtle differences in the symptom experience. Third, most of the participants were recruited through either hospital base programs (RACE clinic, AF clinic), where patients came to receive care from a cardiologist or from the community-based cardiology rehab program. Only using these recruitment sites may have limited the transferability of the data, as other locations where patients seek treatment for their symptoms (GP office) where not sampled. Lastly, some of the interviews may have been subject to recall bias as they covered periods ranged between weeks to one year.
6.5. Conclusions

This study offers a greater understanding of the perceptions, evaluations and responses to AF in the pre-diagnosis period. Participants overwhelmingly experienced a complicated and prolonged pre-diagnosis period, with almost half of all participants experiencing symptoms for over one year, prior to diagnosis.

The key findings of this research concerning symptom perception included the overall prevalence of symptoms in the pre-diagnosis period, how awareness of symptoms was evoked through the participants’ bodily senses - seeing, feeling and hearing, the importance of rest and activity in the awareness of heart-related symptoms, and the greater severity and frequency with which women experienced AF symptoms. Another key finding linked to perception was the identification of the importance of viewing symptoms retrospectively, whereby individuals identified more symptoms that may otherwise gone unnoticed. Finally, the journey to AF symptom awareness was rarely straightforward or linear. Rather, the participants’ experiences demonstrated that for most there was an ebb and flow, over time, to becoming aware, as pieces of information were accumulated regarding the sensation(s) they felt.

The symptom evaluation period was influenced by several key factors; including expectations, the influence of symptoms, inside knowledge and knowledge gaps. These key factors helped shape and inform the individual theories. Theories were formed through speculation – defined as the process of forming tentative theories or conjectures to account for the symptoms experienced – when there was insufficient evidence to form a steadfast explanation for symptoms. Theories formed by the participants included, ‘it is nothing really’, followed by ‘I’m just getting older,’ ‘I must be stressed or anxious,’ ‘all too familiar- chronic health conditions,’ ‘it’s my fault,’ ‘just pushing myself too hard,’ and ‘something is wrong with my heart.’

Another unique contribution of the current study was the understanding of how individuals evaluated their symptoms. The study found that individuals evaluated their symptoms using several
approaches, which included comparing self with others, reaching out to friends and family, and testing symptom legitimacy in different ways – including exercise and monitoring the body during symptoms. Additionally, participants evaluated their symptoms by eliminating all other possible explanations for their symptoms in the search of a theory which fit their symptoms.

Lastly, in their responses to AF symptoms, the majority of participants experienced an extended pre-diagnosis period. This occurred in part because their choice of non-health care seeking for their symptoms meant attempting self-treatment rather than health care seeking, and partly because of HCP delays, linked to their symptoms’ not being recognized or being disregarded at the time of health care seeking. Disrupting theories described events or influences on the symptom experience that altered the participant’s predominant or ongoing theory that prompted health care seeking.

Participants in the LDG displayed an overall lack of concern, which stemmed from complications associated with confounding comorbid conditions, infrequent or inconsistent symptoms and/or attributing their symptoms to other non-illness related issues. Second, those who experienced the longest pre-diagnosis period reported a greater lack of understanding of what their symptoms meant; they considered themselves healthy, when the symptoms of AF began, and they received more normal test results than those in the EDG. Conversely, participants in the EDG had more personalized experience of cardiac disease and correctly evaluated their symptoms as coming from their heart.

Finally, this study investigated the role of gender and age in the global AF symptom experience. Overall, women experienced greater difficulty than men did in evaluating and responding to their symptoms in a timely manner. They also misunderstood their risk of cardiovascular disease, and had trouble understanding the significance of their symptoms. Additionally, when compared to men, women demonstrated a greater lack of familiarity with the symptoms of AF, and often struggled to obtain a diagnosis from their HCP following treatment seeking. Men on the other hand, displayed a greater tendency to reach out to their partners for help in the evaluation and response to their symptoms. Lastly, older adults were more accepting of their symptoms and reported less concern
about them, whereas younger participants had different perceptions of their risk of cardiovascular disease.

This research is an important ‘piece of the puzzle’ as it sheds further light on the prolonged pre-diagnosis period, experienced by many individuals, following the onset of AF symptoms. In essence, this extended period, prior to health seeking, is the result of individuals’ not having enough information to make an informed evaluation, the subtlety, variability and intermittency of symptoms, and the overall lack of concern about the symptoms of AF. Most importantly, women experienced inequities in receiving adequate treatment when they did seek treatment from their HCP. This gender issue must be further explored in future research. Researchers and HCPs would be afforded a unique opportunity, within future research and practice, to assist the public in recognising and responding to the symptoms of AF, in an urgent manner. This in turn might greatly reduce the negative outcomes associated with the non-treatment of this very treatable condition.
References


Buccelletti, F., Di Somma, S., Iacomini, P., Galante, A., Pugliese, F., Alegiani, F., ... & Franceschi, F., (2013). Assessment of baseline characteristics and risk factors among Emergency Department patients presenting with recent onset atrial fibrillation: a
retrospective cohort study. European Review for Medical and Pharmacological Sciences, 17(1), 22-27.


Dracup, K., & Moser, D. K. (1997). Beyond sociodemographics: Factors influencing the
decision to seek treatment for symptoms of acute myocardial infarction. *Heart &
doi:org/10.1016/S0147-9563(97)90082-0.

and actions in their preventing and handling of atrial fibrillation. *European Journal of
Cardiovascular Nursing*, 12(2), 132-139.

Elias, T., & Lowton, K. (2014). Do those over 80 years of age seek more or less medical
help? A qualitative study of health and illness beliefs and behaviour of the oldest old.
*Sociology of health & illness*, 36(7), 970-985.

the qualitative literature. *Current Sociology*, 57(2), 155-191.

important because it comes and goes”—patients' accounts of intermittent symptoms
preceding a pancreatic cancer diagnosis: a qualitative study. BMJ open, 4(2),
e004215.

Fitzmaurice, D. A., Hobbs, F. R., Jowett, S., Mant, J., Murray, E. T., Holder, R., ... & Allan,
T. F. (2007). Screening versus routine practice in detection of atrial fibrillation in
patients aged 65 or over: cluster randomised controlled trial. *The British Medical

Freedman, B., Camm, J., Calkins, H., Healey, J. S., Rosenqvist, M., Wang, J., ... & Boriani,
G. (2017). Screening for atrial fibrillation: a report of the AF-SCREEN international

Frewen, J., Finucane, C., Cronin, H., Rice, C., Kearney, P. M., Harbison, J., & Kenny, R. A.
(2013). Factors that influence awareness and treatment of atrial fibrillation in older


McCabe, P. J., Barton, D. L., & DeVon, H. A. (2017). Older Adults at Risk for Atrial Fibrillation Lack Knowledge and Confidence to Seek Treatment for Signs and
Symptoms. SAGE Open Nursing, Retrieved from
http://journals.sagepub.com/doi/abs/10.1177/2377960817720324


Appendices

Appendix A: Letter to Potential Participants

April 2013

Dear Dr. / Nurse _____________,

You have been identified as a primary health care provider who may have an interest in assisting in a research study conducted through UBC Okanagan entitled, “The Symptom Experience in Patients with New Onset Atrial Fibrillation.” The overall goal of the study is to explore the AF symptom experiences, perceptions, evaluations, and responses of adults in the pre-diagnosis period of AF, and to interpret the reasons for the decisions made. To do this we plan to conduct interviews and administer a short survey to:

1. **To** explore the symptom experience as perceived by adults (>19 years of age) during the pre-diagnosis period of AF by (i) identifying and describing the symptom experiences and perceptions of AF patients preceding diagnosis; (ii) comparing the influences of age and gender on the AF symptom experience; and (iii) exploring the perspectives of patients who may have misinterpreted their symptoms.

2. **To** explore individuals’ evaluations of AF symptoms during the pre-diagnosis period by (i) identifying and describing individuals’ evaluations of AF symptoms preceding diagnosis; and (ii) comparing age and gender influences on symptom evaluation.

3. **To** explore individuals’ responses to AF symptoms during the pre-diagnosis period by (i) identifying and describing factors that influenced the choice of responses during the symptom experience (misinterpretation of symptoms, symptom severity, transient nature of symptoms) and (ii) comparing the participants’ responses to symptoms based upon age and gender.

If you are interested in participating in this study we would ask that you introduce the study to all patients who have been diagnosed with AF in the last 3 months, and give them an “Invitation and Permission to be Contacted” letter from the research team.

If you have any questions please contact Ryan Wilson by email (ryan.wilson@ubc.ca) or by telephone (250-807-8010). Please let R. Wilson know by ____________ if you are interested in being a part of the recruitment process.

Sincerely yours,

Ryan Wilson, PhD Candidate, RN on behalf of the team:
Kathy Rush, PhD, RN  Carol Laberge, PhD, RN
Linda Hatt PhD        Colin Reid, PhD
Appendix B: Recruitment Script

The Symptom Experience in Patients with New Onset Atrial Fibrillation

PHYSICIAN NURSE AND NURSE PRACTITIONER SCRIPT
FOR RECRUITMENT OF ADULTS WITH AF

I have been asked to tell you about a research study that explores heart symptoms and symptom experiences of patients with atrial fibrillation (irregular heartbeat) in order to better understand patients’ perceptions, evaluations and decisions to seek treatment. Despite the rising prevalence of AF, there remains a poor understanding about the symptom experiences of patients prior to receiving their AF diagnosis, and how these experiences influence treatment seeking. The researchers hope to use this information to find ways to better support adults to recognize these symptoms and seek early treatment.

If you choose to participate in the study, a researcher will conduct a 60-90 minute interview with you in person. The interview can take place at your home or at another mutually agreed upon location.

I have two sheets that give you more details about this study. You can see that at this point the researchers only want to know if you would be interested in having someone call you and provide more details about the study. If you are interested in talking to someone from the research group about the study, you will need to check the box and sign in the space at the bottom of one or both sheets.

Thank you for your consideration in participating in this study.
Appendix C: Contact Form

PERMISSION TO CONTACT FORM

Study Title: The Symptom Experience in Patients with New Onset Atrial Fibrillation

This is to tell you about a research study being conducted at the University of British Columbia Okanagan. The researchers at UBC Okanagan are asking for your permission to contact you with more information regarding this study. The study's main purpose is to understand what symptoms adults experience from atrial fibrillation (AF), a condition that causes an irregular heartbeat. Furthermore, this study focuses on how people evaluate and respond to symptoms during the period of time prior to diagnosis. The researchers hope to use this information to find ways to better support adults to recognize these symptoms and seek early treatment. They would like to talk to you to arrange a meeting to talk about these issues. You are receiving this letter because you were identified as someone with new onset of atrial fibrillation and may have an interest in participating in this study.

At this time, you are only being asked for your consent to be contacted by one of the members of the research team to hear more about the study. To give consent to be contacted please sign this form. Those who consent will receive an Information and Consent form to take home. The Information and Consent Form tells you more about the study and your rights as a study participant. The Information and Consent Form will be signed later on if you agree to participate. If you indicate that you would like to be contacted, someone from the research team will call you by telephone and provide you with more details about the study. At that time, you can make a decision about whether you want to take part in the study. Taking part in this study is entirely up to you. You may refuse to take part or may withdraw at any time without it affecting you or your continuing medical care.

For more information about the study, please contact:
Ryan Wilson, RN, PhD Candidate
UBC Okanagan, Principal Investigator
Tel: 250-807-8010 or ryan.wilson@ubc.ca

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. You may also contact the Interior Health Research Ethics Board through the Research Office at 250-870-4602.

Please indicate your willingness to be contacted to receive more information about the study:

☐ I would like to receive more information about the study

________________________________ ______________________________________
Older Adult Name (please print) Signature Phone and email
Appendix D: Older Adult Consent and Information Form

Study Title: The Symptom Experience in Patients with New Onset Atrial Fibrillation

CONSENT AND INFORMATION FORM: OLDER ADULTS

Principal Investigator:

Ryan Wilson, RN, BSN, PhD Candidate, Lecturer, School of Nursing, University of British Columbia Okanagan
Email: ryan.wilson@ubc.ca
Phone: (250) 807-8010

Supervisor:

Kathy Rush, PhD, RN Associate Professor, School of Nursing, University of British Columbia Okanagan
Email: kathy.rush@ubc.ca
Phone: (250) 807-9561

Committee Members:

Linda Hatt, PhD Associate Professor, Psychology, Barber School of Arts and Science, University of British Columbia Okanagan, Phone: (250) 807-9323

Carol Laberge, PhD, RN Royal Inland Hospital, Kamloops
Office phone: 250 314 2483 carol.laberge@interiorhealth.ca

Colin Reid, PhD Assistant Professor, School of Health and Exercise Science, University of British Columbia Okanagan, Phone: (250) 807-9910

Study Information and Purpose
The purpose of this project is to explore the experiences of people with new onset atrial fibrillation. Specifically, this study will explore what symptoms are experienced prior to diagnosis, how they are evaluated, and how individuals respond following the onset of symptoms.

Who Can Participate?
To participate in this study, you must: 1) be over 19 years of age; 2) have been recently diagnosed with Atrial Fibrillation (confirmed by electrocardiogram) 3) have no problems with memory and recall; 5) able to speak and understand English (if you have some reading challenges we can give some help); 6) able to give your own consent to participate in this study; 7) able to complete a form with minimal assistance.
What Does the Study Involve?

You will be asked to participate in a face-to-face interview within 6 months of your diagnosis. It is anticipated that participating in the study will take up to a total of 2 hours of your time.

What Information Will Be Collected?

During the first interview you will be asked to share your perspectives on a short set of questions.

- What has it been like living with AF.
- Recall your first experience with AF symptoms prior to receiving a diagnosis
- What did you first notice about your symptoms or illness? What did you think was the cause of this?
- How did you decide what was happening to you? Where did you turn to for knowledge or information?
- Were you worried about your situation? What did you think would come of it?
- What may have influenced how you experienced and interpreted your symptoms (e.g. culture, previous history, gender, age)

You will also be asked to complete two other forms that will ask for some personal information (e.g. marital status, living arrangements, and health history and medications.

The interviews will be taped. Audiotapes will be later typed into written text for analysis. The information you provide will be combined with that of other participants to give a broad picture of illness experienced by older adults with new onset AF.

Costs

There will be no costs to you.

Potential Risks

There are few risks to participating in this study other than the risk for fatigue related to a long interview, and potential psychological risk based upon an interview that may revisit symptom experiences related to an upsetting event. There are no anticipated or known physical risks associated with this research.

Benefits

One of the benefits of participating in this study is increasing your awareness of the impact of AF and knowledge of how it symptoms typically present and are acted upon. Participating in this study may bring you the gratification and/or satisfaction that you are helping improve the lives of other older adults like yourself.
Confidentiality

We will do several things to try to make sure your identity remains confidential. The recorded and printed interviews will be made available only to members of the research team. They will be kept for a minimum of 5 years and up to seven years, and will be stored securely in a UBC facility. Only code numbers will identify materials relating to your personal information including medical record information. Made up names will be used in conjunction with the information you provide during the interview to ensure that the information you provide will not be linked to your identity in anyway. All information will be kept in a locked filing cabinet.

The information you provide will be shared with others who study and work with older adults with AF. It will be communicated in written scholarly papers and oral presentations. Your name will not be used in any reporting of the results from this study. We hope that results from the study will be used to guide future research. If you would like a summary of the findings, please include your mailing address in the space provided at the bottom of this form. You will also be given a copy of the signed consent form.

Contact for Concerns about the Rights of Research Participants

You have the right to ask questions, and have those questions answered. If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. You may also contact the Chair of the IH Research Ethics Board through the Research Office at (250) 870-4602 or researchethics@interiorhealth.ca.

Withdrawal from the Study

Your participation in this study is entirely voluntary. You may refuse to participate or you may withdraw from the study at any time during the course of this study without penalty. Your choice to withdraw will in no way affect the care you are receiving in relation to your health care. If you choose to withdraw but do not give permission for any of your data to be used, it will not be used. Audio-recordings will be erased, and all hard copies of your materials will be shredded.

If you choose to participate in this study, please indicate if you would like to receive a research summary and your contact information.

☐ I would like to receive a research summary at the address listed below:
_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________

168
You will be given a copy of this consent form to keep for your records. The researchers will keep a copy for their records.

Participant Consent and Signature to Participate in Study

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. You can refuse to answer any questions we ask, or you can change your answer at any time during the 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 you.

☐ Yes ☐ No Your signature below indicates that you have received a copy of this consent form for your own records.
☐ Yes ☐ No Your signature indicates that the researchers have answered your questions about the study to your satisfaction.
☐ Yes ☐ No Your signature indicates that that you consent to the recording of all interviews.
☐ Yes ☐ No Your signature indicates that you allow access to your medical records for purposes of the research study.
☐ Yes ☐ No Your signature indicates that you consent to participate in this study.

I hereby consent to participate in this study:

__________________________________  ______________________
Participant Signature                      Date

__________________________________  ______________________
Printed Name of Participant                Date

Thank you for your time.
Appendix E: Initial Phone Screening Script - Potential Participants

This is a study that explores heart symptoms and symptom experiences of patients with atrial fibrillation (irregular heartbeat) in order to better understand patients’ perceptions, evaluations and decisions to seek treatment. Despite the rising prevalence of AF, there remains a poor understanding about the symptom experiences of patients prior to receiving their AF diagnosis, and how these experiences influence treatment seeking. Through exploring this period of time prior to diagnosis with patients, the hope is that the study results may serve to promote early identification of AF symptoms, and lead to appropriate strategies to increase awareness of AF symptoms and treatment.

If you choose to participate in the study, I will conduct an interview with you in person that will take approximately 60-90 minutes. One disadvantage to participating may be the long interview. However, we can stop if you become fatigued and complete the interview another time if you are willing. I may need to conduct a follow up 30 minute interview in order to clarify information. I plan to voice record the interview and later transcribe it into a document that I can use to analyse along with other participant interviews. In addition to the 20 dollar honorarium you will receive, another benefit to participating in the research is that the information gained through exploring your symptom experiences may provide scientific information for others with the same or similar condition.

If you are interested to hear more about participating, I will first need to ask you a couple of questions to see if you would be eligible to participate. If you agree to participate, I will get your signed consent. Participation in the study is completely voluntary and there are no consequences to your medical care should you choose not to participate or are ineligible.

(If eligible and willing to participate, schedule an appointment and thank the person. If not eligible or not willing to participate, thank the person for their time.)

Questions:

- Are you 19 years of age or older?
- Have you recently been diagnosed in the last 12 months with atrial fibrillation, or an irregular pulse. Can you recall if an electrocardiogram has confirmed this diagnosis?
- In the last 12 months, have you experienced any of the following symptoms:
  - Palpitations, shortness of breath, fatigue, fainting, sensation of skipped heartbeats, chest pain, or dizziness?
- Have you ever had difficulty with your memory (cognition), or communication associated with dementia or a stroke?
Appendix F: Mini COG

GET THE PATIENT’S ATTENTION, THEN SAY: “I am going to say three words that I want you to remember now and later. The words are: Banana Sunrise Chair. Please say them for me now.” (Give the patient 3 tries to repeat the words. If unable after 3 tries, go to next item.)

SAY ALL THE FOLLOWING PHRASES IN THE ORDER INDICATED:

“Please draw a clock in the space below. Start by drawing a large circle. Put all the numbers in the circle and set the hands to show 11:10 (10 past 11).”

If subject has not finished clock drawing in 3 minutes, discontinue and ask for recall items.

SAY: “What were the three words I asked you to remember?”

_________ _____________ _____________ (Score 1 point for each) 3-Item Recall Score

Score the clock (see other side for instructions):     Normal clock     2 points     Clock Score

Abnormal clock     0 points

Total Score = 3-item recall plus clock score     0, 1, or 2 impaired; 3, 4, or 5 impairment less likely

Mini-Cog™ Copyright S Borson. Reprinted with permission of the author, solely for educational use. May not be modified or used for other purposes without permission of the author (soob@uw.edu). All rights reserved.
CLOCK SCORING
A NORMAL CLOCK HAS ALL OF THE FOLLOWING ELEMENTS:
All numbers 1-12, each only once, are present in the correct order and direction (clockwise) inside the circle.
Two hands are present, one pointing to 11 and one pointing to 2.

ANY CLOCK MISSING ANY OF THESE ELEMENTS IS SCORED ABNORMAL. REFUSAL TO DRAW A CLOCK IS SCORED ABNORMAL

SOME EXAMPLES OF ABNORMAL CLOCKS (THERE ARE MANY OTHER KINDS)

Abnormal Hands

Missing Number
Appendix G: Partners Consent and Information Form

INFORMATION AND CONSENT FORM
FOR PARTNERS OF PARTICIPANTS WITH ATRIAL FIBRILLATION

Study Title: The Symptom Experience in Patients with New Onset Atrial Fibrillation

**Principal Investigator:**

Kathy Rush, PhD, RN  Associate Professor, School of Nursing, University of British Columbia-Okanagan; Phone: (250) 807-9561

**Student Investigator:**

Ryan Wilson, RN, BSN, PhD(C), Lecturer, School of Nursing, University of British Columbia Okanagan
Email: ryan.wilson@ubc.ca  Phone: (250) 807-8010

**Committee Members:**

Linda Hatt, PhD  Associate Professor, Psychology, Barber School of Arts and Science, University of British Columbia Okanagan, Phone: (250) 807-9323

Carol Laberge, PhD, RN  Health Administrator, Royal Inland Hospital, Kamloops
Office phone: 250 314 2483 carol.laberge@interiorhealth.ca

Colin Reid, PhD  Assistant Professor, School of Health and Exercise Science, University of British Columbia Okanagan, Phone: (250) 807-9910

**Study Information and Purpose**

The purpose of this student research project for R. Wilson’s dissertation is to explore the experiences of people with new onset atrial fibrillation. Specifically, this study will explore what symptoms are experienced prior to diagnosis, how they are evaluated, and how individuals respond following the onset of symptoms.

**Who Can Participate?**

Partners of adults with AF, who have given consent for them to participate in the interview process associated with the study. It is estimated that twenty to thirty participants will be involved in this study. The person giving consent for you to participate must meet the following conditions: 1) be over 19 years of age; 2) have been recently diagnosed in the last 12 months.
with Atrial Fibrillation (confirmed by health care provider) 3) have no problems with memory and recall; 5) able to speak and understand English (if you have some reading challenges we can give some help); 6) able to give your own consent to participate in this study; 7) able to complete a form with minimal assistance.

**What Does the Study Involve?**

Your partner has agreed to participate in a face-to-face interview within 12 months of their diagnosis. R. Wilson will meet you and your partner at a prearranged time in your home, or in another place that is suitable and mutually decided upon (e.g. R. Wilson’s office, coffee shop). It is anticipated that participating in the study will take up to a total of 2 hours of your time. A second, interview may be conducted if further information or clarification is required, based upon the analysis of the first interview. If a second interview with your partner is needed, it may occur in person or over the telephone, and will last no longer than 30 minutes.

**What Information Will Be Collected?**

As a partner of a participant in the study, you often become part of that journey and have valuable insights to share and may participate in the interview process with the consent of your partner. During the first interview your partner will be asked to share their perspectives on a short set of questions.

- What has it been like living with AF?
- Recall your first experience with AF symptoms prior to receiving a diagnosis
- What did you first notice about your symptoms or illness? What did you think was the cause of this?
- How did you decide what was happening to you? Where did you turn to for knowledge or information?
- Were you worried about your situation? What did you think would come of it?
- What may have influenced how you experienced and interpreted your symptoms (e.g. culture, previous history, gender, age)

Your partner will also be asked to complete the following forms during the interview period:

- A questionnaire that asks for some personal information (e.g. marital status, living arrangements) and for details of your health history (e.g., medications).
- A form (the CHADSD2-VASc) that gives information about your risk of stroke.
- A Symptom Checklist that assesses how often you have symptoms of atrial fibrillation and how severe the symptoms are.
- A Mini-Cog that screens for your cognitive function.
The interviews will be taped. Audiotapes will be later typed into written text for analysis. The information provided will be combined with that of other participants to give a broad picture of illness experienced by adults with new onset AF.

Costs and Compensation:

There will be no costs to you or your partner. You will receive no payment for your participation. If your partner’s participation for the interview requires travel, your partner will receive up to 20 dollars to pay for travel costs and paid public parking.

Risks

There are few risks to participating in this study other than the possibility of you or your partner feeling upset in recalling the events during the period prior to diagnosis, if they were stressful for you. There are no anticipated or known physical risks associated with this research.

Benefits

One of the benefits of participating in this study is increasing your awareness of the impact of AF and knowledge of how it symptoms typically present and are acted upon. Participating in this study may bring you the gratification and/or satisfaction that you are helping improve the lives of other patients living with AF.

Confidentiality

We will do several things to try to make sure your identity remains confidential. The recorded and printed interviews will be made available only to members of the student research committee. They will be kept for at least 5 years after the study findings have been published and destroyed seven years after publication. Research data will be stored safely in Dr. Kathy Rush’s office in Arts 150. Only code numbers will identify materials relating to your personal information. Made up names will be used in conjunction with the information you and your partner provide during the interview to ensure that the information you provide will not be linked to your identity in anyway. All information will be kept in a locked filing cabinet.

The results of the study will be communicated in written scholarly papers and oral presentations. Additionally, as this research is for R. Wilson’s dissertation, the results will be made publicly available through the Internet on UBC’s cIRcle, which is a free collection of printed research materials by UBC researchers. You or your partners name will not be used in any reporting of the results from this study. We hope that results from the study will be used to guide future research. If you would like a summary of the findings, please include your mailing address in the space provided at the bottom of this form. You will also be given a copy of the signed consent form.
Contact with Questions

If you have any questions or need more information about the study, please contact:
Ryan Wilson, PhD(C),
UBC Okanagan, Student Investigator
Tel: 250-807-8010 or ryan.wilson@ubc.ca

Contact for Concerns about the Rights of Research Participants

If you or your partner have any concerns or complaints 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 Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Participant Complaint Line by email (RSIL@ors.ubc.ca). You may also contact the Chair of the Interior Health Research Ethics Board by phone at 250-870-4602 or via email to researchethics@interiorhealth.ca.

Withdrawal from the Study

Your participation in this study is entirely voluntary. You may refuse to participate or you may withdraw from the study at any time during the course of this study without penalty. Your choice to withdraw will in no way affect the medical care your partner is receiving. If you choose to withdraw after you have taken part in interviews or telephone conversations, all your data be can removed if you no longer want it included within the study.

If you choose to participate in this study, please indicate if you would like to receive a research summary and your contact information.

☐ I would like to receive a research summary at the address listed below:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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. You can refuse to answer any questions we ask, or you can change your answer at any time during the 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 you or your partner’s medical care.

☐ Yes ☐ No Your signature below indicates that you have received a copy of this consent form for your own records.
☐ Yes ☐ No Your signature indicates that the researchers have answered your questions about the study to your satisfaction.
☐ Yes ☐ No Your signature indicates that you consent to the recording of all interviews.
☐ Yes ☐ No Your signature indicates that you consent to participate in this study.

__________________________________________  __________________________
Participant Signature                      Date

__________________________________________
Printed Name of Participant                Date

Thank you for your time.
Appendix H: Interview Guide

Interview Guide

Participant ID Number:___________ Date:__________________________

Time:_____________ Location:_______________

Perception

• Can you tell me your story, how you ended up being diagnosed with AF? Let’s start from the beginning? When did you begin to experience changes in your body that something was not as it should be? What symptoms did you experience?

• Looking back, what did you first notice about your symptoms or illness? When was this? How aware were you of the bodily or psychological changes that were occurring from your AF?

• How frequently did the symptoms occur? Where there some symptoms more intense than others? Did any of the symptoms cause any distress?

(5)

Evaluation

• Once you were aware of the symptoms, how did you decide what they were resulting from, or what they were an indication of? Where did you turn to for knowledge or information?

• Who, if anyone, did you talk to about how you were feeling? What did you think was the cause of this?

(6)

Response

• How worried were you about your situation? What did you think would come of it?

• Can you tell me how you first responded to the symptoms? Did you change anything you
were doing (activities) in your daily life? Did you try to alter anything else in your life (e.g. diet)?

- Is there anything in your childhood or upbringing or culture that might have influenced how you respond in illness?

- Did you experience any emotions as a result of your symptoms?

- Tell me about what made you decide to seek treatment from the medical system?

- What do you recall as being an important factor(s) in deciding about your treatment?

- When making decisions about treatment, how did this experience differ from other experiences that you may have had before?

- Tell me about what made you decide to seek treatment from the medical system?

- How did your perceived consequences of the AF effect your decisions on treatment?
Appendix I: Demographic Information

Demographic Information - Older Adults

1. Age: ______ Years

2. Sex: □ Female □ Male

3. Marital Status:
   □ Single (never married) □ Widowed □ Divorced
   □ Married or Remarried □ Separated □ Other (specify)

4. Race/Ethnicity:
   □ African-Canadian □ Caucasian
   □ Asian □ Hispanic
   □ Aboriginal/First Nations □ Other (specify)_________________________

5. Highest Level of Education:
   □ Less than High School □ Some College
   □ Partial High School □ College/University Graduate
   □ Completed High School □ Other (specify)_________________________

6. Income:
   □ Less than $25,000 □ $51,000 - $75,000
   □ $25,000 - $50,000 □ Over $75,000

7. Place of residence:
   □ Your own detached home □ Apartment/Condominium for all Ages
   □ Seniors’ Apartment Complex □ Assisted living □ Other _____________ (specify)
8. Living arrangements:

- □ Live alone
- □ Live with children
- □ Live with partner
- □ Live with other family members
- □ Live with partner + children
- □ Live with friends
- □ Other ___________________(specify)

9. Where do you live?

- Town/City_________________
- Go south for the winter: □ Yes □ No

10. Has a doctor ever told you that you have any of the following Health Problems:

- □ Arthritis □ Heart Disease □ Diabetes □ Dementia (e.g. Alzheimer’s)
- □ High Blood Pressure □ Sleep Apnea □ Overactive Thyroid Disease
- □ COPD □ Stroke □ Eye Problems □ Depression □ Anxiety
- □ Other __________________________ (specify)

11. Time since AF diagnosis: □ < 1 week □ < 2 weeks □ > 2 weeks □ > 1 month

12. Current work position if employed?
   specify:______________________________

13. Medications You are Currently Taking:

- □ Warfarin (blood thinner)
- □ Antiplatelet (egg ASA, Plavix) (makes your blood less sticky)
- □ Diuretic (e.g. Lasix (water pill))
- □ Calcium Channel Blocker (e.g. Cardizem, Adalat, Norvasc) (controls blood pressure)
- □ β-Blocker (e.g. Metoprolol, Atenolol) (slows the beating of the heart)
☐ α-Blocker (e.g. Terazosin, Prazosin) (controls blood pressure)

☐ Angiotensin-Converting Enzyme Inhibitor (e.g. Ramipril) (controls blood pressure)

☐ Angiotensin II receptor blocker (e.g. Valsartan, Losartan) (controls blood pressure)

☐ Statin (e.g. Lovastatin, Simvastatin) (controls cholesterol)

☐ Antiarrhythmics (e.g. Amiodarone, Digoxin) (controls heart rhythm)

☐ Other ________________

14. Treatment history for AF:

☐ medication only      ☐ medication + cardioversion

☐ medication + cardioversion + ablation  ☐ other __________________ (specify)

15. Choice of treatment following the onset of AF symptoms

Please list all: ___________________________________________________________
_______________________________________________________________________

16. First professional health practitioner sought for AF related symptoms?

☐ Physician  ☐ Chiropractor  ☐ Naturopathic

☐ Massage  ☐ Physiotherapist  ☐ Nurse  ☐ Nurse Practitioner

17. How would you rate your overall health?

☐ Excellent  ☐ Good  ☐ Fair  ☐ Poor
## Appendix J: CHA2DS2 VASc Stroke Risk Assessment

<table>
<thead>
<tr>
<th>Condition</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>C Congestive Heart Failure (or LV dysfunction)</td>
<td>1</td>
</tr>
<tr>
<td>H Hypertension BP &gt; 140/90 Or treated hypertension on medication</td>
<td>1</td>
</tr>
<tr>
<td>A Age ≥ 75 years</td>
<td>2</td>
</tr>
<tr>
<td>D Diabetes Mellitus</td>
<td>1</td>
</tr>
<tr>
<td>S2 Prior stroke or TIA or Thromboembolism</td>
<td>2</td>
</tr>
<tr>
<td>V Vascular disease (e.g. MI, PVD, Aortic plaque)</td>
<td>1</td>
</tr>
</tbody>
</table>

### Score

<table>
<thead>
<tr>
<th>Score</th>
<th>Stroke Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (male) and 1 (female)</td>
<td>Low</td>
</tr>
<tr>
<td>1 (male)</td>
<td>Moderate</td>
</tr>
<tr>
<td>2 or greater</td>
<td>high</td>
</tr>
</tbody>
</table>
Appendix K: Symptom Checklist

SYMPTOM CHECKLIST: Frequency and Severity (V.3)*

Think back over the past month. For each of the symptoms listed below, check (√):

1) How often you had it:  
2) How severe then it was:

<table>
<thead>
<tr>
<th>symptom</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Mild</th>
<th>Moderate</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiredness/lack of energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart fluttering/skipping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart racing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Light-headedness/dizziness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headache</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble concentrating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hard to catch breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling warm/flushed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weakness</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Often</td>
<td>Always</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-------</td>
<td>--------</td>
<td>-----------</td>
<td>-------</td>
<td>--------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest pain, pressure, or fullness, when the heart is racing or fluttering</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest pain, pressure, or fullness, when the heart is <strong>NOT</strong> racing or fluttering</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Bubien, R. S. & Kay, G. N., revised Jenkins, L. S., 1993. (Note: Not to be used or modified without permission)
SYMPTOM CHECKLIST – Frequency and Severity  
Bubien, R.S. & Kay, G.N., revised Jenkins, L.S., 1993 – V.3*

This instrument is formatted into the form of two symptom checklists (SCLs) and quantifies both symptom frequency and severity. The format allows respondents to use check marks (✓) to indicate: 1) the frequency with which they have experienced each symptom (never, rarely, sometimes, often, and always); and 2) severity (mild, moderate, extreme) for each symptom listed. Since the Checklist (SCL) quantifies two aspects of symptom assessment: two independent scores are produced. Reliability and validity should always be estimated separately for each SCL.

Each SCL is scored using assigned numerical values given to responses in each of the two sections. In Symptom Frequency, the values assigned are:

- Never = 0
- Rarely = 1
- Sometimes = 2
- Often = 3
- Always = 4

The Symptom Frequency Score is obtained by summing the numerical responses to each of the 16 items. This schema provides a possible range of scores of 0 to 64. The higher the Frequency Score, the greater the frequency with which symptoms are experienced.

In Symptom Severity, the numerical values assigned to responses are:

- Mild = 1
- Moderate = 2
- Extreme = 3

The Symptom Severity Score is obtained by summing the numerical responses to each of the items which have been experienced providing a total score that could range from 0 (if no symptoms listed have been experienced) to 48. The higher the Severity Score, the greater the severity of the symptoms experienced.

Reliability of each of the SCLs should be calculated by using Cronbach’s alpha to estimate internal consistency at each data collection point. Initial work on content validity was done from review of the SCLs by clinicians with expertise in caring for patients with atrial fibrillation. 

LSJ 8/94
### Appendix L: Demographic Tables

#### Table 1 Demographic Information

<table>
<thead>
<tr>
<th>Category</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43-59</td>
<td>6</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-67</td>
<td>6</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>68-75</td>
<td>8</td>
<td>31</td>
<td></td>
<td></td>
</tr>
<tr>
<td>76 +</td>
<td>6</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
<td>50</td>
<td>13</td>
<td>50</td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>50</td>
<td>13</td>
<td>50</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>26</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Married</td>
<td>19</td>
<td>73.1</td>
<td>19</td>
<td>73.1</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>7.7</td>
<td>2</td>
<td>7.7</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
<td>11.5</td>
<td>3</td>
<td>11.5</td>
</tr>
<tr>
<td><strong>Living arrangements</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Live Alone</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Live with children</td>
<td>2</td>
<td>7.7</td>
<td>2</td>
<td>7.7</td>
</tr>
<tr>
<td>Live with partner</td>
<td>19</td>
<td>73.1</td>
<td>19</td>
<td>73.1</td>
</tr>
<tr>
<td>Live with other family members</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Live with partner and children</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Live with friends</td>
<td>2</td>
<td>7.7</td>
<td>2</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>Highest Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial high school</td>
<td>3</td>
<td>11.5</td>
<td>3</td>
<td>11.5</td>
</tr>
<tr>
<td>Completed high school</td>
<td>6</td>
<td>23.1</td>
<td>6</td>
<td>23.1</td>
</tr>
<tr>
<td>Some college</td>
<td>9</td>
<td>34.6</td>
<td>9</td>
<td>34.6</td>
</tr>
<tr>
<td>College/university graduate</td>
<td>8</td>
<td>30.8</td>
<td>8</td>
<td>30.8</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>less than 25000</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>25000 to 50000</td>
<td>7</td>
<td>26.9</td>
<td>7</td>
<td>26.9</td>
</tr>
<tr>
<td>51000 to 75000</td>
<td>10</td>
<td>38.5</td>
<td>10</td>
<td>38.5</td>
</tr>
<tr>
<td>Over 75000</td>
<td>6</td>
<td>23.1</td>
<td>6</td>
<td>23.1</td>
</tr>
<tr>
<td><strong>Current Work Position</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>18</td>
<td>69.2</td>
<td>18</td>
<td>69.2</td>
</tr>
<tr>
<td>Clerk</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Health care</td>
<td>5</td>
<td>19.2</td>
<td>5</td>
<td>19.2</td>
</tr>
<tr>
<td>Service</td>
<td>2</td>
<td>7.7</td>
<td>2</td>
<td>7.7</td>
</tr>
</tbody>
</table>
Table 1 Demographic Information

<table>
<thead>
<tr>
<th>Category</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comorbid Conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>9</td>
<td>34.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHF</td>
<td>2</td>
<td>7.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
<td>7.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>9</td>
<td>34.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep apnea</td>
<td>4</td>
<td>15.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypothyroid</td>
<td>4</td>
<td>15.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPD</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke/ TIA</td>
<td>4</td>
<td>15.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>2</td>
<td>7.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>1</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vascular disease</td>
<td>1</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>26.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No comorbid condition</td>
<td>5</td>
<td>19.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Warfarin</td>
<td>5</td>
<td>19.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Novel Oral Anticoagulant (NOAC)</td>
<td>14</td>
<td>53.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antiplatelet</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diuretic</td>
<td>5</td>
<td>19.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calcium Channel Blocker</td>
<td>4</td>
<td>15.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beta-Blocker</td>
<td>15</td>
<td>57.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Angiotensin Converting inhibitor</td>
<td>7</td>
<td>26.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Angiotensin Receptor Blocker</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antiarrhythmic</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mini Cognitive Test Scores</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>23</td>
<td>88.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHADS-VASC Scores</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>34.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>19.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>15.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>10</td>
<td>38.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>14</td>
<td>53.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
<td>7.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Range</td>
<td>Mean</td>
<td>SD</td>
<td>Total</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-------</td>
<td>------</td>
<td>-----</td>
<td>-------</td>
</tr>
<tr>
<td>Knowledge of AF prior to diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>2</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heard of it but little understanding</td>
<td>16</td>
<td>64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never heard of it</td>
<td>7</td>
<td>28</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix M: Symptom Perception Matrix

<table>
<thead>
<tr>
<th>Symptom Perception</th>
<th>Female</th>
<th>Male</th>
<th>67 and under</th>
<th>68 and over</th>
<th>EDG</th>
<th>LDG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest Pressure or pain</td>
<td>5</td>
<td>4</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Heart fluttering or related perception</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>• beating or racing or flutter or</td>
<td>6</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>palpitations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Blood Rushing</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>• heart jumping</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>• heart pounding</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>• erratic pulse</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Leg Swelling</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Sweating</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>GI symptoms</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Neurological Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blurred Vision</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Dizzy</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Headache</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Light-headed</td>
<td>3</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental sharpness, attentiveness or</td>
<td>3</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>concentration</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restless or agitated</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Stressed or feeling uptight and anxious as</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>a symptom</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Syncope or near syncope</td>
<td>5</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Weakness, lethargy or fatigue</td>
<td>8</td>
<td>5</td>
<td>8</td>
<td>5</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Activity Intolerance</td>
<td>5</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Noticing Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abrupt severe onset enhanced awareness of</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awareness of heart</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>I did not know it was my heart</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Increased awareness of heart and symptoms</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>post-diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No awareness of symptoms until looking</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>back post diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleeping (interrupts sleep)</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Stillness enhances awareness of symptoms</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>5</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Respiratory related perceptions</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>6</td>
</tr>
</tbody>
</table>
## Appendix N: Symptom Checklist Frequency and Severity Matrix

<table>
<thead>
<tr>
<th>Item</th>
<th>N of participants who reported this symptom</th>
<th>Mean</th>
<th>Range</th>
<th>Minimum</th>
<th>Maximum</th>
<th>St. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiredness or lack of energy</td>
<td>24</td>
<td>3.1923</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>1.02056</td>
</tr>
<tr>
<td>Tiredness Severity</td>
<td>24</td>
<td>1.5385</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>.76057</td>
</tr>
<tr>
<td>Heart Fluttering/Skipping</td>
<td>20</td>
<td>2.4615</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>.98917</td>
</tr>
<tr>
<td>Heart Fluttering/Skipping Severity</td>
<td>20</td>
<td>1.5000</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>1.06771</td>
</tr>
<tr>
<td>Heart Racing</td>
<td>21</td>
<td>2.4231</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>.94543</td>
</tr>
<tr>
<td>Heart Racing Severity</td>
<td>21</td>
<td>1.6154</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>1.09825</td>
</tr>
<tr>
<td>Light-headedness/dizziness</td>
<td>21</td>
<td>2.3846</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>.85215</td>
</tr>
<tr>
<td>Light-headedness/dizziness Severity</td>
<td>21</td>
<td>1.4615</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>.98917</td>
</tr>
<tr>
<td>Headache</td>
<td>14</td>
<td>1.8077</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>.93890</td>
</tr>
<tr>
<td>Headache Severity</td>
<td>14</td>
<td>.7692</td>
<td>2.00</td>
<td>.00</td>
<td>2.00</td>
<td>.81524</td>
</tr>
<tr>
<td>Trouble Concentrating</td>
<td>17</td>
<td>2.1154</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>1.03255</td>
</tr>
<tr>
<td>Trouble Concentrating Severity</td>
<td>17</td>
<td>.9231</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>.84489</td>
</tr>
<tr>
<td>Hard to catch breath</td>
<td>18</td>
<td>2.2692</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>1.07917</td>
</tr>
<tr>
<td>Hard do catch breath Severity</td>
<td>18</td>
<td>1.1538</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>.92487</td>
</tr>
<tr>
<td>SOB</td>
<td>13</td>
<td>2.0000</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>1.16619</td>
</tr>
<tr>
<td>SOB Severity</td>
<td>13</td>
<td>.9231</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>1.01678</td>
</tr>
<tr>
<td>Feeling Warm/Flushed</td>
<td>15</td>
<td>1.8462</td>
<td>2.00</td>
<td>1.00</td>
<td>3.00</td>
<td>.83390</td>
</tr>
<tr>
<td>Feeling Warm/Flushed Severity</td>
<td>15</td>
<td>.8462</td>
<td>2.00</td>
<td>.00</td>
<td>2.00</td>
<td>.83390</td>
</tr>
<tr>
<td>Sweating</td>
<td>11</td>
<td>1.8462</td>
<td>3.00</td>
<td>1.00</td>
<td>4.00</td>
<td>.88056</td>
</tr>
<tr>
<td>Sweating Severity</td>
<td>11</td>
<td>.8462</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>.83390</td>
</tr>
<tr>
<td>Weakness</td>
<td>21</td>
<td>2.3077</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>1.08699</td>
</tr>
<tr>
<td>Weakness Severity</td>
<td>21</td>
<td>1.1923</td>
<td>3.00</td>
<td>.00</td>
<td>3.00</td>
<td>.84943</td>
</tr>
<tr>
<td>Poor Appetite</td>
<td>5</td>
<td>1.4231</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>.98684</td>
</tr>
<tr>
<td>Condition</td>
<td>Count</td>
<td>Mean</td>
<td>SD</td>
<td>Median</td>
<td>Min</td>
<td>Max</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------</td>
<td>--------</td>
<td>-------</td>
<td>--------</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Poor Appetite Severity</td>
<td>5</td>
<td>.4000</td>
<td>3.00</td>
<td>0.00</td>
<td>3.00</td>
<td>.91287</td>
</tr>
<tr>
<td>Nausea</td>
<td>9</td>
<td>1.4615</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>.85934</td>
</tr>
<tr>
<td>Nausea Severity</td>
<td>9</td>
<td>.5769</td>
<td>3.00</td>
<td>0.00</td>
<td>3.00</td>
<td>.98684</td>
</tr>
<tr>
<td>Difficulty Sleeping</td>
<td>19</td>
<td>2.8077</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>1.49718</td>
</tr>
<tr>
<td>Difficulty Sleeping Severity</td>
<td>19</td>
<td>1.2308</td>
<td>3.00</td>
<td>0.00</td>
<td>3.00</td>
<td>.95111</td>
</tr>
<tr>
<td>Chest Pressure when heart racing</td>
<td>16</td>
<td>2.3077</td>
<td>4.00</td>
<td>1.00</td>
<td>5.00</td>
<td>1.22537</td>
</tr>
<tr>
<td>Chest Pressure when heart racing Severity</td>
<td>16</td>
<td>1.0385</td>
<td>3.00</td>
<td>0.00</td>
<td>3.00</td>
<td>.95836</td>
</tr>
<tr>
<td>Chest Pressure when heart not racing</td>
<td>12</td>
<td>1.7308</td>
<td>2.00</td>
<td>1.00</td>
<td>3.00</td>
<td>.87442</td>
</tr>
<tr>
<td>Chest pressure when heart not racing Severity</td>
<td>12</td>
<td>.7692</td>
<td>2.00</td>
<td>0.00</td>
<td>2.00</td>
<td>.90808</td>
</tr>
</tbody>
</table>
## Appendix P: Independent T-test-Age Differences in Perception.

Independent samples T-test. Age differences in perception.

<table>
<thead>
<tr>
<th>Variable</th>
<th>t</th>
<th>DF</th>
<th>Sig.</th>
<th>Mean</th>
<th>95% Confidence Interval</th>
<th>Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Light-headedness/dizziness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>severity below</td>
<td>2.363</td>
<td>24</td>
<td>.027</td>
<td>.84524</td>
<td>.10692 .58365</td>
<td></td>
<td></td>
</tr>
<tr>
<td>68 and N 11</td>
<td>Mean</td>
<td>2.0000</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>above</td>
<td>Mean</td>
<td>1.0714</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor Appetite Severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>67 and N 11</td>
<td>2.184</td>
<td>23</td>
<td>.039</td>
<td>.74675</td>
<td>.03941 .45409</td>
<td></td>
<td></td>
</tr>
<tr>
<td>below</td>
<td>Mean</td>
<td>.8182</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>68 and N 14</td>
<td>Mean</td>
<td>.0714</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>67 and N 11</td>
<td>2.192</td>
<td>24</td>
<td>.038</td>
<td>.69048</td>
<td>.04049 .34047</td>
<td></td>
<td></td>
</tr>
<tr>
<td>below</td>
<td>Mean</td>
<td>1.818</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>68 and N 14</td>
<td>Mean</td>
<td>1.142</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea Severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>67 and N 11</td>
<td>2.713</td>
<td>24</td>
<td>.012</td>
<td>.94048</td>
<td>.22510 .65585</td>
<td></td>
<td></td>
</tr>
<tr>
<td>below</td>
<td>Mean</td>
<td>1.0909</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>68 and N 14</td>
<td>Mean</td>
<td>.1429</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix O: Rest to Activity Table

<table>
<thead>
<tr>
<th>Rest</th>
<th>Mild Activity</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Red = heart related perceptions</strong></td>
<td><strong>Blue = respiratory related perceptions</strong></td>
<td></td>
</tr>
<tr>
<td>Anne - first noticed a pounding in her chest while sitting or reading</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brenda - laid down after first experiencing dizziness and nausea and began to notice her heart racing as she lay on her left side</td>
<td>Brenda - first became aware of her symptoms after lunch when she became nauseated and dizzy.</td>
<td></td>
</tr>
<tr>
<td>Ben's first noticeable symptom was lethargy. Falling asleep while reading or watching television</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinton - first noticed his heart racing while sitting in his chair watching television.</td>
<td>Clinton - described experiencing heart racing while on the golf course over a period of several years.</td>
<td></td>
</tr>
<tr>
<td>Donna - Described palpitations that would come on at night while laying on her left side</td>
<td>Donna gradually became aware of her symptoms attributing her SOB to asthma. She described noticing SOB while walking especially when she came to a hill.</td>
<td></td>
</tr>
<tr>
<td>Dan - awoke in the morning and noticed his heart was fluttering while he was still in bed. He then proceeded to seek treatment at the ER.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ellen - noticed her heart racing at night when she laid down.</td>
<td>Ellen - would experience SOB and fatigue with exercise. She noticed she couldn’t handle the amount of activity she was use too.</td>
<td></td>
</tr>
<tr>
<td>Edward - first noticed symptoms while laying down at night. He described his heart as fibrillating and the feeling of blood rushing from one side to the other.</td>
<td>Farah - described first becoming aware of her heart during stressful events. She noticed while at work and under stress, she would feel what she described as a ‘flop’ or palpitation, almost as if someone had startled her.</td>
<td></td>
</tr>
<tr>
<td>Gillian - first noticed fluttering at night while trying to fall asleep</td>
<td>Gillian - also experienced a lack of energy or fatigue while exercising</td>
<td></td>
</tr>
<tr>
<td>Helen - first noticed what she described as heart pounding at night when she was going to sleep or asleep.</td>
<td>Fred - first noticed a ‘flutter’ or ‘murmur’ in the evening after supper. He also described experiencing a lack of concentration or focus while at work.</td>
<td></td>
</tr>
<tr>
<td>Irene - first noticed an upset stomach while trying to fall asleep. She described it as her stomach coming out or a rumbling inside.</td>
<td>Greg - first became aware of SOB while walking and swimming. He described not being able to keep up with the group during walking</td>
<td></td>
</tr>
<tr>
<td>Henry - described experiencing his first symptoms while laying down at night or sitting in his chair where he could feel his heart racing. Henry also described</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rest</td>
<td>Mild Activity</td>
<td>Activity</td>
</tr>
<tr>
<td>------</td>
<td>--------------</td>
<td>---------</td>
</tr>
<tr>
<td>experiencing restless legs when he would try to sit still.</td>
<td>Joyce had no awareness of symptoms until after diagnosis. She now experiences flutters when she awakes in the morning. <strong>Also described mild SOB in the morning</strong></td>
<td>John described becoming aware of a heavy heartbeat, sweating and nausea while exercising an occasionally in the shower.</td>
</tr>
<tr>
<td><a href="#">Joyce</a> woke in the morning with heart racing and palpitations and went to the ER</td>
<td>Isaac awoke in the morning with heart racing and palpitations and went to the ER</td>
<td></td>
</tr>
<tr>
<td>Also described mild SOB in the morning</td>
<td><a href="#">Karen</a> also experienced fatigue, falling asleep a lot while watching TV</td>
<td>Karen first noticed SOB with walking especially when she came to a hill.</td>
</tr>
<tr>
<td><a href="#">Isaac</a> awoke in the morning with heart racing and palpitations and went to the ER</td>
<td><a href="#">John</a> described becoming aware of a heavy heartbeat, sweating and nausea while exercising an occasionally in the shower</td>
<td></td>
</tr>
<tr>
<td>Kevin first noticed a heart pounding or flutter at night when he was going to sleep but never thought too much about it. He also developed chest pain while sitting on his deck having a glass of wine.</td>
<td><a href="#">Karen</a> also experienced fatigue, falling asleep a lot while watching TV</td>
<td></td>
</tr>
<tr>
<td><a href="#">Karen</a> also experienced fatigue, falling asleep a lot while watching TV</td>
<td><a href="#">Len</a> first became aware of his SOB while playing tennis. He had to quit the match early because of his severe breathing difficulties.</td>
<td>Monty first noticed SOB and heart racing while golfing. He explained his symptoms would become very noticeable with every hill he had to walk up.</td>
</tr>
<tr>
<td><a href="#">Kevin</a> first noticed a heart pounding or flutter at night when he was going to sleep but never thought too much about it. He also developed chest pain while sitting on his deck having a glass of wine.</td>
<td><a href="#">Lydia</a> awoke with a racing heart in the middle of the night. She described intense symptoms like a heartbeat she could hear and see pounding in her chest, and almost fainting.</td>
<td></td>
</tr>
<tr>
<td><a href="#">Lydia</a> awoke with a racing heart in the middle of the night. She described intense symptoms like a heartbeat she could hear and see pounding in her chest, and almost fainting.</td>
<td><a href="#">Margret</a> first experienced heart racing and light-headiness with mild activity such as working or showering.</td>
<td>Monty first noticed SOB and heart racing while golfing. He explained his symptoms would become very noticeable with every hill he had to walk up.</td>
</tr>
<tr>
<td><a href="#">Margret</a> first experienced heart racing and light-headiness with mild activity such as working or showering.</td>
<td><a href="#">Neil</a> awoke in the middle of the night and became aware of his heart pounding. He described how he could actually see his heart beating in his chest.</td>
<td>Monty first noticed SOB and heart racing while golfing. He explained his symptoms would become very noticeable with every hill he had to walk up.</td>
</tr>
</tbody>
</table>