

UCSF

UC San Francisco Electronic Theses and Dissertations

Title

The Development and Evaluation of a Mindfulness-Education Intervention to Reduce Symptoms and Improve Quality of Life Among Patients with Paroxysmal Atrial Fibrillation

Permalink

<https://escholarship.org/uc/item/7kx0r48g>

Author

Ottoboni, Linda

Publication Date

2017

Peer reviewed|Thesis/dissertation

The Development and Evaluation of a Mindfulness-Education Intervention to Reduce
Symptoms and Improve Quality of Life Among Patients with Paroxysmal Atrial
Fibrillation

Linda K. Ottoboni

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

In Nursing

In the GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Copyright 2017
by
Linda K. Ottoboni

Acknowledgements

The committee chair for this dissertation was Janine Cataldo, PhD, RN, Associate Professor and Chair, Department of Physiological Nursing. The other committee members included Jill Howie-Esquivel, PhD, ACNP, Associate Professor, University of Virginia; Frederick M. Hecht, MD, Professor of Medicine, UCSF; Mintu Turakhia, MD, MAS, Associate Professor, Palo Alto Veterans Medical Center; Roberta S. Rehm, PhD, RN, Professor, Department of Family Health Care Nursing.

The author wants to especially thank Dr. Janine Cataldo, for her direct supervision of the research, her consistent, tireless support, and the in-depth feedback received was instrumental to the study completion. The dissertation quality was further enhanced by the combined efforts of the entire committee, mentoring and sharing their unique perspectives throughout the study. Steve Paul, PhD, Principle Statistician, Department of Nursing, provided assistance with the detailed, comprehensive data analysis. A special thanks to the generous contribution from dear friend and meditation mentor, Cassie Schindler, for creating the meditation audios and video.

The author wants to thank the study participants who graciously shared their stories and took the time to engage in the activities of the intervention. Additionally, she wishes to acknowledge the influence of professional colleagues with which she has had the privilege to work beside throughout her nursing career. They have contributed to her ability to understand the complex concepts inherent in cardiac electrophysiology and unequivocally, they have provided the role modeling and inspiration to always deliver kind, compassionate patient care.

Last, but most importantly, a special thanks to my loving husband, Gary, and my family, Lucas and Katie, and Briana, for the sacrifices of family time they endured and for their enthusiasm, never-ending support, and encouragement throughout the entire project.

Abstract

Background:

Atrial fibrillation (AF) currently affects up to 5 million people in the US with a projected prevalence of up to 15 million by 2050. Patients with AF have the higher hospitalization rates compared with all other cardiovascular patients and AF is associated with an overall increase in mortality. Current treatment guidelines for AF include stroke risk reduction; along with rhythm restoration and rate control targeted at symptom reduction. Catheter ablations are the preferred treatment because they are able to restore normal conduction with a subsequent reduction in morbidity and mortality. Yet, rhythm restoration is not consistently achieved, so symptoms can prevail, along with a compromised quality of life (QOL). Therefore, there is a need for effective and affordable interventions that are focused on symptom reduction and improved QOL.

The symptom experience in individuals who live with paroxysmal atrial fibrillation is poorly understood. Symptoms associated with PAF can be disabling, often disproportionate to the severity of disease. There is limited knowledge related to the lived experience of individuals with PAF. Also, there is no conceptual model available to provide a foundation for the building of knowledge related to the clinical phenomenon of those living with PAF. The influence of negative illness perception, or a health perception more aligned with illness than wellness, has been associated with higher prevalence of symptoms and decreased QOL. Acquiring further insight into the lived experience, directly from patients, will enrich our understanding of the concepts that impact this patient population. There is little information related to patients challenges with PAF and what resources they would most benefit from to reduce symptoms, improve QOL and reduce their negative illness perception. An intervention that is designed

based on a conceptual model and direct patient recommendations will be tested for feasibility and efficacy on symptom reduction, QOL improvement, and reduced negative illness.

Objective: The specific aims of this dissertation were to: 1) Explore the lived experience of patients with PAF and collect ideas on resources they perceive are essential for managing PAF, 2) Develop a conceptual model that can be used to advance our knowledge related to the clinical experience of living with PAF; and to guide the design and evaluation of future interventions targeted at alleviating symptoms, improving overall QOL, and reducing negative illness perception for individuals with PAF, 3) Determine the feasibility and efficacy potential of a nurse delivered intervention that includes mindfulness meditation and education to reduce symptoms, decrease negative illness, perception and improve symptom outcomes (QOL and functional status).

Method: Based on a literature review and direct clinical experience with patients that experience PAF, a proposed conceptual model was constructed from the synthesis of two existing theories. The proposed conceptual model was foundational for the development of the two studies described below.

The first study, *Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation* used a constructivist Grounded Theory approach to obtain the direct thoughts and feelings of individuals with PAF. The GT design included the iterative process of open coding, memo writing, focused coding and finally, the generation of theoretical categories that provide the foundation for a conceptual model.

The second study, *A Feasibility and Efficacy Study of a Nurse Delivered Mindfulness-Education Intervention for Paroxysmal Atrial Fibrillation Patients to Reduce Symptoms, Decrease Negative Illness Perception, and Improve Symptom Outcome (QOL and functional*

status), was a mixed-methods study to evaluate the potential application and impact of a mindfulness-education intervention that was nurse delivered (MEND AF) was designed to support the challenges of living with PAF. The intervention was tested for its feasibility and efficacy using a prospective, pre-posttest, design to determine the effects of the intervention on symptoms, QOL, and negative illness perceptions. A nurse-led clinic in a single center provided symptomatic PAF patients with MEND AF, six weeks of assigned guided meditation practice and educational modules. Efficacy was evaluated using initial and final assessment measures: Symptom Frequency/Severity Checklist, Cardiac Anxiety Questionnaire, Fatigue Severity Scale, the Pittsburg Sleep Quality Index, and Atrial Fibrillation Effect on QOL Questionnaire.

The feasibility of MEND AF in terms of acceptability, recruitment, implementation, practicality, adaptation, and integration was achieved using mixed methods. The number of participants eligible compared to those recruited, enrolled and those who completed the intervention. The number of meditation practice minutes was self-reported. Descriptive, qualitative, semi-structured interviews were completed to collect data directly from the participants on their willingness to engage in the intervention, its perceived utility, the ease of engagement, and the clarity of education content.

Results: The GT qualitative study resulted in numerous patient narratives and the emergence of the major categories: Disruptive Symptoms, Altered Health Perception, AF Action Plan, and Quality of Life were constructed during the inductive data GT analysis with development of the theoretical code, “Designing Strategies to Enable Living Well with PAF”. The theoretical code provides a conceptual model for improved understanding of individuals with PAF and also for designing and evaluating interventions that may result in improved outcomes.

For MEND AF efficacy, a significant reduction in AF symptom frequency (19.71 to

13.14; $p=0.004$) and severity (15.46 to 11.04; $p=0.001$) was found. Anxiety, fatigue and sleep disturbance scores were decreased; but not significantly. A significant improvement in QOL (89.09 to 90.47; $p=0.011$) and subscales, Treatment Concern (89.50 to 91.34; $p=0.007$) and Symptom Severity (89.23 to 90.84; $p=0.003$).

For MEND AF feasibility, the intervention was deemed feasible based on qualitative and quantitative data. Over half of those eligible to participate, consented. Of those, 84% completed the intervention. All participants that completed the intervention, reported reading all of the modules and 85% practiced the recommended number of meditation minutes. All participants verbally stated that they found the intervention to be useful and enjoyable. All but one, anticipated continuing the meditation practice.

Conclusions: Participants struggle to meet the challenges of living with PAF. Necessary accommodations to effectively manage PAF were received with varied acceptance. The ability to regain a health perception more aligned with wellness than illness following the diagnosis of PAF was taxing for many, especially if PAF represented their first medical diagnosis. The ability to create an individualized integrative management plan was vital to the success of retaining a high QOL and minimizing symptoms. Participants felt that they had received inadequate education and resources to enable them to adjust to the diagnosis of PAF. Therefore, participants provided multiple ideas for desired resources to enhance outcomes in areas of education, support, and self-management strategies.

This study enabled the development of a novel conceptual model that can be used to design future patient interventions. The model will provide a foundation for intervention testing, but likewise, will allow testing of the model.

The mixed methods second study was the first study to examine the feasibility and efficacy of a mindfulness meditation and AF education intervention for PAF patients. The multifaceted intervention should be further evaluated with a control group or a factorial design to provide evidence that the intervention is more effective than components of the intervention or no intervention. Results suggest that individuals who struggle with symptoms and a reduced QOL from PAF could benefit from the MEND AF intervention, but will require additional testing to determine its clinical efficacy prior to broader implementation.

Table of Contents

Chapter 1 Introduction.....	1
Problem Statement.....	1
Background and Significance	2
Specific Aims.....	6
Study Design and Methods	6
Organization of the Dissertation	8
References.....	11
Chapter 2 Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation	16
Abstract.....	17
Introduction.....	18
Methods.....	19
Results.....	21
Category 1: Disruptive Symptoms.....	22
Category 2: Altered Health Perception	24
Category 4: Quality of Life.....	28
Conceptual Model.....	29
Discussion	30
Conclusion	35
References.....	36
Figure 2.1. Proposed Conceptual Model: Self-Regulation Symptom Management Model	39
Chapter 3 The Development of a Conceptual Model to Design and Evaluate Interventions that Enables Individuals to Live Well with Paroxysmal Atrial Fibrillation.....	45

Abstract	46
Introduction.....	47
Critique of Relevant Theoretical Models.....	48
Proposed Conceptual Model: The Self-Regulation Symptom Management Model	54
Using the SSMM to Design a Nurse Delivered Mindfulness and Education Intervention	56
The Conceptual Model: Designing Strategies to Enable Living Well with PAF	58
Conclusion	60
References.....	62
 Chapter 4 A Mindfulness-Education Intervention that is Nurse Delivered to Reduce Symptoms and Improve Quality of Life in Patients with Paroxysmal Atrial Fibrillation the MEND-AF Study.....	 74
Abstract.....	75
Introduction.....	76
Methods.....	78
Results.....	82
Discussion.....	84
References.....	88
 Chapter 5: Conclusion	 103
Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation	103
A Conceptual Model to Guide the Development and Evaluation of an Intervention that Enables Individuals to Live Well with PAF	105
A Mindfulness-Education Intervention that is Nurse Delivered to Reduce Symptoms and Improve Quality of Life in Patients with Paroxysmal Atrial Fibrillation: MEND-AF Study	105
Limitations	106

Summary	107
References	109

List of Figures

Figure 1.1. Proposed Conceptual Model: Self-Regulation Symptom Management Model	5
Figure 2.1. Proposed Conceptual Model: Self-Regulation Symptom Management Model.....	39
Figure 2.2. Positional Mapping Of Experiences And Perceived Needs.....	40
Figure 2.3. Conceptual Model: Designing Strategies to Enable Living Well with PAF.....	41
Figure 3.2. Five Domains of Illness Representations.....	67
Figure 3.3. Conceptual Model of the Relationships between Illness Representations, Coping Strategies, Symptoms and Psychological Stress.	68
Figure 3.4. Conceptual Model of the Theory of Symptom Management	69
Figure 3.5. Conceptual Model of the Self-Regulation Symptom Management Model.....	70
Figure 3.6. The Conceptual Model for the Evaluation of MEND AF.....	71
Figure 3.7. Theoretical Framework for Designing and Evaluating Interventions for Individuals with Paroxysmal Atrial Fibrillation.....	72
Figure 3.8. The New Conceptual Model to Evaluate MEND AF.....	73
Figure 4.1. Participant Screening and Recruitment Process.....	95
Figure 4.2. MEND AF Weekly Phone Guide.....	96

List of Tables

Table 2.1. Demographics from the Population.....	42
Table 2.2 –AF ACTION PLAN – Prescribed Plan and Individualized Plan	43
Table 4.1. MEND AF Study Procedures	97
Table 4.2. MEND AF Weekly Assignments	98
Table 4.3. MEND AF Demographic Data of Participants.....	99
Table 4.4. Medical History	100
Table 4.5. PAF Treatment History	101
Table 4.6. MEND AF t-Tests and Effect Sizes for Initial and Final Scores on Measured Variables	102

Chapter 1: Introduction

Problem Statement

Atrial fibrillation (AF) is the most common heart rhythm disorder, currently affecting at least six million people and responsible for annual treatment costs of \$6.6 billion (Chugh et al., 2014; Kim, Johnston, Chu, Dalal, & Schulman, 2011). AF is expected to impact 12-15 million people by the year 2050 due to its increasing prevalence with age and association with cardiovascular risk factors (Miyasaka et al., 2006; Naderi et al., 2014).

AF occurs when multiple, deviant, atrial electrical signals replace the single, electrical impulse that normally initiates atrial and ventricular contraction. The subsequent irregular rhythm and loss of atrial contraction causes atrial blood pooling. Atrial blood pooling or stasis contributes to a five-fold greater risk of stroke from clot dislodgement than for those in normal sinus rhythm (Mozaffarian et al., 2016). The irregular rhythm and often, rapid rate contributes to substantial symptoms during AF (e.g. palpitations, shortness of breath, chest pain, fatigue, anxiety, dizziness, exercise intolerance, and insomnia (Patel et al., 2014). Many individuals with AF experience a symptom burden and reduced quality of life (QOL) that is disproportionate to the severity of the disease (Dorian et al., 2000), while others have no symptoms at all (Thompson et al., 2014). Symptoms associated with AF are poorly understood, because they are not consistently associated with the recurrence of AF or a rapid heart rate (Patel et al., 2014). Specifically, those individuals with paroxysmal atrial fibrillation (recurrent, unexpected episodes of AF that spontaneously revert to normal sinus rhythm in < 7 days) were rated as having more debilitating symptoms using a European Heart Rhythm Association Symptom Classification (1-4; asymptomatic to disabling symptoms), and a consistently lower QOL (Freeman et al., 2015), than individuals with persistent AF (continuous AF > 7 days) or chronic AF (continuous AF > 12

months). A conceptual model to further our understanding of the clinical phenomena of symptoms in those individuals with paroxysmal atrial fibrillation (PAF) is needed.

Current AF Management Guidelines are primarily aimed at stroke reduction and AF elimination with lesser emphasis being placed on symptom management strategies (Kirchhof et al., 2016). However, treatments that focus on the elimination of AF (e.g., catheter/surgical ablations, electrical cardioversions, and medications) are costly and are often ineffective for long-term restoration of normal sinus rhythm and elimination of symptoms (citation).

With the projected increase in the incidence of AF, its associated morbidity and mortality and health care costs; more affordable and effective interventions are needed to decrease symptom burden and improve QOL for patients with AF. Therefore, the foci of this dissertation were to construct a conceptual model on the clinical phenomena of symptoms in PAF and to develop an intervention to reduce symptoms and improve QOL in patients with PAF.

Background and Significance

Atrial fibrillation (AF) is the most common cardiac arrhythmia disorder in the United States, affecting up to two percent of the general population (Chugh, Roth, Gillum, & Mensah, 2014). AF is an irregular rhythm driven by multiple, chaotic, electrical signals that replace the single atrial impulse that sustains normal sinus rhythm. The loss of atrial contraction during AF can cause a subsequent decrease in cardiac output, especially when accompanied by a rapid ventricular rate; and result in atrial blood pooling and stasis, increasing the risk of stroke from clot dislodgement. AF symptoms include palpitations, shortness of breath, chest pain, dizziness, anxiety, fatigue, and sleep disturbance (M. Rienstra et al., 2012). Increased frequency and severity of specific AF symptoms, such as anxiety (Thrall, Lip, Carroll, & Lane, 2007), sleep disturbance (Goren, Liu, Gupta, Simon, & Phatak, 2013), and fatigue have been consistently

associated with decreased quality of life (QOL) and an increased number of hospitalizations (Freeman et al., 2015).

AF is classified by symptom onset, duration and termination and is categorized as paroxysmal (self-terminating within 7 days), persistent (lasts longer than 7 days), or permanent (AF is accepted and rhythm control efforts cease; Paulus Kirchhof et al., 2016). One classification of AF is paroxysmal atrial fibrillation (PAF) that includes sporadic episodes of AF lasting for at least 30 seconds with spontaneous termination and a return to normal sinus rhythm in less than seven days. (Calkins et al., 2017). The abrupt onset of PAF can be distressing and PAF patients report greater AF symptom severity than patients with persistent AF (Freeman et al., 2015; Patel et al., 2013) .

Patients with AF have an increased stroke and all-cause mortality risk when compared with individuals in normal sinus rhythm (Lubitz et al., 2013; Mozaffarian et al., 2015). Current AF Management Guidelines focus primarily on the reduction of stroke risk, the restoration of a normal sinus rhythm, and heart rate control. A lesser emphasis is now placed on the alleviation of AF symptoms (Paulus Kirchhof et al., 2016). There are three approaches to AF treatments: 1) stroke risk reduction treatments (i.e., aspirin, anti-coagulants and/or life style changes) (Paulus Kirchhof et al., 2016); 2) heart rate control while in AF (i.e., medications) and 3) heart rhythm maintenance or restoration to sinus rhythm (i.e., medications, cardioversions, and catheter/surgical ablations) (Calkins et al., 2017) . Rhythm restoration with catheter/surgical ablation is the preferred treatment due to the documented morbidity and mortality associated with AF (Chyou, Hunter, Mollenkopf, Turakhia, & Reynolds, 2015; Miyasaka et al., 2006). Yet, the superiority of rhythm control for decreasing morbidity/mortality compared to rate control has not been proven (Hagens et al., 2004; Roy et al., 2008; Wyse, Waldo, DiMarco, Rosenberg, &

Schron, 2002). When a catheter ablation results in sinus rhythm restoration, AF symptom reduction and improved QOL are often achieved (Brachmann et al., 2017; Calkins et al., 2017; Takigawa et al., 2014). However, maintenance of sinus rhythm is challenging and despite comprehensive treatment, AF often recurs and AF symptoms persist (Gehi et al., 2012; Thompson et al., 2014). Therefore, effective non-invasive interventions that target AF symptom reduction are needed.

Recently, management of PAF has included the integration of mind-body practices along with more traditional treatments for the improvement of physical, mental, emotional, and spiritual well-being (Lakkireddy et al., 2013). There is evidence that Yoga intervention outcomes are associated with a reduced number of PAF occurrences, decreased anxiety levels, and improved QOL (Doliwa, Rosenqvist, & Frykman, 2012; Lakkireddy et al., 2013). Two clinically relevant components of yoga are movement and meditation, but movement can be difficult for some AF patients. Meditation, without movement has been found to reduce both symptom frequency and severity in patients with coronary artery disease (Olivo, Dods; Ray et al., 2014; Schneider et al., 2012 Nyklíček, I., Dijkstra, S. C., Lenders, P. J., Fonteijn, W. A., & Koolen, J. J. (2014) . To date, the effect of meditation on AF symptoms among PAF patients has not been studied.

The initial diagnosis of PAF can be unanticipated, perceived as a serious health threat, and result in a negative illness perception. A negative illness perception is a perception that is more aligned with illness than wellness (Dalteg, Benzein, Sandgren, Fridlund, & Malm, 2013; P. J. McCabe, Rhudy, & DeVon, 2015), is positively associated with both AF symptom frequency and severity (Foxwell, Morley, & Frizelle, 2013) and is inversely associated with QOL (Lane, Langman, Lip, & Nouwen, 2009). There is empirical evidence that an improved understanding

of AF etiology, the disease process and its treatment is associated with a decrease in negative illness perception (P. J. McCabe & Barnason, 2012; P. J. McCabe, Schad, Hampton, & Holland, 2008). Therefore, research is needed to test whether a mindfulness meditation, education on AF etiology, and AF disease treatment has the potential to reduce AF symptom frequency and severity, decrease negative illness perception, and improve both QOL and functional status among patients with PAF.

A proposed conceptual framework to guide this dissertation is presented in Figure 1.

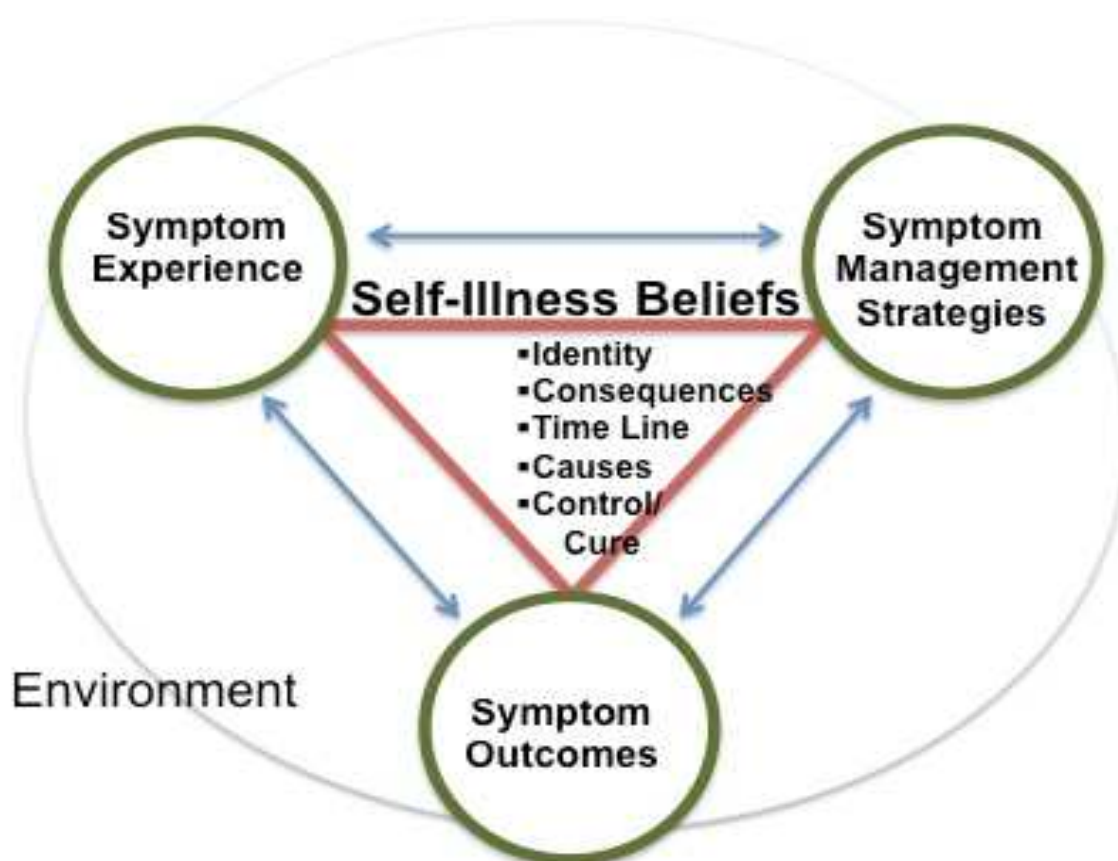


Figure 1.1. Proposed Conceptual Model: Self-Regulation Symptom Management Model

The concepts from the Symptom Management Theory: 1) symptom experience, 2) symptom management, and 2) symptom outcomes. Self-illness beliefs, from the Self-Regulation Model are reliant on the five domains of illness representation: identity, consequences, time line, causes, control, and cure. The environment is influential to all of them as when, where, you are, and whom you are with can change the entire experience.

Specific Aims

The specific aims of this dissertation were to: 1) Explore the experiences and perceived needs of those living with paroxysmal atrial fibrillation; 2) Develop a conceptual model to guide the design and evaluation of an intervention that enables individuals to live well with PAF, and 3) Determine the feasibility and efficacy potential of a nurse delivered intervention that includes mindfulness meditation and education to reduce symptoms, decrease negative illness perception and improve symptom outcomes (QOL and functional status).

Study Design and Methods

This mixed methods study began with a literature review of existing theoretical symptom management models and evidenced based clinical practice for individuals with AF. A proposed conceptual model, the Self-Regulation Symptom Management Model (SSMM) was developed to represent the clinical phenomena of AF was developed. The SSMM included the integration of key concepts from two previously existing theories, the Symptom Management Theory (Dodd et al., 2001) and The Theory of Self-Regulation (Bandura, 1991). The relationships between symptoms experienced, symptom outcomes and symptom management were the premise of the SSMM, but the inclusion of the concept of illness perception seemed essential to further include in the proposed conceptual model. Illness perception was included to further our understanding of the relationships between symptom frequency, symptom severity, and symptom outcomes, i.e., QOL, that could not be explained with the Symptom Management Theory, exclusively. This proposed conceptual model, SSMM, provided the fundamental foundation for the development of the interview guide used in the qualitative study and the design of the symptom management intervention.

The qualitative study, “*Experiences and Perceived Needs of People Living with Paroxysmal Atrial Fibrillation*” included in-person interview data acquired using an interview guide created from the original SSMM, field notes, and conceptual memos. The method of constructivist grounded theory (GT) was used to allow the exploration of various dimensions with the ultimate goal of developing a conceptual framework that would represent the experience of those individuals with PAF. The analysis of the GT study provided the categories of Disruptive Symptoms, Altered Health Perception, AF Action Plan and Quality of Life and the evolution of a novel theoretical framework, “*Designing Strategies to Enable Living Well with PAF*” which evolved from the analysis of the GT study and further advanced the preliminary theoretical model, the SSMM. This theoretical framework can be used in future design and evaluation of symptom management interventions for individuals with PAF and provide opportunities for further testing of the model.

The initial interviews from the qualitative study and the SSMM supported the design of the mixed-methods, interventional study, *A Feasibility and Efficacy Study of a Nurse Delivered Mindfulness-Education Intervention for Paroxysmal Atrial Fibrillation Patients to Reduce Symptoms, Decrease Negative Illness Perception, and Improve Symptom Outcome (QOL and functional status)*. Qualitative data was collected to determine the feasibility of the intervention, while pre-post quantitative measures were collected to evaluate the difference between the groups at baseline and after completion of the six-week intervention. The intervention was determined to be feasible based on demand, acceptability, integration, acceptability, demand, and implementation; and has the potential to reduce overall AF symptom frequency/severity and the specific symptoms of anxiety, fatigue, and sleep disturbance; decrease negative illness perception; and improve QOL and functional status.

Organization of the Dissertation

This dissertation consists of five chapters. This first chapter describes the clinical significance of atrial fibrillation, and paroxysmal atrial fibrillation (PAF), specifically. The clinical management of PAF is reviewed, along with the challenges faced by individuals with PAF to alleviate symptoms and restore their QOL. Specific study aims are provided and the methods to achieve them are reviewed. Chapters two, three, and four provide the manuscripts that have been written for submission and include details of the studies completed along with their findings and opportunities for translation into practice. Chapter five concludes the dissertation with an overview of the research and its contribution to the body of knowledge related to symptom management of patients with PAF.

Chapter two presents the first manuscript entitled, “*Experiences and Perceived Needs of People Living with Paroxysmal Atrial Fibrillation*”. Chapter two is focused on the first aim of the dissertation, explore the lived experience of patients with PAF and collect ideas on resources they perceive are essential for managing PAF. Chapter two presents the study design, sample, methods and results of the grounded theory, qualitative study completed on individuals with PAF. The purpose of this manuscript was to further our understanding of the perceived experiences and needs of those with PAF. The results of Chapter two provide us with clear examples of the gaps in current care provided and patient unmet needs. Additionally, it highlights participants’ ideas for resources that can be provided to potentially alleviate symptoms and improve their QOL. This grounded theory study supported the development of the conceptual model that is described in Chapter three. This manuscript has been accepted for submission to the journal, *Nursing Research*.

Chapter three is a manuscript that describes the evolution of a conceptual model related to the clinical phenomena of PAF. This chapter will address the second aim of the dissertation, develop a conceptual model to guide our future study of symptom management in individuals with PAF. Chapter three is entitled, “*The Development of a Conceptual Model to Design and Evaluate Interventions That Enable Individuals to Live Well with Paroxysmal Atrial Fibrillation*”. This chapter will describe the preliminary theoretical exploration that progressed into the proposed conceptual model, the SSMM, and then the final evolution of the theoretical code, Designing Strategies to Enable Living Well with PAF. The development of this conceptual model can be used to guide the design and evaluation of symptom management interventions, along with future studies to test the model. This manuscript will be submitted to the *Advances in Nursing Science Journal*.

Chapter four is a manuscript entitled, “A Mindfulness-Education Intervention that is Nurse Delivered to Reduce Symptoms and Improve Quality of Life in Patients with Paroxysmal Atrial Fibrillation: the MEND-AF Study. This manuscript presents a subset of study findings from the mixed methods interventional study that was done [A Feasibility and Efficacy Study of a Nurse Delivered Mindfulness-Education Intervention for Paroxysmal Atrial Fibrillation Patients to Reduce Symptoms, Decrease Negative Illness Perception, and Improve Symptom Outcome (QOL and functional status)]. The manuscript will focus on the study findings relative to the third aim, but limited to the efficacy findings. It will provide the method, sample, quantitative results, and discussion relative to findings focused on the efficacy of the intervention in symptom reduction and improved QOL. This manuscript has been prepared for publication submission to the *Heart Rhythm Journal*.

The results from the mixed methods study that focused specifically on feasibility, the remainder of the third aim, will not be included in this dissertation. The feasibility and qualitative findings from the mixed methods study will be presented in a separate manuscript entitled, *“A Study to Determine the Feasibility of a Mindfulness-Education Intervention that is Nurse-Delivered to Patients with Paroxysmal Atrial Fibrillation.”* As of this time, the reporting of the measured pre-posttest findings related to illness perception and functional status have not been defined.

In chapter five, the findings from the dissertation are summarized and synthesized. The findings of the dissertation will be compared to current knowledge in this area, with indications for its utility. Limitations of each of the studies completed in the dissertation will be provided and opportunities for future research in this area will be explored.

References

- Bandura, A. (1991). Social Cognitive Theory of Self-Regulation. In *Organization Behavior and Human Decisions Processes* (Vol. 50, pp. 248–287). Palo Alto, CA: Academic Press. Retrieved from <http://ucsfcat.library.ucsf.edu/record=b1322524~S0>
- Brachmann, J., Lewalter, T., Kuck, K.-H., Andresen, D., Willems, S., Spitzer, S. G., ... Senges, J. (2017). Long-term symptom improvement and patient satisfaction following catheter ablation of supraventricular tachycardia: insights from the German ablation registry. *European Heart Journal*, 0, 1–10. <https://doi.org/10.1093/eurheartj/ehx101>
- Calkins, H., Hindricks, G., Cappato, R., Kim, Y.-H., Saad, E. B., Aguinaga, L., ... Yamane, T. (2017). 2017 HRS/EHRA/ECAS/APHRS/SOLAECE Expert Consensus Statement on Catheter and Surgical Ablation of Atrial Fibrillation. *Heart Rhythm*. <https://doi.org/10.1016/j.hrthm.2017.05.012>
- Chugh, S. S., Havmoeller, R., Narayan, K., Singh, D., Rienstra, M., Benjamin, E. J., ... Murray, C. J. L. (2014). Worldwide Epidemiology of Atrial Fib- A global burden of disease 2010 study. *Circulation*, 129, 837–847. <https://doi.org/DOI:10.1161/CIRCULATIONAHA.113.005119>
- Chugh, S. S., Roth, G. A., Gillum, R. F., & Mensah, G. A. (2014). Global Burden of Atrial Fibrillation in Developed and Developing Nations. *Global Heart*, 9(1), 113–119. <https://doi.org/10.1016/j.gheart.2014.01.004>
- Chyou, J. Y., Hunter, T. D., Mollenkopf, S. A., Turakhia, M. P., & Reynolds, M. R. (2015). Individual and Combined Risk Factors for Incident Atrial Fibrillation and Incident Stroke: An Analysis of 3 Million At-Risk US Patients. *Journal of the American Heart Association*, 4(7), e001723. <https://doi.org/10.1161/JAHA.114.001723>
- Dabrowski, R., Opolski, G., Włodarczyk, P., Kiliszek, M., & Ponikowski, P. (2014). Demographic and clinical characteristics of patients with atrial fibrillation and cardioversion as planned therapeutic option in the international registry of cardioversion of atrial fibrillation “RHYTHM-AF.” *Kardiologia Polska*. <https://doi.org/10.5603/KP.a2014.0067>
- Dalteg, T., Benzein, E., Sandgren, A., Fridlund, B., & Malm, D. (2013). Managing Uncertainty in Couples Living With Atrial Fibrillation: *The Journal of Cardiovascular Nursing*, 1. <https://doi.org/10.1097/JCN.0b013e3182a180da>
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., ... others. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33(5), 668–676.

- Doliwa, P. S., Rosenqvist, M., & Frykman, V. (2012). Paroxysmal atrial fibrillation with silent episodes: Intermittent versus continuous monitoring. *Scandinavian Cardiovascular Journal*, 46(3), 144–148. <https://doi.org/10.3109/14017431.2012.661873>
- Dorian, P., Jung, W., Newman, D., Paquette, M., Wood, K., Ayers, G. M., ... Luderitz, B. (2000). The impairment of health-related quality of life in patients with intermittent atrial fibrillation: implications for the assessment of investigational therapy. *Journal of the American College of Cardiology*, 36(4), 1303–1309.
- Foxwell, R., Morley, C., & Frizelle, D. (2013). Illness perceptions, mood and quality of life: A systematic review of coronary heart disease patients. *Journal of Psychosomatic Research*, 75(3), 211–222. <https://doi.org/10.1016/j.jpsychores.2013.05.003>
- Freeman, J. V., Simon, D. N., Go, A. S., Spertus, J., Fonarow, G. C., Gersh, B. J., ... others. (2015). Association Between Atrial Fibrillation Symptoms, Quality of Life, and Patient Outcomes. *Circulation: Cardiovascular Quality and Outcomes*, CIRCOUTCOMES–114.
- Freeman, J. V., Simon, D. N., Go, A. S., Spertus, J., Fonarow, G. C., Gersh, B. J., ... Piccini, J. P. (2015). Association Between Atrial Fibrillation Symptoms, Quality of Life, and Patient Outcomes Results From the Outcomes Registry for Better Informed Treatment of Atrial Fibrillation (ORBIT-AF). *Circulation: Cardiovascular Quality and Outcomes*, 8(4), 393–402. <https://doi.org/10.1161/CIRCOUTCOMES.114.001303>
- Gehi, A. K., Sears, S., Goli, N., Walker, T. J., Chung, E., Schwartz, J., ... Mounsey, J. P. (2012). Psychopathology and Symptoms of Atrial Fibrillation: Implications for Therapy: Gehi et al. Psychopathology and Symptoms of Atrial Fibrillation. *Journal of Cardiovascular Electrophysiology*, 23(5), 473–478. <https://doi.org/10.1111/j.1540-8167.2011.02264.x>
- Goren, A., Liu, X., Gupta, S., Simon, T. A., & Phatak, H. (2013). Quality of Life, Activity Impairment, and Healthcare Resource Utilization Associated with Atrial Fibrillation in the US National Health and Wellness Survey. *PLoS ONE*, 8(8), e71264. <https://doi.org/10.1371/journal.pone.0071264>
- Hagens, V. E., Ranchor, A. V., Van Sonderen, E., Bosker, H. A., Kamp, O., Tijssen, J. G. P., ... Van Gelder, I. C. (2004). Effect of rate or rhythm control on quality of life in persistent atrial fibrillation: results from the Rate Control versus Electrical Cardioversion (RACE) study. *J. Am. Coll. Cardiol*, 43(2), 241–257.
- Kim, M. H., Johnston, S. S., Chu, B.-C., Dalal, M. R., & Schulman, K. L. (2011). Estimation of Total Incremental Health Care Costs in Patients With Atrial Fibrillation in the United States. *Circulation: Cardiovascular Quality and Outcomes*, 4(3), 313–320. <https://doi.org/10.1161/CIRCOUTCOMES.110.958165>

- Kirchhof, P., Benussi, S., Kotecha, D., Ahlsson, A., Atar, D., Casadei, B., ... Zeppenfeld, K. (2016). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *European Heart Journal*, 37(38), 2893–2962. <https://doi.org/10.1093/eurheartj/ehw210>
- Lakkireddy, D., Atkins, D., Pillarisetti, J., Ryschon, K., Bommana, S., Drisko, J., ... Dawn, B. (2013). Effect of Yoga on Arrhythmia Burden, Anxiety, Depression, and Quality of Life in Paroxysmal Atrial Fibrillation. *Journal of the American College of Cardiology*, 61(11), 1177–1182. <https://doi.org/10.1016/j.jacc.2012.11.060>
- Lane, D. A., Langman, C. M., Lip, G. Y. H., & Nouwen, A. (2009). Illness perceptions, affective response, and health-related quality of life in patients with atrial fibrillation. *Journal of Psychosomatic Research*, 66(3), 203–210. <https://doi.org/10.1016/j.jpsychores.2008.10.007>
- McCabe, P. J., & Barnason, S. A. (2012). Illness Perceptions, Coping Strategies, and Symptoms Contribute to Psychological Distress in Patients With Recurrent Symptomatic Atrial Fibrillation: *The Journal of Cardiovascular Nursing*, 27(5), 431–444. <https://doi.org/10.1097/JCN.0b013e31821e7ab1>
- McCabe, P. J., Rhudy, L. M., & DeVon, H. A. (2015). Patients' experiences from symptom onset to initial treatment for atrial fibrillation. *Journal of Clinical Nursing*, 24(5–6), 786–796. <https://doi.org/10.1111/jocn.12708>
- McCabe, P. J., Schad, S., Hampton, A., & Holland, D. E. (2008). Knowledge and self-management behaviors of patients with recently detected atrial fibrillation. *Heart & Lung: The Journal of Acute and Critical Care*, 37(2), 79–90. <https://doi.org/10.1016/j.hrtlng.2007.02.006>
- Miyasaka, Y., Barnes, M. E., Gersh, B. J., Cha, S. S., Bailey, K. R., Abhayaratna, W. P., ... Tsang, T. S. M. (2006). Secular Trends in Incidence of Atrial Fibrillation in Olmsted County, Minnesota, 1980 to 2000, and Implications on the Projections for Future Prevalence. *Circulation July 11, 2006*, 114(2), 119–125. <https://doi.org/10.1161/CIRCULATIONAHA.105.595140>
- Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., ... others. (2016). Heart Disease and Stroke Statistics—2016 Update A Report From the American Heart Association. *Circulation*, CIR–0000000000000350.
- Naderi, S., Wang, Y., Miller, A. L., Rodriguez, F., Chung, M. K., Radford, M. J., & Foody, J. M. (2014). The Impact of Age on the Epidemiology of Atrial Fibrillation Hospitalizations. *The American Journal of Medicine*, 127(2), 158.e1–158.e7. <https://doi.org/10.1016/j.amjmed.2013.10.005>

- Nyklíček, I., Dijkstra, S. C., Lenders, P. J., Fonteijn, W. A., & Koolen, J. J. (2014). A brief mindfulness based intervention for increase in emotional well-being and quality of life in percutaneous coronary intervention (PCI) patients. *Journal of Behavioral Medicine*, 37(5), 135-44.
- Olivo, E. L., Dodson-Lavelle, B., Wren, A., Fang, Y., & Oz, M. C. (2009). Feasibility and effectiveness of a brief meditation-based stress management intervention for patients diagnosed with or at risk for coronary heart disease: A pilot study. *Psychology, Health & Medicine*, 14(5), 513–523. <https://doi.org/10.1080/13548500902890087>
- Patel, D., McConkey, N. D., Sohaney, R., McNeil, A., Jedrzejczyk, A., & Armaganijan, L. (2013). A systematic review of depression and anxiety in patients with atrial fibrillation: the mind-heart link. *Cardiovascular Psychiatry and Neurology*, 1–11. <https://doi.org/doi.org/10.1155/2013/159850>
- Patel, N., Chung, E. H., Mounsey, J. P., Schwartz, J. D., Pursell, I., & Gehi, A. K. (2014). Effectiveness of Atrial Fibrillation Monitor Characteristics to Predict Severity of Symptoms of Atrial Fibrillation. *The American Journal of Cardiology*, 113(10), 1674–1678. <https://doi.org/10.1016/j.amjcard.2014.02.022>
- Ray, I. B., Menezes, A. R., Malur, P., Hiltbold, A. E., Reilly, J. P., & Lavie, C. J. (2014). Meditation and Coronary Heart Disease: A Review of the Current Clinical Evidence. *The Ochsner Journal*, 14(4), 696–703.
- Rienstra, M., Lubitz, S. A., Mahida, S., Magnani, J. W., Fontes, J. D., Sinner, M. F., ... Benjamin, E. J. (2012). Symptoms and Functional Status of Patients With Atrial Fibrillation: State of the Art and Future Research Opportunities. *Circulation*, 125(23), 2933–2943. <https://doi.org/10.1161/CIRCULATIONAHA.111.069450>
- Roy, D., Talajic, M., Nattel, S., Wyse, D. G., Dorian, P., Lee, K. L., ... Waldo, A. L. (2008). Rhythm Control versus Rate Control for Atrial Fibrillation and Heart Failure. *New England Journal of Medicine*, 358(25), 2667–2677. <https://doi.org/10.1056/NEJMoa0708789>
- Schneider, R. H., Grim, C. E., Rainforth, M. V., Kotchen, T., Nidich, S. I., Gaylord-King, C., ... Alexander, C. N. (2012). Stress Reduction in the Secondary Prevention of Cardiovascular Disease: Randomized, Controlled Trial of Transcendental Meditation and Health Education in Blacks. *Circulation: Cardiovascular Quality and Outcomes*, 5(6), 750–758. <https://doi.org/10.1161/CIRCOUTCOMES.112.967406>
- Takigawa, M., Takahashi, A., Kuwahara, T., Okubo, K., Takahashi, Y., Watari, Y., ... Isobe, M. (2014). Long-Term Follow-Up After Catheter Ablation of Paroxysmal Atrial Fibrillation. *Circulation: Arrhythmia and Electrophysiology*, 7(2), 267–273. <https://doi.org/10.1161/CIRCEP.113.000471>

- Thompson, T. S., Barksdale, D. J., Sears, S. F., Mounsey, J. P., Pursell, I., & Gehi, A. K. (2014). The Effect of Anxiety and Depression on Symptoms Attributed to Atrial Fibrillation: Depression, Anxiety, And Atrial Fibrillation. *Pacing and Clinical Electrophysiology*, 37(4), 439–446. <https://doi.org/10.1111/pace.12292>
- Thrall, G., Lip, G., Carroll, D., & Lane, D. (2007). Depression, Anxiety, and Quality of Life in Patients With Atrial Fibrillation. *CHEST Journal*, 132(4), 1259. <https://doi.org/10.1378/chest.07-0036>
- Wyse, D. G., Waldo, A. L., DiMarco, J. P., Rosenberg, Y., & Schron,. (2002). A Comparison of Rate Control and Rhythm Control in Patients with Atrial Fibrillation. *New England Journal of Medicine*, 347(23), 1825–1833. <https://doi.org/10.1056/NEJMoa021328>

Chapter 2

Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation

Authors: 1. Linda K. Ottoboni, PhD(c), RN

University of California, San Francisco

Department of Physiological Nursing

2. Janine Cataldo, PhD, RN

University of California, San Francisco

Associate Professor and Chair, Department of Physiological Nursing

3. Roberta S. Rehm, PhD, RN, FAAN

University of California, San Francisco

Professor, Department of Family Health Care Nursing

Corresponding Author: Linda Ottoboni

(H) 1435 Enchanted Way, San Mateo, CA 94402

Email: lottoboni@ucsf.edu; Phone: 650-498-5914; Fax: 650-725-7568

Conflict of Interest: None for any author

Source of Funding: Legacy Grant from the Stanford Nursing Alumnae Fund

Target Journal: Nursing Research

Page number: 16, excludes title page, abstract, references, tables, figures

Number of tables/figures: 5

Format: AMA

Key Words: atrial fibrillation, symptom management, quality of life, grounded theory research

Abstract

Background: Paroxysmal atrial fibrillation (PAF) increases the risk of stroke and can result in pronounced symptoms. Current treatment modalities are targeted at stroke risk reduction, rhythm restoration, rate control, and symptom reduction. These may be inadequate in meeting the perceived needs of those with PAF. Engaging PAF patients in identifying resources they can use in their quest to achieve optimal outcomes is essential in designing patient-focused interventions.

Objective: Specific study aims were to: 1). Explore participants' experiences and expectations when living with PAF and, 2). Collect participants' ideas on which resources they perceive as being essential in managing PAF.

Method: We used a constructivist Grounded Theory approach, including the iterative process of open coding, memo writing, focused coding and finally, the generation of theoretical categories that provide the foundation for a conceptual model.

Results: The major categories: Disruptive Symptoms, Altered Health Perception, AF Action Plan, and Quality of Life were constructed during the inductive data analysis with development of the theoretical code, "Designing Strategies to Enable Living Well with PAF". The theoretical code provides a framework for identifying and evaluating interventions that may result in improved outcomes.

Conclusions: Participants' ability to incorporate the diagnosis of PAF into a revised health perception is vital to the success of creating an integrative management plan for living well with PAF. Participants provided multiple ideas for desired resources to enhance outcomes in areas of education, support, and self-management strategies.

Introduction

Atrial fibrillation (AF) is currently the most common cardiac rhythm disorder (Mozaffarian et al., 2016). Because of its increased prevalence with age and cardiac risk factors, it is estimated that it will impact 12 million people in the US by 2030 (Ball, Carrington, McMurray, & Stewart, 2013; Mozaffarian et al., 2016; Naderi et al., 2014).

In AF, the single electrical impulse responsible for normal sinus rhythm is replaced with multiple, chaotic, electrical signals that causing the atria to “quiver” rather than contract. Loss of atrial contraction during AF potentiates atrial clot formation, the substrate responsible for 25% of all strokes (Chyou, Hunter, Mollenkopf, Turakhia, & Reynolds, 2015; Go et al., 2014). Therefore, stroke prevention is the primary treatment strategy in the AF treatment guidelines (January et al., 2014; Kirchhof et al., 2016). The remainder of AF-guideline practices are targeted at AF elimination/reduction and heart rate management to provide symptom relief,

Previous studies report that AF patients, globally, struggle to manage their disease and retain living their lives as they had prior to AF. Individuals with AF may delay seeking initial treatment because the symptom presentation is intermittent or vague (McCabe, Rhudy, & DeVon, 2015), or they fear that their symptoms may represent a life-threatening disease (Dalteg, Benzein, Sandgren, Fridlund, & Malm, 2013; Ekblad, Rønning, Fridlund, & Malm, 2013; Hoegh et al., 2015). Lifestyle modifications implemented by individuals to adapt to AF have been highlighted in prior studies (Altioek, Yilmaz, & Rencüsoğullari, 2015; Ekblad, Rønning, Fridlund, & Malm, 2013; Hoegh et al., 2015). The perceived impact of those modifications on the quality of their lives and their families’ lives varied from little to significant impact (Dalteg, Benzein, Sandgren, Fridlund, & Malm, 2013; Hoegh et al., 2015). The inclusion of AF education was identified as a primary source of support for individuals with AF (Lane, Barker, & Lip, 2015).

An improved understanding of AF reinforces the importance of adherence to their prescribed treatment plan (Altiook et al., 2015; P. McCabe, 2011).

Yet, there are few interventions designed specifically to support the needs of individuals with AF to restore and maintain a normal life. Prior interventions for individuals with AF have been aimed at anticoagulation education and adherence (Clarkesmith, Pattison, Xuereb, & Lane, 2016); integrated care delivery model to improve guideline adherent practices (Hendriks et al., 2012); interventions for reduction of symptoms and AF occurrence that included yoga (Lakkireddy et al., 2013); acupuncture (Lombardi, Belletti, Battezzati, & Lomuscio, 2012), and nutritional supplements (Kanmanthareddy et al., 2015).

Atrial fibrillation is classified by frequency and duration; (a) paroxysmal atrial fibrillation (PAF)-sporadic episodes lasting >30 seconds and terminate spontaneously within <7 days, (b) persistent AF- sustained episode lasting > 7 days requiring medical intervention for termination, or (c) chronic AF-permanent AF with no further termination efforts (Kirchhof et al., 2016). Individuals with paroxysmal atrial fibrillation (PAF) have a high level of symptom severity (Freeman et al., 2015). Therefore, this study was completed on individuals with PAF, specifically, to acquire information on their lived experience with PAF and resources they believe are essential to preserving their quality of life. The specific study aims were to:

- 1) Explore participants' experiences and expectations when living with PAF and, 2) Collect participants' ideas on which resources they perceive as being essential in managing PAF.

Methods

Grounded Theory

The method of constructivist grounded theory (GT) was used to explore the perceived impact of AF on participants' lives and their perceived needs to achieve optimal QOL with the

goal of developing a conceptual model (Charmaz, 2014). Grounded theory is built on the conceptual foundation of Symbolic Interactionism (SI) or a perspective that presumes individuals act toward things based on the meanings of those things, and their meaning originates from the social interaction that individuals have with each other and are further shaped and managed through a self-interpretive process (Blumer, 1969).

Sample

Institutional Review Board approval was obtained from the investigators' university and recruitment sites. Participants were referred from clinics, contacted the researcher directly in response to recruitment flyers and snowball sampling, hearing about the study from other participants. Eligible patients were greater than 18 years old, had a PAF diagnosis within 3 years, a symptomatic PAF recurrence within 1 year, were English speaking, and did not have hearing or speech cognitive defects.

Data collection

Informed consent was obtained and participants provided demographic data, then were engaged in a 45 to 90-minute recorded interview in the clinic or a quiet, public location. An open-ended, semi-structured interview guide (see Table 1) was designed based on a conceptual model, the Self-Regulation Symptom Management Model, which combined the key concepts from The Symptom Management Theory (Dodd et al., 2001) and the Self-Regulation Theory (Leventhal & Cameron, 2012) (see Figure 1). This conceptual model was proposed so the study results would promote the design of a self-care intervention for PAF patients and allow further development of the conceptual model. Theoretical sampling was achieved by recruiting individuals that could provide data to fill in gaps around specific PAF experiences (Morse et al., 2016). Interviews were continued until theoretical saturation was achieved, whereby no new

theoretical insights were being collected and the conceptual understanding was well developed (Corbin & Strauss, 2015). Thereafter, member checking was done to confirm/clarify concepts that had been derived from the previous analysis.

Data Analysis

A multistep data analysis process was used, including open coding and focused coding using Dedoose, a qualitative software program (Charmaz, 2014). Field notes and conceptual memos were completed throughout the analysis to document the researchers' thoughts on relating codes and developing categories and finally, a theoretical code and conceptual model were developed. Reflexivity was incorporated into field notes and memos to allow the first author to reflect on prior clinical experience with AF patients as an arrhythmia CNS and to ensure that findings stayed true to the data collected (Charmaz, 2014). Because the iterative coding process occurred simultaneously with data collection, analysis was validated as emerging understandings and developing categories were discussed with participants in ongoing interviews. Positional mapping was used to explore and define the relationships between experiences and perceived needs of individuals with PAF (Clarke, 2005), Figure 2. Finally, a conceptual model was developed to indicate the relationships between the major categories and the theoretical code related to the phenomena of the AF lived experience and desired supports to optimize living well with AF, Figure 3.

Results

Approved consents were signed by eighteen participants who provided twenty interviews, including two second interviews completed for data clarification/expansion with demographics listed in Table 2.

Interviews represented a variety of experiences regarding challenges related to PAF. The details differed substantially amongst the individual participants, but four common theoretical categories emerged from the systematic data analysis of open coding, memos, and focused coding from the data: *Disruptive Symptoms*, *Altered Health Perception*, *AF Action Plan*, and *Quality of Life*. These categories provided evidence for the development of the conceptual model for the theoretical code, Designing Strategies to Enable Living Well with PAF.

Category 1: Disruptive Symptoms

Participants' initial presentation of PAF either struck with a vengeance when accompanied with high ventricular heart rates or they experienced spurious, vague, unexplained symptoms (e.g., episodic heart fluttering or reduced stamina), "At the beginning I wouldn't really know that I was in it until I'd kind of get this uneasy feeling and I'd think okay, great, I know something is happening" (P9). Some participants admitted that it persisted for several weeks, months, or even years without being diagnosed, "*Quite a while after I started having it- it was diagnosed (P12).*" During this time, they experienced an array of ambivalent feelings, e.g., confusion, fear, and anxiety. Most participants ignored transient and unfamiliar symptoms and blamed them on something else, believing them to be insignificant and unnecessary to report to their clinicians.

When symptoms could no longer be ignored, participants feared they represented a potentially serious illness and finally relayed concerns to their clinicians. A female participant shared her experience with her clinician who trivialized her symptoms, "*He reached across the desk, touched me on the forearm and said, 'It's anxiety or menopause. Go back to your primary care (P12).'*" When participants had symptoms that were misinterpreted as other health problems, e.g. flu, angina, and they were misdiagnosed, the prescribed treatment was

inappropriate and, thus, ineffective. This compounded their frustration and further delayed appropriate PAF treatment.

Five participants were diagnosed during their initial health care pursuit with unbearable symptoms and an irregular, rapid heart rate. Others with similarly substantial symptoms had PAF that terminated spontaneously prior to arriving at the health care facility and one participant recalled being told, *“Oh well, nothing’s happening now (P14)”*. These participants voiced their frustration with the inability to secure the electrocardiogram essential to confirm a PAF diagnosis, especially for those with transient, subtle symptoms. One participant wished she had been told sooner that her symptoms could have been related to AF, along with instructions on what she could have done to have improved the likelihood of getting it diagnosed sooner, as she recalled the words of a nurse during her fourth ED visit, *“You know, we’re concerned that you might be having atrial fib attacks (P7).”* Other participants shared similar experiences.

Following a diagnosis, symptoms were unique, but remained troublesome. A few participants recalled relayed their symptom experience, *“It’s uncomfortable but it’s not painful, it’s just unsettling (P9)”*; *“...there was definitely some shortness of breath and there was just this really, really, uncomfortable feeling of being very aware of my heartbeat and having it be so erratic (P5)”*. Another participant’s symptoms were distinct, *“the feeling of a heartbeat wildly, thumping in your chest like a ping pong ball (P10)”*. Those participants who did not experience substantial symptoms were more attentive to slight changes, *“I can stroll but I can’t walk and if I move in a normal way, I’d have to stop and rest (P12)”*; *“my heart tumbles and when I go into a-fib, there is a pause and then tumbling, and then it doesn’t come back to normal” (P11)*.

Category 2: Altered Health Perception

For 11 participants, PAF was their first major medical diagnosis, causing them to view themselves as ill along the illness-wellness continuum. The reality that their health may now be a limiting factor to their lives and future plans was startling. Asymptomatic individuals whose diagnosis was an incidental finding, e.g. treadmill test, screening ECG, experienced disbelief. These participants voiced the challenge of trying to incorporate a new, potentially chronic diagnosis, into their previous perception of good health. *“I had always viewed myself as healthy until they found AF on my ECG and that changes your perception of your personal well-being.”* (P7)

“Got my attention but not a direct health threat (P14)”, was the contrasting sentiment from a participant who imagined his symptoms had represented a much worse diagnosis, so the diagnosis of PAF was received with a sense of relief. Participants < 65 years were alarmed by the diagnosis and said that it forced them to acknowledge that they no longer controlled their own destinies. PAF could interfere with job responsibilities, caring for children, or participating in activities they enjoyed, *“this didn't come in my vision plans of being 47 and having something like this (P6)”*. Older participants accepted that PAF represented the natural evolution of aging, *“I don't think it's fixable and that it is – you know, maybe it's controllable but it's not going to go away and it's just a sign of getting older, which I hadn't really thought too much about (P9)”*

Participants voiced their need to acknowledge that a PAF recurrence could produce uncomfortable symptoms and arrive at an inopportune time, but the threat of a future stroke weighed more heavily. *“I think a lot about stroke, I would say that I am not always thinking about it but I am often thinking about it (P3)”*. The fear of a stroke during asymptomatic PAF occurrences was voiced by many participants, *“... that is something that I worry about- having*

silent episodes.... (P3)". Three participants voiced being particularly overwhelmed when their AF diagnosis was made while seeking treatment for stroke symptoms. The acute stroke event and the chronic AF diagnosis was especially impactful in altering their health perception, *"Having a stroke was a game changer (P2)."*

The interaction with clinicians, specifically at diagnosis, was pivotal in establishing their health perception. A positive interaction remembered by one individual, *"My internist told me, 'don't worry about it, lots of people have it and do well (P4)'"*. By contrast to those who recalled receiving more negative messages, *"You have atrial fib, don't worry. It's only going to get worse (P2); 'You're in atrial fibrillation and this is very dangerous... you could have a stroke and die (P5)"; and "the kind of stroke you're going to get is going to be massive; it will kill you (P14)"*. All participants with prescribed anticoagulants denied any reluctance to adhere to their regimen because of their desire to reduce their risk of stroke.

Finally, the diagnosis was often associated with a poor understanding of PAF; what it was, how they developed it, why they developed it, how it is treated, and whether it would go away. Their ability to put PAF into perspective was reliant on the information they received. *"This is a very common condition... for some people, it is very uncomfortable. For other people, it is not (P4)"* was a comment that a participant recalled with gratitude that he had received such simple, yet direct information.

Category 3: AF Action Plan

The AF Action Plan included both prescribed treatments and self-management activities. After diagnosis of PAF, each individual was promptly provided with a prescribed treatment plan that included medication and/or procedures. Most participants remembered that the details of the prescribed *AF Action Plan* were given to them, *"you will take these meds, at least for the next*

year and then we'll see (P16). But, none of them could recall being included in a discussion exploring the other available treatment options, nor the rationale for why the selected Action Plan had been chosen for them.

The first few weeks of embarking on the prescribed medical regimen were described as being particularly unpredictable, resembling a roller coaster, *“few days after I started the medication, I became light-headed...I felt very, very weak and I took my blood pressure and it was very low and my pulse was down to about 47(P15)”*. Participants experienced PAF recurrences, fast and slow heart rates, and medication side effects, e.g., hypotension and profound fatigue. Participants shared that they wondered why they had asked their providers few questions or no questions and reflected upon the complete trust they had of their clinicians during this vulnerable time. However, one participant had strong feelings about that trust being forfeited, *“I trusted them -until they screwed up- there is nothing in the world quite like misplaced trust (P2)”*.

Participants described their health condition using simple words, without certainty or a clear understanding, *“I know that they told me it was atrial fibrillation because of my heart valve, but I was not sure how they were connected (P10)”*. Unusual words were used to describe an electrical cardioversion, denoting fear and unfavorable memories, *“they can only try to electrocute you 3 times ... and then they were going to do the ablation and then the cardiovert (P2)”*; *“the most scary part of AF is having to go get my heart restarted.....(P5).”* Participants who had undergone an ablation(s) expressed gratitude to have gained time without AF, regardless of the duration or ultimate outcome. However, they also perceived the ablation procedure as overwhelming, especially one participant stating, *“It's a lot more than meets the eye... It's humbling but humiliating... It's been a difficult thing to go through (P5)”*

Participants, inclusive of all education levels, recalled their inability to understand what was shared with them by their clinician, due to their unfamiliarity with medical terminology, compounded by their inability to process what was being told to them, *“Doctors, You guys speak a different language—when you’re in a doctor’s office, you’ve got something that is threatening you- you don’t always remember what goes on (P1).”* All participants expressed the need to have deliberately designed AF information that was delivered in language they could understand, supplemented with written materials they could later review. Motivated participants described being overwhelmed by the number of websites related to AF when they pursued additional AF information via Internet access, and acknowledged that they would have benefitted from being directed to the most reliable sites. Most participants voiced a desire for more education from the health care team, but one participant did not perceive education to be the responsibility of the health team, *“They’re more inclined to say here’s the treatment. They’re not into the education business.... And that’s fine (P9.)”*

Participants recalled inadequate emphasis given to the discussion of creating an individualized AF Action Plan, e.g., identification of specific triggers, reducing associated risk factors, reviewing reportable treatment effects, and overcoming the challenges of incorporating the prescribed Action Plan into their daily lives. Beyond the prescribed treatments, only four participants described being given specific parameters and instructions about how they could personally contribute to the effectiveness of the AF Action Plan, *“but I also believe that providers are the key to success, they have a window of opportunity (P8)”*. One participant with the foresight to forge ahead by developing a personal strategy for managing a PAF recurrence stated, *“You can’t be reliable, you need to have an AF plan” (P18)*. Other participants described selecting places to travel based on health care availability, planning activities they enjoyed with

the inclusion of alternate plans if they experienced an AF recurrence, and packing additional medication for emergencies. Those with deliberate, pre-planned strategies to manage a PAF episode if it occurred were more able to perceive the recurrence as a detour, as opposed to derailment.

Category 4: Quality of Life

The impact that PAF had on the participants' lives depended largely on the frequency of PAF recurrences, symptoms, medication tolerance, procedures performed, and their ability to engage in enjoyable activities. But equally important or more important, was their response to their illness. One participant expressed her coping strategy was, *"keeping it out of your head and keeping it in your chest (P18)"*, which she explained was her conscious reminder not to dwell on the uncertainty of the next PAF recurrence or the increased risk of stroke, or it would affect her overall wellness. Another participant described a similar perspective; *"It's not like a toothache, right, where you're saying oh.... I think I just have to tough this out until I can get home. That's not the case with this atrial fib....So don't make it more – you know, don't get into a panic over this" (P9).*

One participant mourned the loss of his previous robust life, *"I do not have the stamina that I had before, it is easy to tell when I go for a bike ride with my buddies and I can't keep up (P6)."* The phenomenon of misguided activity reduction was reported by half of participants in this study and resulted in weight gain and increased stress, further contributing to an individuals' overall cardiovascular risk and potential PAF exacerbation. Many other participants described making the choice to discontinue activities they previously enjoyed, as this participant shared, *"I've lost a lot of motivation to write because this has been a very difficult chapter of my life- I*

tend to write things that are very positive and this experience for me has not been so positive. So, I've been on the sidelines with that (P4)."

"I believe that I have done as well as I have because I was proactive and self-directed (P8)". Those who perceived themselves as living well with AF were those participants who had accepted their diagnosis and were forging ahead, only in a slightly different direction, *"I'm different in this, ...But once I'm able to say okay, there's nothing I can do, there's a surrendering, a yielding that happens. And when that happens, – it's crazy to say, but kind of the symptom goes away (P8).* A few participants credited their keen awareness of their body, which enabled them to monitor their symptoms and optimally guide their activity choices, as key to their success, *"I think making people more body aware is really important (P4)".*

Conceptual Model

The major categories that emerged from this study were: *Disruptive Symptoms*, *Altered Health Perception*, *AF Action Plan*, and *Quality of Life*. The interactions and interdependence among the categories are illustrated in the conceptual model for the theoretical code, *Designing Strategies to Enable Living Well with PAF* (see Figure 3).

The category of Disruptive Symptoms characterizes symptom confusion prior to diagnosis, the uncertainty/fear of recurrence after diagnosis along with the varied symptoms that occur with PAF. Ultimately, symptoms lead to the pivotal point of a diagnosis that triggers a myriad of thoughts and emotions and often, shifts health perception from wellness to illness. The Altered Health Perception category represents the dynamic state of health perception that can impact the other categories with a shifting along the wellness-illness continuum. The prescribed portion of the AF Action Plan is determined promptly, with little or no emphasis on opportunities for self-management. Pre-occupation with illness motivated most participants to

engage in the prescribed portion of the AF Action Plan that was determined promptly by their health care provider, along with their own individualized AF Action Plan, which represents each person's efforts to regain their prior health state. The final category, Quality of Life, is interdependent on the residual symptom experience, the ability to integrate the diagnosis of PAF into a health perspective that aligned more closely with wellness than illness, and the effectiveness of the prescribed therapies and chosen self-management strategies to prevent and manage PAF occurrences. The categories affect one another, but the effect is continually filtered through the lens of Altered Health Perception.

Discussion

This study has provided narratives of participants that illustrate the challenging areas of managing PAF, but also highlights opportunities for resources that could be incorporated into the care of individuals with PAF to enhance symptom outcomes and improve QOL. In addition, this study enabled the development of a conceptual model that can be used for the design and evaluation of future symptom management interventions for individuals with PAF.

Participants in this study affirmed that the diagnosis of PAF unraveled their perception of health. The reality of their illness prompted a personal struggle and transition from perceived wellness to perceived illness as previously described by others (Auyeung et al., 2016; Dalteg et al., 2017; McCabe et al., 2011). However, the current study goes on to describe the successful incorporation of the AF diagnosis with participants validating that they can regain a perception of health that is more well and less ill, along the illness-wellness continuum. The progression through the dynamic process was unique for each, as they have different lives and different values in which they need to incorporate the diagnosis, consistent with other research (Ekblad et al., 2013; Hoegh et al., 2015). This study revealed that haphazard comments made by all

members of the health care team throughout their care lingered with individuals and greatly influenced their ability or inability to assimilate the diagnosis of PAF/AF into a more positive health perception. The manner in which the illness-wellness perception is framed within their lives impacted their symptom experience, the management strategies they engaged in, and their outcomes were defined by the combination of all of these factors.

The looming uncertainty of stroke and AF recurrence, adherence to treatment regimens, and required modifications are disruptive to maintaining a general sense of well-being. But, less clear, is 1) how much modification is tolerated before it significantly impacts QOL, 2) how much variation occurs between individuals, and 3) which resources are useful in reducing the impact on QOL. The variety of modifications required to accommodate AF with the least disruption was previously explored by others (Dalteg, Benzein, Sandgren, Fridlund, & Malm, 2014; Ekblad et al., 2013; Hoegh et al., 2015), but without consensus on the optimal degree of modification is tolerated before QOL is disrupted. Participants in this study mostly voiced acceptance of their prescribed AF Action Plan (i.e., anticoagulants and antiarrhythmics), which has not been consistently found in other studies (Clarkesmith, Lip, & Lane, 2017; Lane, Ponsford, Shelley, Sirpal, & Lip, 2006). In this study, those participants who perceived “accommodations” as their individualized strategy or plan, seemed to have a greater sense of wellness; possibly due to their sense of empowerment and ability to control, or at least impact, their PAF. Those that described the personal strategy that they had developed for managing PAF, their AF Action Plan, perceived it as essential to their success in living well with AF.

Clinical Implications

The results of this study support several key areas to guide clinical practice. Activity reduction is often a spontaneous “accommodation” that occurs because of increased fatigue

reducing motivation for exercising and the fear of prompting a recurrence of PAF. The overall reduction of cardiovascular risk factors has been shown to reduce symptoms and AF burden (Pathak et al., 2015), and our current AF guidelines (Kirchhof et al., 2016) recommend lifestyle changes be incorporated into patient education for improved prognostic gains, as well as achieving symptomatic goals (Abed et al., 2013; Mascitelli & Goldstein, 2013; Mattioli, Miloro, Pennella, Pedrazzi, & Farinetti, 2013; Pathak et al., 2014, 2015). Therefore, the inclusion of exercise guidelines and lifestyle modifications that promote cardiovascular risk reduction should be considered for each patient.

Delays in making a diagnosis of individuals with PAF/AF noted by McCabe (2012) over 5 years ago, continue to occur. Clinicians need to more effectively probe nebulous symptoms that are described by patients (i.e., unexplained lack of energy, fatigue, or sporadic heart irregularities) with hastier use of more accessible, more convenient, and more reliable ambulatory monitoring to screen and diagnose them (Byrnes & Costantini, 2017). This is especially true in older patients that have comorbidities associated with higher risk of AF (e.g. hypertension, diabetes, obesity, sleep apnea, heart failure) that are describing intermittent symptoms of dizziness, palpitations, and fatigue (Anumonwo & Kalifa, 2016; Chyou, Hunter, Mollenkopf, Turakhia, & Reynolds, 2015). These select, high risk groups could also benefit from targeted education about the signs/symptoms associated with AF with instructions to promptly report related or unexplained symptoms. Earlier referral to arrhythmia specialists (i.e., electrophysiologists and specialized AF advanced practice nurses) may promote prompt access to comprehensive education and guideline adherent clinical treatments (Hendriks et al., 2012).

The delivery of AF education is not consistently provided along the disease trajectory to enable individuals to incrementally comprehend the complexities of AF and AF treatment.

Initially, the health care team develops a prescribed treatment plan that is focused on stroke risk prevention and managing the rhythm disorder. At this point, less emphasis is placed on individual care goals because the patient's rudimentary understanding of PAF does not allow them to weigh in on treatment decisions without fully understanding the risks and benefits of available treatment options. participant narratives confirm that AF education provided during the initial presentation of PAF is overwhelming. Although the clinical presentation, itself, is not so difficult to comprehend, the relationships between electrical conduction, heart rate, heart function, symptoms, clot formation, stroke risk, treatment options, and goals of treatment contribute to its complexity. This phenomenon has been previously described by others (Clarkesmith et al., 2017; Lane, Aguinaga, et al., 2015; McCabe, 2011; McCabe et al., 2015). Therefore, simply reviewing reportable symptoms related to PAF recurrence, potential adverse treatment effects, and signs/symptoms of a stroke are important to emphasize at the initiation of treatment, with specific guidelines for contacting the clinician or seeking care more urgently.

Once a fundamental level of AF comprehension is attained, individuals with AF can more easily (a) define their personal goals for treatment, (b) engage in discussions related to exploring the treatment options and, (c) make treatment decisions. Then, respectful of the pronounced variance amongst individuals' desire to engage in the management of their AF, each individual should be given the opportunity and guidance to create a personally tailored AF Action Plan that embraces their priorities and motivations using appropriate strategies for that individual, see Table 2. According to current guidelines (Kirchhof et al., 2013; Kirchhof, et al., 2016; Lane, Barker, & Lip, 2015) clinicians have the responsibility to provide adequate education at optimal times so that individuals with PAF/AF can actively contribute to informed treatment decisions.

Unfortunately, the results from this study illustrate that many individuals do not reach the level of comprehension required to participate in treatment discussions such as these or they are never provided the occasion to do so. Participants recalled efforts made by their clinicians to engage in crucial conversations related to prognosis and treatment options, but at times that they were so overwhelmed by the enormity of the situation that they were unable to hear them, so timing of conversations is also critical. Thus, after ensuring that individuals are cognizant of the complexities of AF and its treatment, clinicians should consider spending time with individuals to create an individualized AF Action Plan that addresses each person's unique needs and willingness or reluctance to make accommodations. as it may be key in enabling them to restore their QOL or "live well" with PAF.

A variety of teaching methods (i.e., written materials, visuals, videos, websites, and interactive blogs) should be included in the arsenal of educational resources because everyone has different learning needs. Reliable, trustworthy websites should be highlighted to guide motivated individuals searching for additional AF information. The teach-back approach which has been used successfully in heart failure patient education, to determine ongoing comprehension of complex concepts (White, Garbez, Carroll, Brinker, & Howie-Esquivel, 2013), may be appropriate for PAF patients. Finally, education should provide: 1) content that is easily comprehended in layman terms, 2) clear, concise facts related to AF and its treatment with word selection that conveys empathy and compassion, 3) simple to complex principles delivered incrementally over time, and 4). education in a format that can be accessed at a time and place conducive to learning.

Strengths

Participants represented were varied in age, education and economics, included both men and women, and participants represented multiple clinic settings. Theoretical sampling was used to support development of the conceptual model and assure theoretical saturation.

Limitations

The sample size was small, from one region of the country, English speaking and predominantly Caucasian.

Conclusion

The conceptual model established in this study can be used to design and evaluate future interventions to reduce symptoms and improve the QOL in AF. Several education and self-management interventions have been identified that can be evaluated amongst PAF patient groups in the future to determine their impact on symptoms and QOL. A teach back strategy that emphasizes important concepts for patient education in PAF/AF patients should be designed and tested for improved understanding of AF.

References

- Altioik, M., Yilmaz, M., & Rencüsoğullari, I. (2015). Living with Atrial Fibrillation: An Analysis of Patients' Perspectives. *Asian Nursing Research*, 9(4), 305–311. doi.org/10.1016/j.anr.2015.10.001
- Auyeung, V., Patel, J. P., Abdou, J. K., Vadher, B., Bonner, L., Brown, A., ... Arya, R. (2016). Anticoagulated patient's perception of their illness, their beliefs about the anticoagulant therapy prescribed and the relationship with adherence: impact of novel oral anticoagulant therapy – study protocol for The Switching Study: a prospective cohort study. *BMC Hematology*, 16(1). https://doi.org/10.1186/s12878-016-0061-9
- Ball, J., Carrington, M. J., McMurray, J. J. V., & Stewart, S. (2013). Atrial fibrillation: Profile and burden of an evolving epidemic in the 21st century. *International Journal of Cardiology*, 167(5), 1807–1824. https://doi.org/10.1016/j.ijcard.2012.12.093
- Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Prentice-Hall.
- Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Los Angeles: Sage.
- Chyou, J. Y., Hunter, T. D., Mollenkopf, S. A., Turakhia, M. P., & Reynolds, M. R. (2015). Individual and Combined Risk Factors for Incident Atrial Fibrillation and Incident Stroke: An Analysis of 3 Million At-Risk US Patients. *Journal of the American Heart Association*, 4(7), e001723. https://doi.org/10.1161/JAHA.114.001723
- Clarksmith, D. E., Lip, G. Y. H., & Lane, D. A. (2017). Patients' experiences of atrial fibrillation and non-vitamin K antagonist oral anticoagulants (NOACs), and their educational needs: A qualitative study. *Thrombosis Research*, 153, 19–27. https://doi.org/10.1016/j.thromres.2017.03.002
- Dalteg, T., Benzein, E., Sandgren, A., Fridlund, B., & Malm, D. (2013). Managing Uncertainty in Couples Living With Atrial Fibrillation: *The Journal of Cardiovascular Nursing*, 1. https://doi.org/10.1097/JCN.0b013e3182a180da
- Dalteg, T., Sandberg, J., Malm, D., Sandgren, A., & Benzein, E. (2017). The heart is a representation of life: an exploration of illness beliefs in couples living with atrial fibrillation. *Journal of Clinical Nursing*, n/a-n/a. https://doi.org/10.1111/jocn.13742
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., ... others. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33(5), 668–676.
- Ekblad, H., Rønning, H., Fridlund, B., & Malm, D. (2013). Patients' well-being: experience and actions in their preventing and handling of atrial fibrillation. *European Journal of Cardiovascular Nursing*, 12(2), 132–139. https://doi.org/10.1177/1474515112457132

- Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., ... on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. (2014). Executive Summary: Heart Disease and Stroke Statistics--2014 Update: A Report From the American Heart Association. *Circulation*, 129(3), 399–410. <https://doi.org/10.1161/01.cir.0000442015.53336.12>
- Hoegh, V., Cummings, E., Riahi, S., Lundbye-Christensen, S., Frederiksen, K., & Delmar, C. (2015). A year in the life of a person recently diagnosed with atrial fibrillation in Denmark. *International Journal of Person Centered Medicine*, 5(4), 166–181.
- January, C. T., Wann, L. S., Alpert, J. S., Calkins, H., Cleveland, J. C., Cigarroa, J. E., ... Yancy, C. W. (2014). 2014 AHA/ACC/HRS Guideline for the Management of Patients With Atrial Fibrillation A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines and the Heart Rhythm Society. *Circulation*, CIR.0000000000000041. <https://doi.org/10.1161/CIR.0000000000000041>
- Kirchhof, P., Benussi, S., Kotecha, D., Ahlsson, A., Atar, D., Casadei, B., ... Zeppenfeld, K. (2016). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *European Heart Journal*, 37(38), 2893–2962. <https://doi.org/10.1093/eurheartj/ehw210>
- Lane, D. A., Aguinaga, L., Blomström-Lundqvist, C., Boriani, G., Dan, G.-A., Hills, M. T., ... Hurwitz, J. (2015). Cardiac tachyarrhythmias and patient values and preferences for their management: the European Heart Rhythm Association (EHRA) consensus document endorsed by the Heart Rhythm Society (HRS), Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE). *EP Europace*, 17(12), 1747–1769. <https://doi.org/10.1093/europace/euv233>
- Lane, D. A., Barker, R., & Lip, G. Y. H. (2015). Best Practice for Atrial Fibrillation Patient Education. *Current Pharmaceutical Design*, 21(5), 533–543.
- Lane, D. A., Ponsford, J., Shelley, A., Sirpal, A., & Lip, G. Y. H. (2006). Patient knowledge and perceptions of atrial fibrillation and anticoagulant therapy: Effects of an educational intervention programme. *International Journal of Cardiology*, 110(3), 354–358. <https://doi.org/10.1016/j.ijcard.2005.07.031>
- Leventhal, H., & Cameron, L. D. (2012). *Common Sense Model of Self-Regulation of Health and Illness*. Taylor and Francis/Hoboken.
- McCabe, P. (2011). What patients want and need to know about atrial fibrillation. *Journal of Multidisciplinary Healthcare*, 413. <https://doi.org/10.2147/JMDH.S19315>
- McCabe, P. J., Barnason, S. A., & Houfek, J. (2011). Illness Beliefs in Patients with Recurrent Symptomatic Atrial Fibrillation: Patients with Symptomatic AF. *Pacing and Clinical Electrophysiology*, 34(7), 810–820. <https://doi.org/10.1111/j.1540-8159.2011.03105.x>

- McCabe, P. J., Rhudy, L. M., & DeVon, H. A. (2015). Patients' experiences from symptom onset to initial treatment for atrial fibrillation. *Journal of Clinical Nursing*, 24(5–6), 786–796. <https://doi.org/10.1111/jocn.12708>
- Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., ... others. (2016). Heart Disease and Stroke Statistics—2016 Update A Report From the American Heart Association. *Circulation*, CIR–0000000000000350.
- Naderi, S., Wang, Y., Miller, A. L., Rodriguez, F., Chung, M. K., Radford, M. J., & Foody, J. M. (2014). The Impact of Age on the Epidemiology of Atrial Fibrillation Hospitalizations. *The American Journal of Medicine*, 127(2), 158.e1-158.e7. <https://doi.org/10.1016/j.amjmed.2013.10.005>
- Pathak, R. K., Middeldorp, M. E., Meredith, M., Mehta, A. B., Mahajan, R., Wong, C. X., ... Sanders, P. (2015). Long-Term Effect of Goal-Directed Weight Management in an Atrial Fibrillation Cohort: A Long-Term Follow-Up Study (LEGACY). *Journal of the American College of Cardiology*, 65(20), 2159–2169. <https://doi.org/10.1016/j.jacc.2015.03.002>

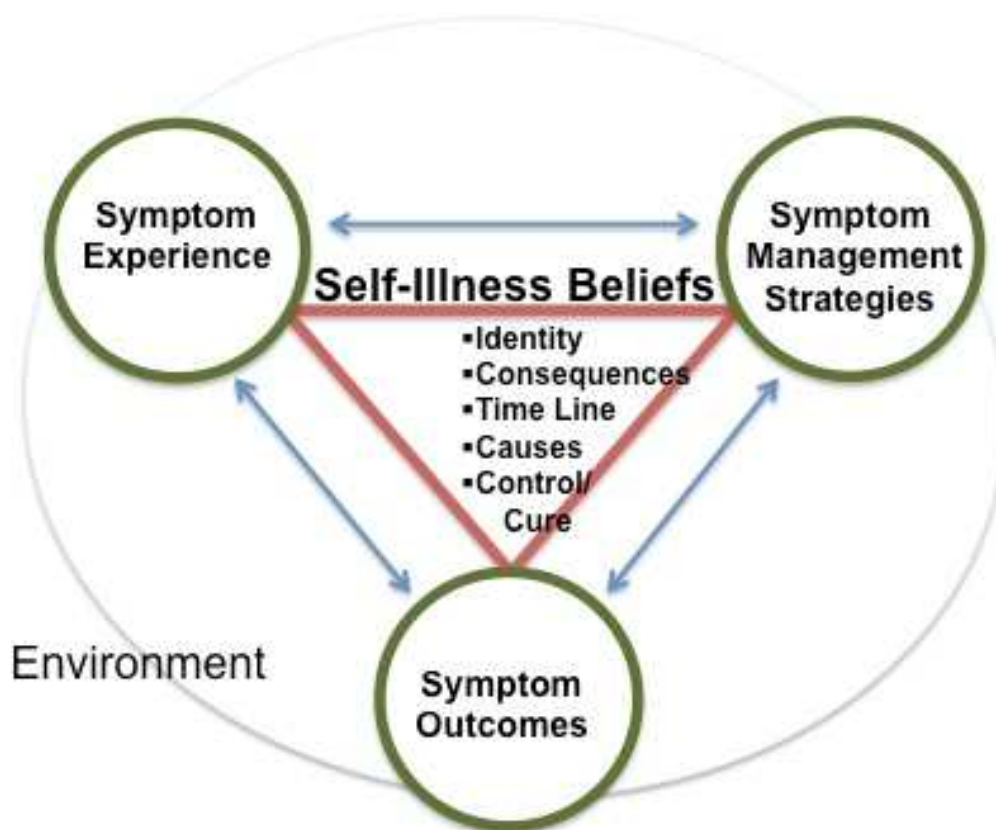


Figure 2.1. Proposed Conceptual Model: Self-Regulation Symptom Management Model

The three concepts from the Symptom Management Theory: symptom experience, symptom management and symptom outcomes. These dimensions are all included in the proposed conceptual model, Self- Regulation Symptom Management Model, with the inclusion of the self-illness beliefs or five domains of illness representation borrowed from the Self-Regulation Model: identity, consequences, time line, causes, control, and cure. The environment is influential to all of them as where you are, whom you are with, and when it is which can change the entire experience.

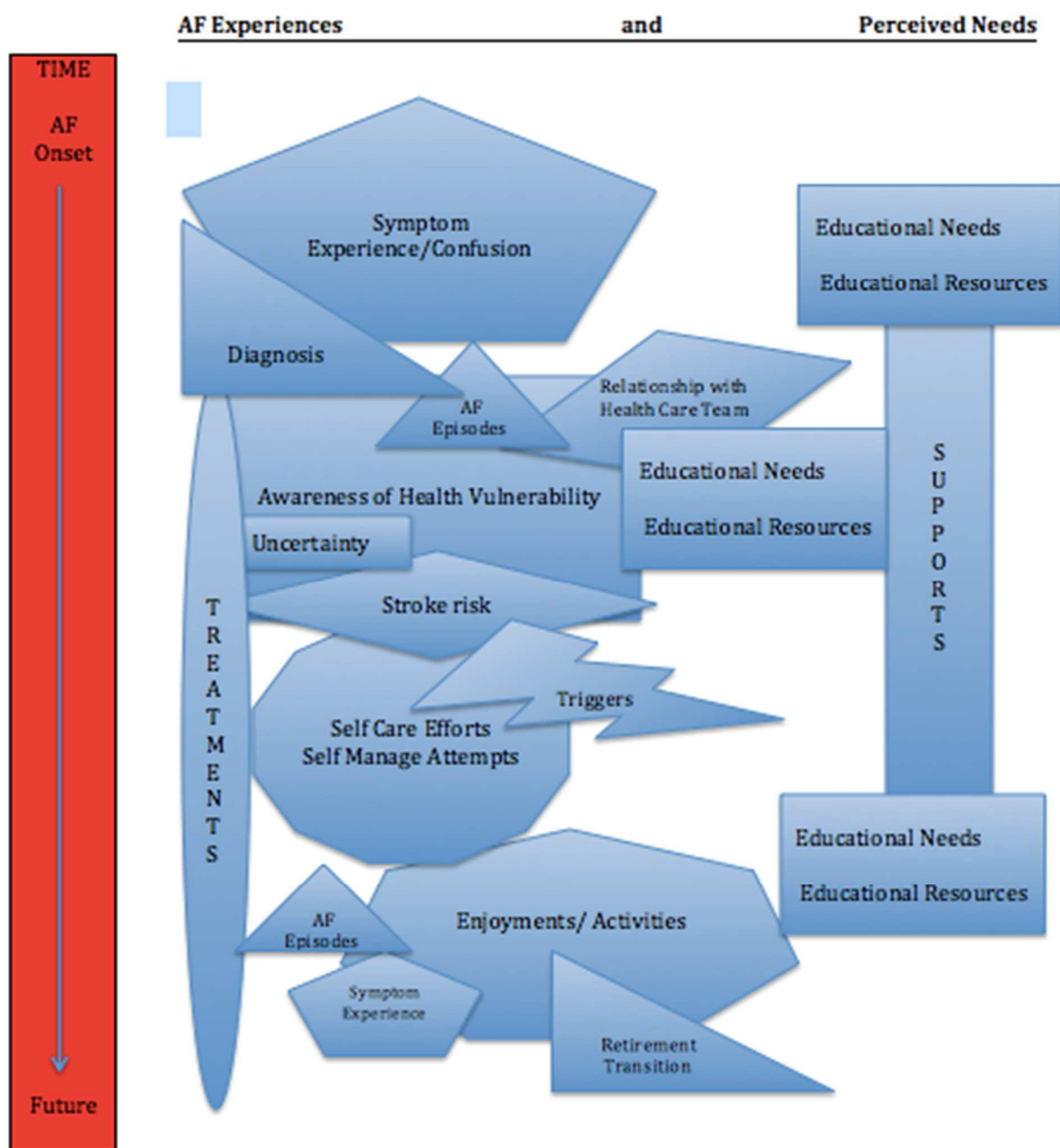


Figure 2.2. Positional Mapping Of Experiences And Perceived Needs

The vertical axis represents a timeline with diagnosis at the top and the future at the bottom. Horizontally, PAF experiences are on the left with perceived needs toward the right. There was a noted clustering of PAF experiences during initial diagnosis with some reduction over time spent with disease. Perceived need for resources was greater initially, as well, but support and education were desired throughout the timeline.

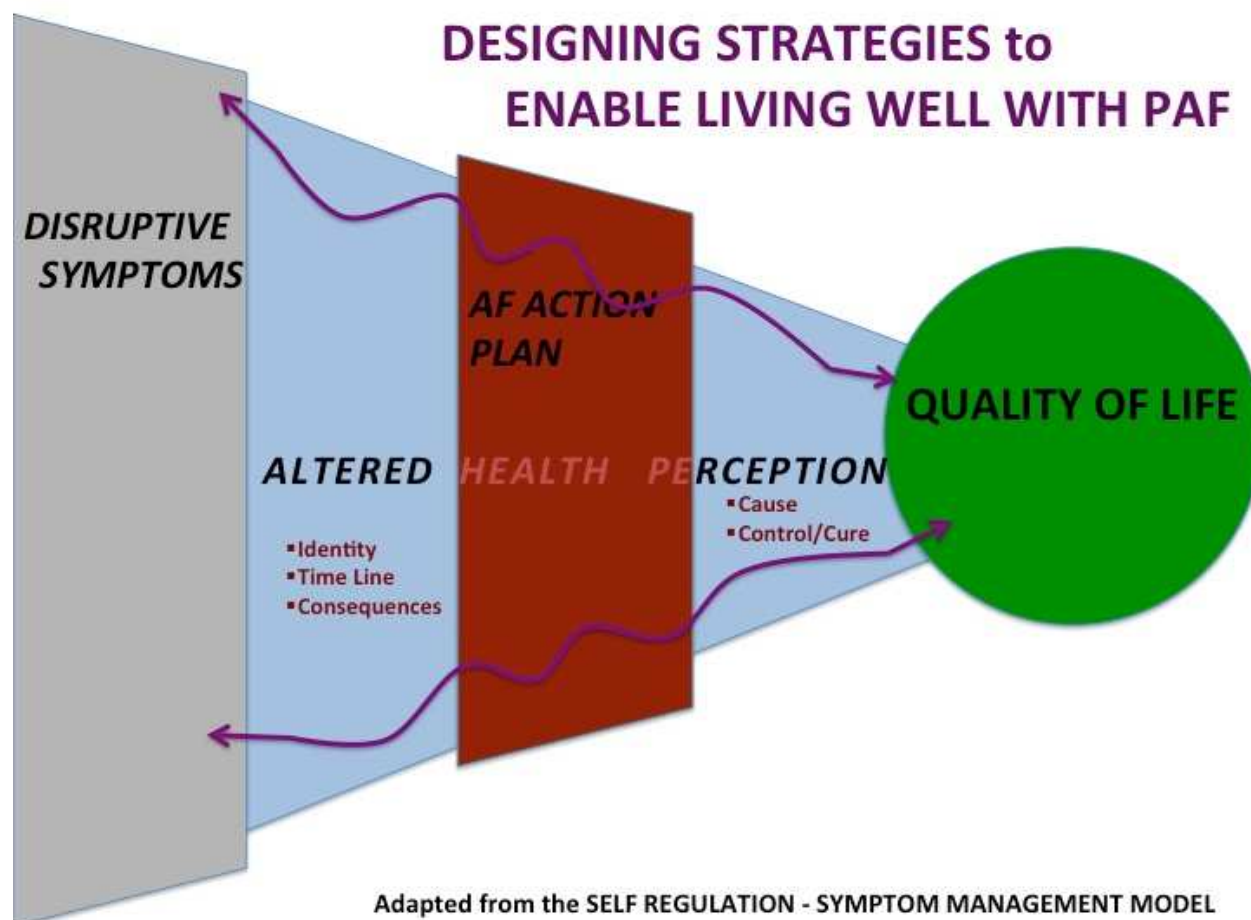


Figure 2.3. Conceptual Model: Designing Strategies to Enable Living Well with PAF

The theoretical code, *Designing Strategies to Enable Living Well with PAF*, resulted from this grounded theory qualitative study, providing a theoretical framework for the examination and evaluation of a symptom management intervention. Disruptive Symptoms represents the symptoms that are confusing and disruptive to normal life. Altered Health Perception represents the dynamic perception of health based on identity, time line, consequences, cause, control/cure associated with PAF. An AF Action Plan represents the prescribed plan that includes medication and procedures and the individualized plan that includes self-management strategies. Quality of Life represents the overall outcomes of PAF.

Table 2.1. Demographics from the Population

	M	(SD)
Age years (range 37-83)	64.83	(13.06)
BMI	28.11	(7.94)
Persons in Household	2.11	(1.02)
N=18	n	(%)
Male Gender	9	50.0
Race		
Asian	1	5.6
White	16	88.9
Hispanic	1	5.6
Education Level		
AA degree	2	11.2
BA/BS degree	3	16.7
Graduate Education	13	72.2
Employment Status		
Unemployed	3	16.7
Part Time	5	27.8
Full Time / Self-Employed	7	38.8
Retired	5	27.8
Health Insurance Coverage-Yes	18	100.0
Annual Household Income		
20-100,000	4	22.2
>100,000-200,000	5	27.8
>200,000	7	38.9
Not disclosed	2	11.1
Marital Status		
Single without partner	1	5.6
Married	13	72.2
Living with partner	2	11.1
Divorced/Widowed	2	11.1
Medications		
Rate Control	9	50.0
Rhythm Control	7	46.6
Anticoagulation	15	83.3
Comorbidities		
CAD/Heart Failure	4/1	22.2/5.6
Hypercholesterolemia/DM	4/0	22.2/0
Depression/Other	1/4	5.6/22.2

Table 2.2 – AF ACTION PLAN – Prescribed Plan and Individualized Plan

Strategies	AF Action Plan –Prescribed Medications and Procedures	AF Action Plan- Individualized Self- Management Strategy
AF Disease Education	<ul style="list-style-type: none"> • AF etiology and Disease Process • Treatment options – review medications and procedures for rhythm control and rate control 	
Stroke Risk Education	<ul style="list-style-type: none"> • How does AF contribute to a stroke? • Anticoagulation and Stroke Reduction • When is an Anticoagulant Prescribed? • Signs and Symptoms of a Stroke • Importance of Medication Adherence 	
What to Report and to Whom	<ul style="list-style-type: none"> • Potential Adverse Medication Affects • Specific Parameters on Rate and Rhythm that Needs to Be Reported • Specific information on whom to call 	
When Is Urgent Care Required	<ul style="list-style-type: none"> • Provide Specific Parameters that can Guide the Use of Emergent/Urgent care 	
Symptom Identification		<ul style="list-style-type: none"> • List Common AF Symptoms • Identify Your symptoms • Identify Symptoms that cause You Distress • Identify Strategies to Alleviate Distress if possible
Trigger Identification		<ul style="list-style-type: none"> • Define What Triggers Are • List Common Triggers • Provide Tracking Tool to Identify Prevalent Triggers • Determine what Triggers Can Be Avoided or Managed
Managing PAF Episode		<ul style="list-style-type: none"> • Be aware of how you feel prior to PAF episode- “differently?” • Identify options for responding to that sensation, e.g., yoga, meditation, deep breathing • Discuss parameters for managing an episode with your HC provider, i.e., heart rate, medications

Table 2.2 – AF ACTION PLAN – Prescribed Plan and Individualized Plan (cont'd)

Strategies	AF Action Plan – Prescribed	AF Action Plan- Individualized
Additional Strategies to Reduce Your Risk of AF		<ul style="list-style-type: none"> • Sleep apnea evaluation and treatment • Cardiovascular risk factor reduction in any areas that exceed American Heart Association recommendations (blood pressure, weight, cholesterol, blood sugar, diet, activity, or smoking) • Manage stress- engage in strategies (e.g., meditation, yoga, tai chi, biofeedback, acupuncture) • Recognize depression and obtain treatment

CHAPTER 3

The Development of a Conceptual Model to Design and Evaluate Interventions that Enables Individuals to Live Well with Paroxysmal Atrial Fibrillation

Authors: Linda K. Ottoboni, PhD(c), RN, FHRS_{1,2}

Roberta Rehm, PhD, RN₂

Jill Howie-Esquivel, PhD₃

Janine Cataldo, PhD, RN₂

₁Stanford Healthcare, 300 Pasteur Drive, Stanford, CA 94305

₂Department of Physiological Nursing, University of California, San Francisco, CA

₃School of Nursing, University of Virginia, Charlottesville, VA 22908

Corresponding Author: Linda Ottoboni

(H) 1435 Enchanted Way, San Mateo, CA 94402

Phone: 650-498-5914; Fax: 650-725-7568

Conflict of Interest: None (any of the authors?)

Source of Funding: Indirectly, GT study -Legacy Grant from Stanford Nursing Alumnae

Page limit:15-30

Number of figures/tables: 8 (Limit 8)

Journal of interest: Advances in Nursing Science

Abstract

This paper provides a conceptual model to support the premise that symptom reduction and improved QOL may be as important for individuals living with paroxysmal atrial fibrillation (PAF) as restoration of normal rhythm. Without an adequate theory to describe the clinical phenomena of patients that experience PAF, the *Self-Regulation Symptom Management Model (SSMM)* evolved. It was a synthesized, proposed model from two relevant theories (the Symptom Management Theory and the Theory of Self-Regulation). Finally, a theoretical code, *Designing Strategies to Enable Living Well with PAF*, that emerged from the grounded theory, data analysis is presented.

Key Words:

Paroxysmal atrial fibrillation, atrial fibrillation, grounded theory, conceptual model, symptom management, theoretical framework

Statement of Significance:

The symptom experience in individuals who live with paroxysmal atrial fibrillation is poorly understood. No conceptual model previously existed to explain or examine this clinical phenomenon, nor to advance symptom management. Therefore, this paper provides a novel conceptual model that can be used to design future interventions and will allow for testing of the model.

Introduction

Atrial fibrillation (AF) is the most common cardiac rhythm disorder, affecting 1-2% of the entire population¹, and because of its increased prevalence with age it rises to 10% in those > 80 years old². AF is an independent predictor for mortality and is responsible for a five times greater risk of stroke than those in normal sinus rhythm³. AF is characterized by chaotic, irregular, electrical signals that bombard the ventricles causing an irregular, often rapid, heart rate. Irregularity and the absence of synchronized atrial contractions compromise cardiac performance and can result in symptoms of palpitations or noted heart irregularity, shortness of breath, chest pain, fatigue, anxiety, dizziness, exercise intolerance, and insomnia⁴. Symptom severity does not necessarily correlate with frequency or duration of AF, as some people experience severe symptoms in the absence of arrhythmias, while others have few or no symptoms with extensive arrhythmia occurrences^{5,6}.

Stroke prevention, rhythm restoration, rate control and cardiovascular risk reduction are the primary treatment goals for AF^{7,8,9}. AF management based on current guidelines does not ensure that symptoms are minimized or that QOL is optimized. Yet, both are important and there is evidence that symptom distress and reduced QOL are associated with increased hospitalizations and mortality¹⁰. Reported symptom severity in AF is widely variable, does not consistently correlate with AF incidence, and may be significantly influenced by anxiety¹¹. Compared to healthy controls, individuals with AF have a greater reduction in QOL. When compared to individuals with significant structural cardiovascular disease, individuals with AF continue to have a greater reduction in QOL^{12,13}, especially for those with paroxysmal and permanent AF¹⁴. Individuals with paroxysmal atrial fibrillation (PAF) are the targeted

population of this theoretical discussion because the abrupt, recurrent episodes that are characteristic of PAF are often associated with increased symptoms and anxiety¹⁵.

The purpose of this paper is to present a theoretical model to support the premise that treatment and care goals that include symptom relief and improved QOL may be as important as the absence of arrhythmias for this population. This paper will: 1) provide a critique of two theoretical models relevant to the experience of PAF patients: the Symptom Management Theory and the Theory of Self-Regulation; 2) introduce the initial conceptual model of the *Self-Regulation Symptom Management Model (SSMM)*; 3) apply the SSMM to the development and evaluation of a mindfulness meditation and education intervention, that is nurse delivered, for the reduction of symptoms among patients with PAF (MEND-AF), and 4) describes the evolution of SSMM to the conceptual model, *Designing Strategies to Enable Living Well with PAF*.

Critique of Relevant Theoretical Models

Two theories were reviewed, the Symptom Management Theory and the Theory of Self-Regulation, for their general applicability to the phenomenon of PAF and the inclusion of the theoretical constructs of symptom distress and self-management strategies.

Theory of Self-Regulation (TSR)

The TSR was developed to explain factors that influenced decision making related to making behavior change. More specifically, the theory was used to identify and better understand factors associated with either resistance or motivation to change. The original TSR was based on the principle that people possess self-reflective and self-reactive capabilities that enable them to exercise control over their own thoughts, beliefs, motivation and actions¹⁶, along with the idea that action will only be taken if there is a discrepancy between what one has and what one wants. Initially, the TSR comprised three concepts: Self Observation, Judgment

Feedback, and Self-Reaction (see Figure 1). Self-regulation, emotional and behavioral, implies that choices are made based on anticipated consequences, and then goals are set with the motivation to produce behaviors that are intended to meet personal intentions and desires. Self-regulation occurs when a group of psychological sub-functions are developed and activated for self-directed change¹⁷.

The TSR evolved over time to a perceptive, cognitive model of self-regulation. Rather than its application being limited to behavior modification, the newly revised theory provides a model that represents the complexity of concepts associated with the response to illness. The TSR borrowed from Lazarus's Stress and Coping Theory¹⁹ and attempts to identify domains that influence a patient's perceptions, appraisals and coping mechanisms related to their illness (see Figure 2). Illness representations are the focus of TSR and represent the cognitive "common-sense" domains of health threats: 1) Identity (kind of disease and its symptoms, e.g. flu with cough and cold); 2) Time-line (e.g., disease onset, treatment time, and duration); 3) Causes (i.e., reason why they feel they have the illness); 4) Imagined or real consequences (e.g., loss of work); and 5) Control (i.e., degree to which disease can be controlled, cured, or prevented²⁰. Each individual develops an illness representation based on the five domains of illness perceptions and external stimuli (e.g., family member with diabetes, or being informed of being at high risk for developing diabetes). Therefore, illness representation is dynamic and can be altered by a change occurring within any one of the five domains of illness perceptions or external stimuli.

A new diagnosis generates the development of an illness representation based on the individual's current illness perceptions and compared to their previous health assessment. If their illness perception is more negative or more aligned with illness than wellness, it prompts a

response to make a change, or self-regulate. This response is the coping strategy, (procedure or action) which is triggered, and evolves related to past experience. For example, if cough medicine works to relieve a cough, then a person uses it again. However, if the cough medicine works initially and then fails, another strategy would most likely be used to manage the cough. Coping strategies are selected based on their expected benefit, perceived dose-response relief, anticipated time line, and potential consequences¹⁸. Disease threats external to the person can trigger an avoidance coping strategy. Therefore, coping strategies are dynamic, altered by changes in illness representation and previous effectiveness.

The TSR was used to study people with PAF and persistent AF who experienced symptoms compared to those with AF that did not experience symptoms²¹. The measure of Illness Perception included the five cognitive domains of illness perceptions in the formation of an illness representation in the TSR: disease identity, time line, causes, consequences, and cure. Emotional coping, problem focused coping, venting of emotion, mental disengagement, and behavioral disengagement were included in a coping measure, COPE. The Psychosocial Adjustment to Illness Scale (PAIS) measured health orientation, domestic environment, extended family relations, social environment, and psychological distress. The only difference in illness perceptions between the symptomatic and asymptomatic groups was “disease identity”, which was significantly higher in the symptomatic group. Increased symptoms were positively correlated with increased psychological distress as measured by the PAIS. There was no correlation between disease severity and adjustment to illness. Illness perceptions were not found to be associated with coping strategies, but they were found to be inversely correlated with psychological adjustment. Thereby, suggesting more negative illness perceptions are associated with greater psychological distress, independent of symptoms.

McCabe²² conducted a similar study of the TSR comparing individuals with PAF and persistent AF with high symptom severity to those with a lower symptom severity (see Figure 3). Findings did not suggest that an increase in symptom severity contributed to greater psychological distress, but more negative illness perceptions were found to be associated with greater psychological distress, supporting the previous findings reported by Steed²¹. The two domains of illness perception, identity (disease and symptoms) and time-line (duration of disease and treatment) contributed to greater psychological distress, when patients were unable to understand the AF disease process and when AF was viewed as a cyclical, serious condition with social and financial consequences²². In addition, the single coping strategy, "focusing on and venting emotion," was found to be associated with higher psychological distress²². Therefore, illness perceptions that are more negative may have a greater impact on psychological distress than symptom experience; and less comprehension of the AF disease process and the treatment trajectory may be associated with less effective coping strategies, which in turn could increase psychological distress.

Symptom Management Theory (SMT)

The three essential components of the SMT include: 1) symptom experience, 2) symptom management strategies, and 3) symptom status outcomes (see Figure 4). These concepts are situated within the three spheres of nursing science dimensions: person, health/illness, and environment. The dimensions encircle the symptom concepts to depict the dynamic symptom presentation reliant on the context of the patient's environment, health status, beliefs, ideas, and presence of other symptoms²³. The SMT acknowledges the complex, yet authentic, experience of all persons.

The concept of symptom experience is the individual's perception, evaluation and response to a symptom, or the alteration from the person's "normal" state. An alteration from the "normal" state can be perceived in symptom frequency (how often), symptom severity (how bad), and distress (how bothersome). Symptom perception, symptom evaluation and symptom response are individual aspects of the symptom experience, but occur simultaneously and are interconnected and inter-reliant. The symptom experience may include one or several synergistic symptoms, known as symptom clusters

The second concept, symptom management strategies, includes any effort or strategy to reduce, minimize or relieve symptoms. Symptom management strategies need to specify who, what, when, where and how the strategy will be delivered. Manipulation of any specification alters the strategy and can potentially result in a different outcome (e.g., a cardiac rehabilitation strategy that is delivered in an outpatient rehabilitation setting versus a program that could be done at home, or frequency/duration of any intervention). The selection of a symptom management strategy is influenced by the existing symptom experience, but also considers outcomes of previously used strategies and the current context in which the symptom occurs.

The third concept, symptom status outcomes include measurable outcomes that validate the improvement or deterioration in symptom status. Improved symptom status outcomes include a reduction in symptom frequency, less severity of symptoms, or decreased distress caused by symptoms (e.g., increased ability to engage in normal daily activities, or improved physical functioning). By contrast, deterioration represents a worsening scenario that moves the patient away from an asymptomatic state. The most recent version of the SMT adds adherence to the theoretical design between the concepts of symptom management and symptom outcomes, but the discussion amongst authors regarding its placement within the model continues²⁴. Although

adherence impacts symptom status outcomes, the inclusion of adherence in symptom management seems more appropriate as it measures the engagement in a recommended treatment strategy.

The three symptom concepts: experience, management and outcomes; are thought to occur simultaneously with any one concept being highly dependent on the other two. In addition, the individual, the environment, and the existing state of health/illness impact the interdependence of the symptom experience, symptom management strategy and symptom status outcomes. The theory emphasizes that any specific symptom does not occur in isolation, but rather impacts the entire person and is affected by all the other characteristics of the person's individual and contextual characteristics, e.g., symptoms are perceived as benign or extreme, depending on what else the individual is already managing. The logical assumption in SMT is that a change in any one dimension is likely to change the overall experience, but that makes the evaluation of any single intervention difficult.

SMT provides a relevant, but as of yet, unused conceptual model for symptom management in the PAF population. For most individuals with PAF, an unexpected arrhythmia occurrence triggers an instantaneous response. The theory identifies the simultaneous occurrence of a symptom and the interdependence of the three concepts of SMT. The experience is dependent on previous experiences and guides the management strategy, which is further dependent upon whether management strategies previously worked or failed to produce desirable symptom outcomes, and the context of the occurrence (e.g., where they are, who they are with, their physical and psychological state, and resources available.)

The SMT illustrates the importance of the feedback mechanism and how the cognitive and emotional responses from previous experiences establish a “normal” state for the perception

of the symptom at its onset. The challenge of using the SMT with its circular design for arrhythmia treatment is the difficulty of defining a measureable intervention effect, as it could impact the symptom experience or only be relative to symptom status outcomes. For example, taking an antiarrhythmic, a medication to reduce the incidence of the arrhythmia, could reduce the symptom experience by reducing the frequency of palpitations, but not alter the individual's ability to engage in physical activity because they may still fear a recurrence of PAF. In this example, the SMT is inadequate in its ability to effectively evaluate the medical intervention. Therefore, the independent use of the SMT in the treatment of individuals with AF is insufficient for identifying areas within the circular theoretical model that may contribute to or improve the symptom experience and alter the outcomes in a negative or positive direction.

Proposed Conceptual Model: The Self-Regulation Symptom Management Model

Because the symptom experience among individuals with PAF is varied and is not always associated with an arrhythmia; a theoretical model is needed that allows for a closer examination of the complex phenomena of the symptom experience in individuals with PAF²⁵. An examination of the symptom experience using the SMT without the inclusion of illness representation that is described in the TSR seems to fall short in being able to entirely portray the lived experience of individuals with PAF. However, the TSR used independently is inadequate in examining the impact of a symptom management intervention. As such, the TSR combined with the SMT, the Self-Regulation Symptom Management Model (SSMM), provides a comprehensive conceptual model for the development and evaluation of a symptom, self-management intervention that targets a reduction in symptoms and illness perception, but with improved symptom status outcomes (e.g. QOL), (see Figure 5).

The key concepts of the SSMM are borrowed from the TSR and the SMT. Illness representation or Self-Illness Beliefs, a fundamental concept in the TSR will be at the center of the model and will be formed by the same “common sense” health threats: identity, time line, cause, consequences, and cure/control of the disease. This was chosen as the central concept because it has been observed clinically and in studies²⁶ that the cognitive illness perceptions may contribute to the individual’s ability to cope or manage PAF and the experienced symptoms. The “self-illness beliefs” of each individual lies somewhere along a wellness-illness continuum and is dynamic, yet influential on each of the symptom concepts.

The three concepts from the SMT: symptom experience, symptom management strategies, and symptom status outcomes are included and are positioned around the concept of illness perception, but are all interrelated as exhibited by the bidirectional arrows. The symptom experience will encompass symptom frequency, symptom severity and symptom distress. The concept of symptom management will represent any intervention to prevent, avoid or alleviate the symptom or PAF recurrence. Symptom management interventions can include procedures, medications, or self-management strategies. The concept, symptom status outcome, is intended to represent physical and psychological well-being of the individual with PAF.

The points of the triangle shape representing “self-illness beliefs” in the center touch each of the symptom concepts to indicate that each of them are affected by the person’s illness perceptions or “self-illness beliefs”. Therefore, it is believed that changing any of the five domains that lie within the self-illness beliefs can alter any of the symptom concepts. The nursing science dimension of person and health/illness are excluded in this combined model, SSMM, because they are represented in the self-illness beliefs at the core of the model. The nursing science dimension, environment, is retained in the SSMM because it represents the

external stimuli that can impact the self-illness beliefs and it can also impact each of the symptom concepts depending on where the person is, what they are doing, when it is, and who they are with will affect the lived symptom experience of individuals with PAF. The environment is depicted in the conceptual model as a sphere that encompasses the entire model and intersects with the key concepts from the SMT.

Previous research completed on individuals with AF and PAF found that self-illness beliefs, or illness perceptions, have a significant impact on overall symptom outcomes^{21, 22, 26, 27}. Therefore, this combined model, SSMM, more appropriately represents the complexity of the response to symptoms, but allows consideration for the response to illness that is dynamic throughout the illness trajectory.

Using the SSMM to Design a Nurse Delivered Mindfulness and Education Intervention

The SSMM was used to design an interview guide for a qualitative study to explore the meaning of PAF in the lives of those who experience it, and to explore the perceived usefulness of resources used for the management of PAF²⁸. Early interview data collection and the initial iterative analysis provided essential information on the perceived impact of PAF on people's lives and their thoughts on potential beneficial resources. This, in conjunction with the newly combined SSMM, was used to design and evaluate the feasibility and possible efficacy of a symptom management strategy (see Figure 6).

The SSMM provided a conceptual model for the study of the feasibility and potential efficacy of a symptom management strategy, Mindfulness Meditation and Education Intervention that is Nurse Delivered, MEND AF. It provided a structure to examine the potential interdependence that may exist between 1) the symptom experience (anxiety, fatigue, and sleep

disturbance), 2) symptom status outcomes (functional status and quality of life), and 3) illness perception.

The goal of MEND AF was to study the delivery of a symptom management strategy that could be used by individuals with PAF. Education was included in the intervention in an effort to improve AF coherence relative to the five domains of illness perception: identity, time line, cause, consequences, and cure/control of the disease. The decision to include AF education was based on the findings of McCabe²² and Lane²⁶, whereby both of them had evidence that increased knowledge could decrease a negative illness perception, moving illness perception more toward wellness along an illness-wellness continuum. The SSMM provided a conceptual model for the inclusion of education and the means to examine the impact of education on illness perception, symptom experience and symptom outcomes.

Mindfulness meditation was included in the intervention with AF education to provide individuals with PAF a symptom self-management strategy that they could utilize independently. Mindfulness meditation teaches individuals to be “present” in the moment as opposed to contemplating events passed or anticipating those in the future²⁹. A meditative intervention targeted at guiding patients through enhanced self-monitoring, self-awareness and clearer observations³⁰, may contribute to their ability to manage a PAF episode. Meditation could also alter the automatic, reflexive, and habitual responses that occur prior to and during a PAF recurrence, allowing for the possibility of a new behavior to be selected, i.e. quiet and focused breathing. This non-judgmental awareness may enhance the accuracy of the self-monitoring assessment and influence self-illness beliefs. Thus, an education and mindfulness meditation intervention could potentially decrease the negative illness perception and reduce the use of the coping strategy, focus on and venting of emotions²².

The Symptom Experience will include the overall measurement of symptom frequency and severity (Symptom Frequency and Severity Checklist³¹); and the specific symptoms of anxiety (Cardiac Anxiety Scale³²), fatigue (Fatigue Severity Scale³³) and sleep disturbance (Pittsburg Sleep Quality Index³⁴).

Symptom Status Outcomes were evaluated with a functional status measure (Six Minute Walk Test³⁵) and a QOL measure (Atrial Fibrillation Effect on Quality of Life Questionnaire³⁶). The combination of these two was intended to evaluate both the physical and psychological outcomes.

Illness Perception was measured with the Brief Illness Perception Questionnaire³⁷. Knowledge of AF was evaluated with the Atrial Fibrillation Knowledge Scale³⁸ to determine if a change in knowledge would be reflected in the Illness Perception. The results of the Knowledge Scale would also allow the content that was included in the educational materials to be evaluated.

The impact of the environment was examined with interview questions included in the mixed methods design. Participant interviews were aimed at determining the influences and external stimuli that impacted the lived experience of individuals with PAF. The qualitative data could be used to evaluate the feasibility of the intervention from the perspective of the participants. Limited efficacy would be evaluated by comparing pre- and post-testing scores of the other measures listed.

The Conceptual Model: Designing Strategies to Enable Living Well with PAF

The final analysis of the qualitative study using the Constructivist Grounded Theory continued the evolution of the conceptual model²⁸. The four major categories that emerged from the study included: *Disruptive Symptoms*, *Altered Health Perception*, *AF Action Plan*, and *Quality of Life*. These aligned with the previous SSMM concepts: Symptom Experience, Self-

Illness Beliefs, Symptom Management, and Symptom Outcomes. The interactions and interdependence among the categories are illustrated in the conceptual model for the theoretical code, “Designing Strategies to Enable Living Well with PAF (see Figure 7). Disruptive Symptoms, AF Action Plan, and Quality of Life are comparable to the three components of the SMT: Symptom experience, Symptom management, and Symptom Outcomes. The trapezoid to the left of the diagram that depicts Disruptive Symptoms are often the impetus for setting the AF Action Plan into play and moves toward the conclusive Quality of Life. Altered Health Perception lies beneath all three components to depict that it permeates all components. The wavy arrows connecting the symptom components to suggest that Altered Health Perception acts as a filter amongst all of the other categories, influencing each one of the other categories, but their effect on one another is dependent on the impact each of them have on Altered Health Perception.

The category of Disruptive Symptoms characterizes the symptom confusion that occurs prior to diagnosis, the varied symptoms that occur with PAF episodes, and the uncertainty/fear of having an arrhythmia recurrence. Ultimately, most symptoms eventually lead to a diagnosis of PAF which is the pivotal point in the development of an Altered Health Perception or that time when a myriad of thoughts and emotions shift an individuals’ health perception from wellness to illness. The category entitled, Altered Health Perception, infers that health perception is dynamic and does not need to remain on the illness end of the continuum, but can fluctuate back and forth along the continuum between health and illness. This epitomizes the Altered Health Perception category and mirrors the concept of self-illness beliefs previously discussed in the TSR.

A negative illness perception or illness pre-occupation motivates individuals to pursue strategies and efforts to regain a prior health state which are included in the category, an AF Action Plan. Following a PAF diagnosis, health care providers promptly provide an AF Action plan that includes a medical/procedural plan for managing the arrhythmia, but much less emphasis is given to opportunities of self-management. Individuals with PAF that desire to improve their state of health or wellness often seek out self-management strategies. The resultant category, Quality of Life, is interdependent on the residual symptom experience (Disruptive Symptoms), the health perception status that is reached following the integration of the PAF diagnosis (Altered Health Perception), and the effectiveness of the execution of the AF Action plan, prescribed therapies or chosen self-management strategies. The categories affect one another, but the effect is continually filtered through the lens of Altered Health Perception. The qualitative study has advanced our understanding on the meaning of PAF in the lives of those who experience it and provided a list of resources they perceive would enhance their quality of life, and finally, supported the development of a conceptual model for “Designing Strategies to Enable Living Well with PAF.”

Conclusion

This conceptual model was used to guide the previously described feasibility study, MEND AF (see Figure 8). It is the hope of the author, that this conceptual model can be used to advance our knowledge related to the clinical experience of living with PAF and to guide the design and evaluation of future interventions targeted at alleviating symptoms, improving overall QOL, and reducing negative illness perception for individuals with PAF. Individuals with PAF are also influenced by their illness perception, so including strategies that will assist them in reducing their negative illness perception should be included. Future strategies for reducing

symptoms, improving health perception and improving symptom outcomes should be provided, in conjunction with prescribed treatment. Future feasibility and efficacy studies of symptom management interventions will allow for continued testing of the defined concepts, their relationships between one another, and their “goodness of fit” within the entirety of the conceptual model.

References

1. Chugh SS, Roth GA, Gillum RF, Mensah GA. Global Burden of Atrial Fibrillation in Developed and Developing Nations. *Global Heart*. 2011; 9(1):113–119. <https://doi.org/10.1016/j.gheart.2014.01.004>
2. Naderi S, Wang Y, Miller AL, et al. The Impact of Age on the Epidemiology of Atrial Fibrillation Hospitalizations. *The American Journal of Medicine*. 2014;127(2):158e1-158e7. <https://doi.org/10.1016/j.amjmed.2013.10.005>
2. Mozaffarian D, Benjamin EJ, Go AS, et al. Heart Disease and Stroke Statistics. Update A Report from the American Heart Association. *Circulation*. 2015;CIR–0000000000000350.
4. Rienstra M, Lubitz SA, Mahida S, et al. Symptoms and Functional Status of Patients with Atrial Fibrillation: State of the Art and Future Research Opportunities. *Circulation*. 2012;125(23): 2933–2943. <https://doi.org/10.1161/CIRCULATIONAHA.111.069450>
5. Garimella RS, Chung EH, Mounsey JP, Schwartz JD, Pursell I, Gehi AK. Accuracy of patient perception of their prevailing rhythm: A comparative analysis of monitor data and questionnaire responses in patients with atrial fibrillation. *Heart Rhythm*. 2015;12(4): 658–665. <https://doi.org/10.1016/j.hrthm.2015.01.012>
6. Kupper N, van den Broek KC, Widdershoven J, Denollet J. Subjectively Reported Symptoms in Patients with Persistent Atrial Fibrillation and Emotional Distress. *Frontiers in Psychology*. 2016;4. <https://doi.org/10.3389/fpsyg.2013.00192>
7. Calkins H, Hindricks G, Cappato R, et al. 2017 HRS/EHRA/ECAS/APHRS/SOLAECE Expert Consensus Statement on Catheter and Surgical Ablation of Atrial Fibrillation. *Heart Rhythm*. 2017. <https://doi.org/10.1016/j.hrthm.2017.05.012>
8. January CT, Wann LS, Alpert JS, et al. 2014 AHA/ACC/HRS Guideline for the Management of Patients With Atrial Fibrillation A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines and the Heart Rhythm Society. *Circulation*. 2014; CIR.0000000000000041. <https://doi.org/10.1161/CIR.0000000000000041>
9. Kirchhof P, Benussi S, Kotecha D, et al. 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *European Heart Journal*. 2016; 37(38):2893–2962. <https://doi.org/10.1093/eurheartj/ehw210>
10. Schron E, Friedmann E, Thomas SA. Does Health-Related Quality of Life Predict Hospitalization or Mortality in Patients with Atrial Fibrillation? *Journal of Cardiovascular Electrophysiology*. 2014;25(1):23–28. <https://doi.org/10.1111/jce.12266>

11. Thompson TS, Barksdale DJ, Sears SF, Mounsey JP, Pursell I, Gehi AK. The Effect of Anxiety and Depression on Symptoms Attributed to Atrial Fibrillation: Depression, anxiety, and atrial fibrillation. *Pacing and Clinical Electrophysiology*. 1989; 37(4): 439–446.
<https://doi.org/10.1111/pace.12292>
12. Dorian P, Paquette M, Newman D, et al. Quality of life improves with treatment in the Canadian Trial of Atrial Fibrillation. *American Heart Journal*. 2002;143(6):984–990.
<https://doi.org/10.1067/mhj.2002.122518>
13. Thrall G, Lane D, Carroll D, Lip GYH. Quality of Life in Patients with Atrial Fibrillation: A Systematic Review. *The American Journal of Medicine*. 2006;119(5): 448.e1-448.e19.
<https://doi.org/10.1016/j.amjmed.2005.10.057>
14. Dabrowski R, Opolski G, Włodarczyk P, Kiliszek M, Ponikowski P. Demographic and clinical characteristics of patients with atrial fibrillation and cardioversion as planned therapeutic option in the international registry of cardioversion of atrial fibrillation “RHYTHM-AF.” *Kardiologia Polska*. 2014... <https://doi.org/10.5603/KP.a2014.0067>
15. Rothe von EFA, Goette A, et al. Depression in paroxysmal and persistent atrial fibrillation patients: a cross-sectional comparison of patients enrolled in two large clinical trials. *EP Europace*. 2014;16(6): 812–819. <https://doi.org/10.1093/europace/eut361>
16. Bandura A. Social Cognitive Theory of Self Regulation. In *Organization Behavior and Human Decisions Processes* (Vol. 50, pp. 248–287). Palo Alto, CA: Academic Press: 1991. Retrieved from <http://ucsfcat.library.ucsf.edu/record=b1322524~S0>
17. Wood R, Bandura A. Impact of conceptions of ability on self-regulatory mechanisms and complex decision making. *Journal of Personality and Social Psychology*. 1989; 56(3):407.
18. Leventhal H, Leventhal EA, Contrada R J. Self-regulation, health, and behavior: A perceptual-cognitive approach. *Psychology & Health*. 1998;13(4):717–733.
<https://doi.org/10.1080/08870449808407425>
19. Lazarus RS. *Psychological Stress and the Coping Process*. New York, NY: McGraw-Hill; 1966.
20. Baum A, Singer JE, Leventhal H, Nerenz D, Steele DJ. *Handbook of psychology and health*. Vol. 4. New York: Erlbaum:1984.
21. Steed L, Newman SP, Hardman, SMC. An examination of the Self-Regulation Model in atrial fibrillation. *British Journal of Health Psychology*. 1999; 4(4):337–347.
<https://doi.org/http://dx.doi.org.ucsf.idm.oclc.org/10.1348/135910799168687>

22. McCabe PJ, Barnason SA. Illness Perceptions, Coping Strategies, and Symptoms Contribute to Psychological Distress in Patients with Recurrent Symptomatic Atrial Fibrillation: The Journal of Cardiovascular Nursing. 2012;27(5):431–444. <https://doi.org/10.1097/JCN.0b013e31821e7ab1>
23. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. Journal of Advanced Nursing. 2001;33(5):668–676.
24. Humphreys J, Symptom Management Theory. In: Smith MJ, Liehr PR, eds. Middle Range Theory for Nursing. New York, NY: Springer; 2014: 113.
25. Meleis A. Theoretical Nursing: Development and Progress (Fifth). Wolters Kluwer Health/Lippincott Williams & Wilkins. 2012.
26. Lane DA, Langman CM, Lip GYH, Nouwen A. Illness perceptions, affective response, and health-related quality of life in patients with atrial fibrillation. Journal of Psychosomatic Research. 2009;66(3):203–210. <https://doi.org/10.1016/j.jpsychores.2008.10.007>
27. McCabe PJ, Barnason SA, Houfek J. Illness Beliefs in Patients with Recurrent Symptomatic Atrial Fibrillation: Patients with Symptomatic AF. Pacing and Clinical Electrophysiology. 2011;34(7):810–820. <https://doi.org/10.1111/j.1540-8159.2011.03105.x>
28. Author. Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation. 2017;submitting.
29. Chiesa A, Malinowski P. Mindfulness-based approaches: are they all the same? Journal of Clinical Psychology. 2011;67(4):404–424. <https://doi.org/10.1002/jclp.20776>
30. Wilde MH, Garvin S. A concept analysis of self-monitoring. Journal of Advanced Nursing. 2007; 57(3):339–350. <https://doi.org/10.1111/j.1365-2648.2006.04089.x>
31. Bubien R, Jenkins LS. Test specifications for Symptoms Checklist: Frequency and Severity. University of Wisconsin Milwaukee WI :1993.
32. Eifert GH, Thompson RN, Zvolensky MJ, et al. The Cardiac Anxiety Questionnaire: development and preliminary validity. Behaviour Research and Therapy. 2000;38(10):1039–1053. [https://doi.org/10.1016/S0005-7967\(99\)00132-1](https://doi.org/10.1016/S0005-7967(99)00132-1)
33. Neuberger GB. Measures of fatigue: The Fatigue Questionnaire, Fatigue Severity Scale, Multidimensional Assessment of Fatigue Scale, and Short Form-36 Vitality (Energy/Fatigue) Subscale of the Short Form Health Survey. Arthritis & Rheumatism. 2003;49(S5):S175–S183. <https://doi.org/10.1002/art.11405>

34. Carpenter JS, Andrykowski MA. Psychometric evaluation of the Pittsburgh sleep quality index. *Journal of Psychosomatic Research*. 2017;45(1):5–13.
35. Rostagno C, Gensini, GF. Six minute walk test: a simple and useful test to evaluate functional capacity in patients with heart failure. *Internal and Emergency Medicine*. 2008;3(3):205–212. <https://doi.org/10.1007/s11739-008-0130-6>
36. Spertus J, Dorian P, Bubien R, et al. Development and Validation of the Atrial Fibrillation Effect on Quality-of-Life (AFEQT) Questionnaire in Patients with Atrial Fibrillation. *Circulation: Arrhythmia and Electrophysiology*. 2011; 4(1):15–25. <https://doi.org/10.1161/CIRCEP.110.958033>
37. Broadbent E, Petrie KJ, Main J, Weinman J. The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*. 2006; 60(6):631–637. <https://doi.org/10.1016/j.jpsychores.2005.10.020>
38. Hendriks JM, Crijns HJGM, Tieleman RG, Vrijhoef HJM. The atrial fibrillation knowledge scale: Development, validation and results. *International Journal of Cardiology*. 2013; 168(2):1422–1428. <https://doi.org/10.1016/j.ijcard.2012.12.047>

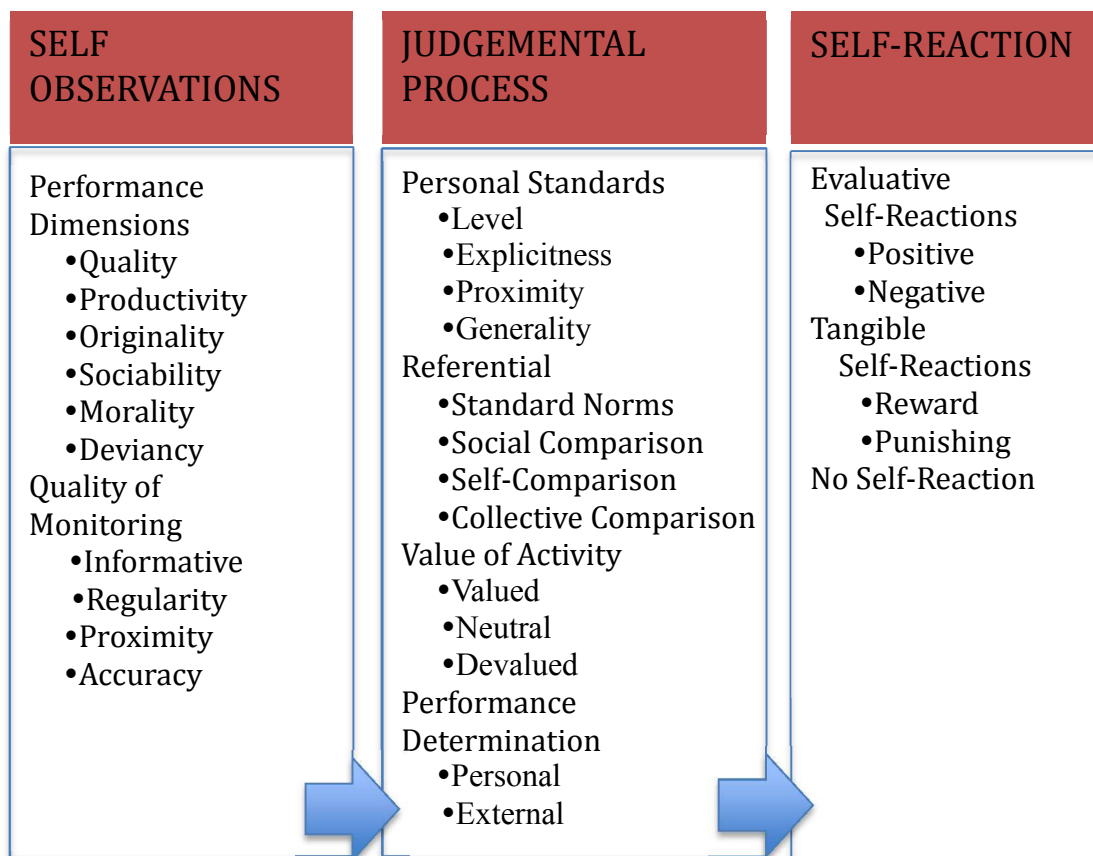


Figure 3.1. Structure of the system of Self-Regulation of Motivation and Action

Through Internal Standards and Self- Reactive Influences, Adapted from “Social Cognitive Theory of Self- Regulation”, by Albert Bandura, 1991, *Organization Behavior and Human Decisions Processes*, p. 249. Copyright 1991 by Academic Press.

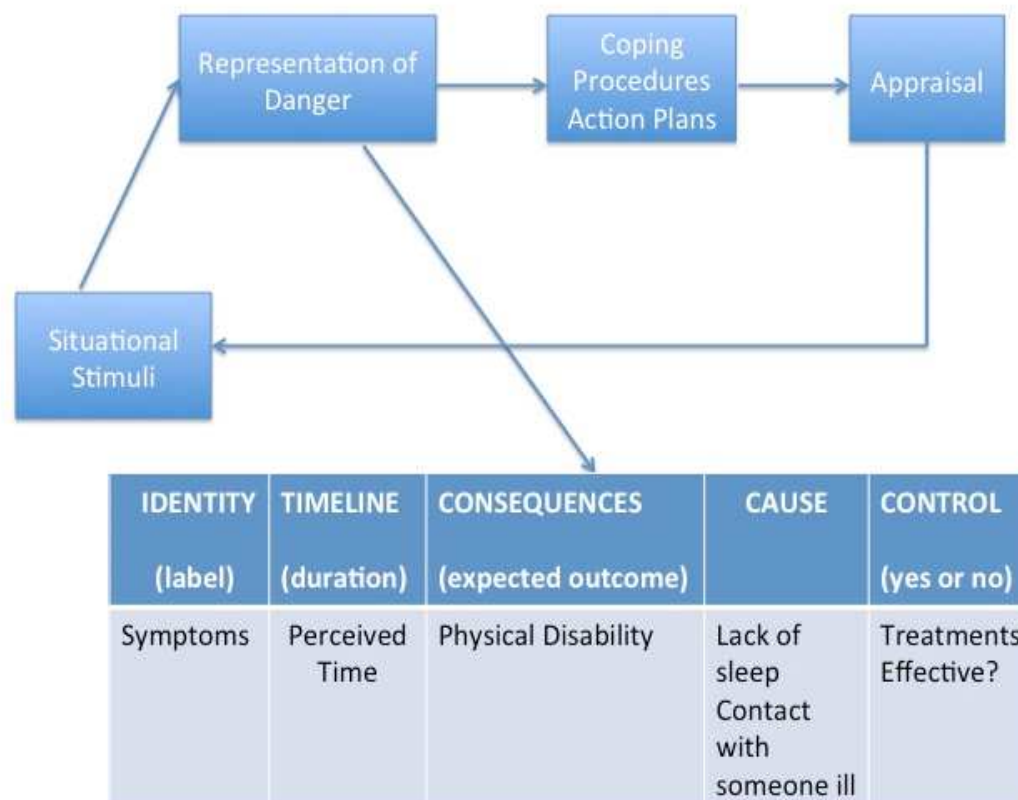


Figure 3.2. Five domains of illness representations.

Adapted from the “Common Sense Model of Self-Regulation of Health and Illness” by H. Leventhal; I. Brissette, and E. A. Leventhal in Common Sense, 2012, *The Self-Regulation of Health and Illness*, p. 50. Copyright 2012 by Taylor and Francis.

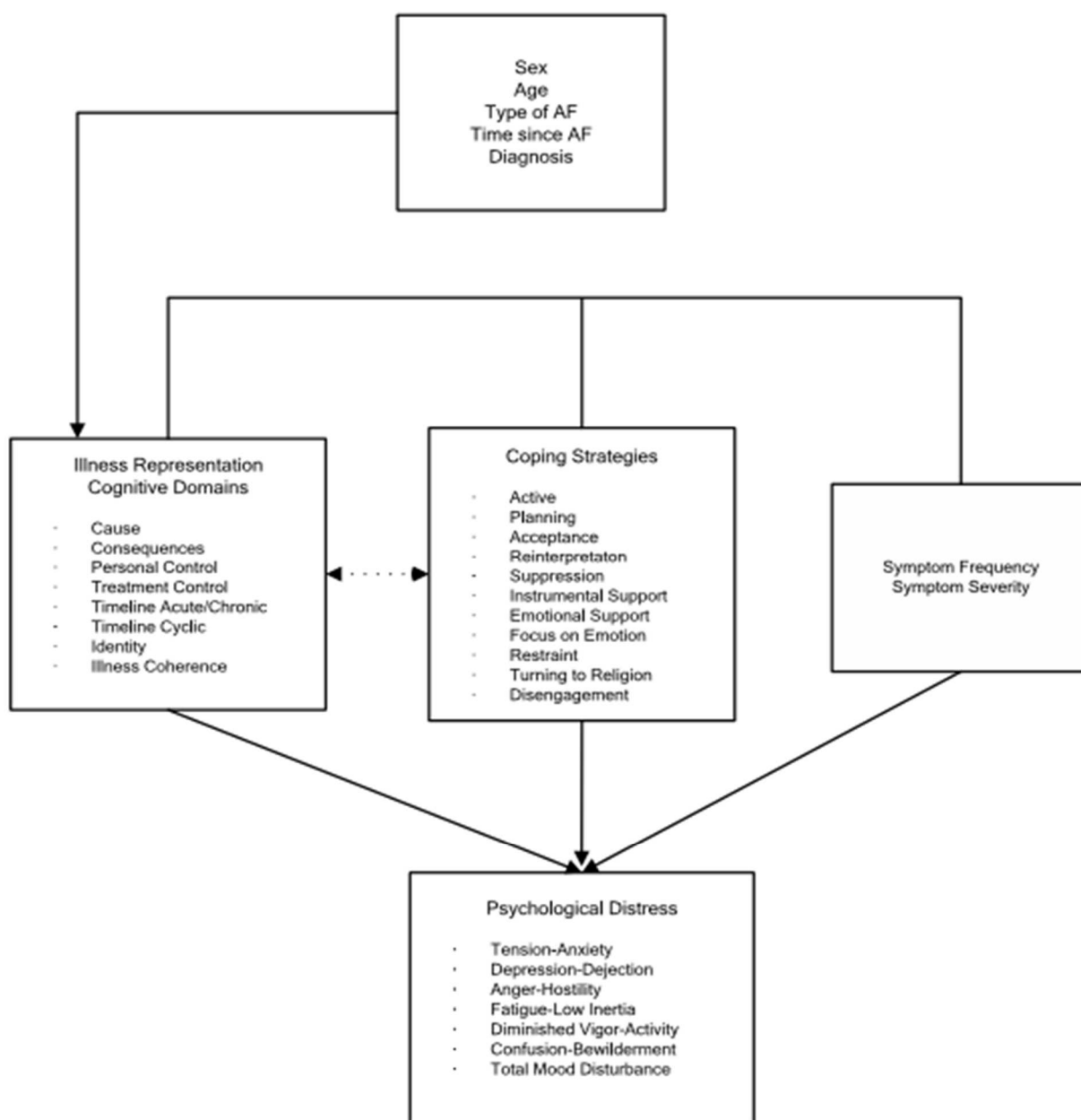


Figure 3.3. Conceptual Model of the Relationships between Illness Representations, Coping Strategies, Symptoms and Psychological Stress.

(Permission requested), McCabe, P. J., & Barnason, S. A. (2012). Illness Perceptions, Coping Strategies, and Symptoms Contribute to Psychological Distress in Patients With Recurrent Symptomatic Atrial Fibrillation: *The Journal of Cardiovascular Nursing*, 27(5), 431–444. <https://doi.org/10.1097/JCN.0b013e31821e7ab1>

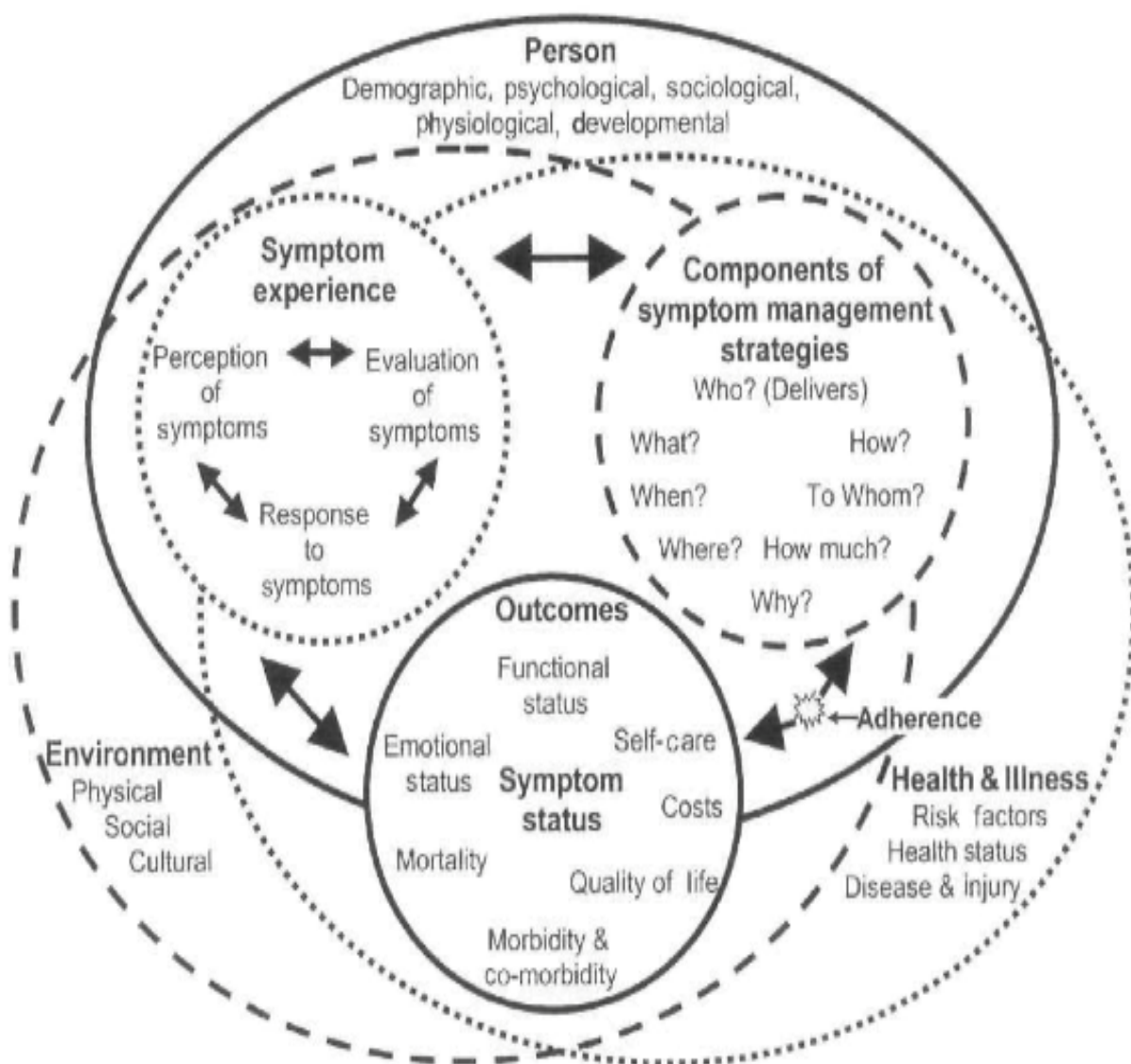


Figure 3.4. Conceptual Model of the Theory of Symptom Management

(Permission requested), "Advancing the Science of Nursing," Humphreys, J., et al, 2014, *Middle Range Theory of Nursing*, p. 143. Copyright 2014 by Springer Publishing Company, LLC.

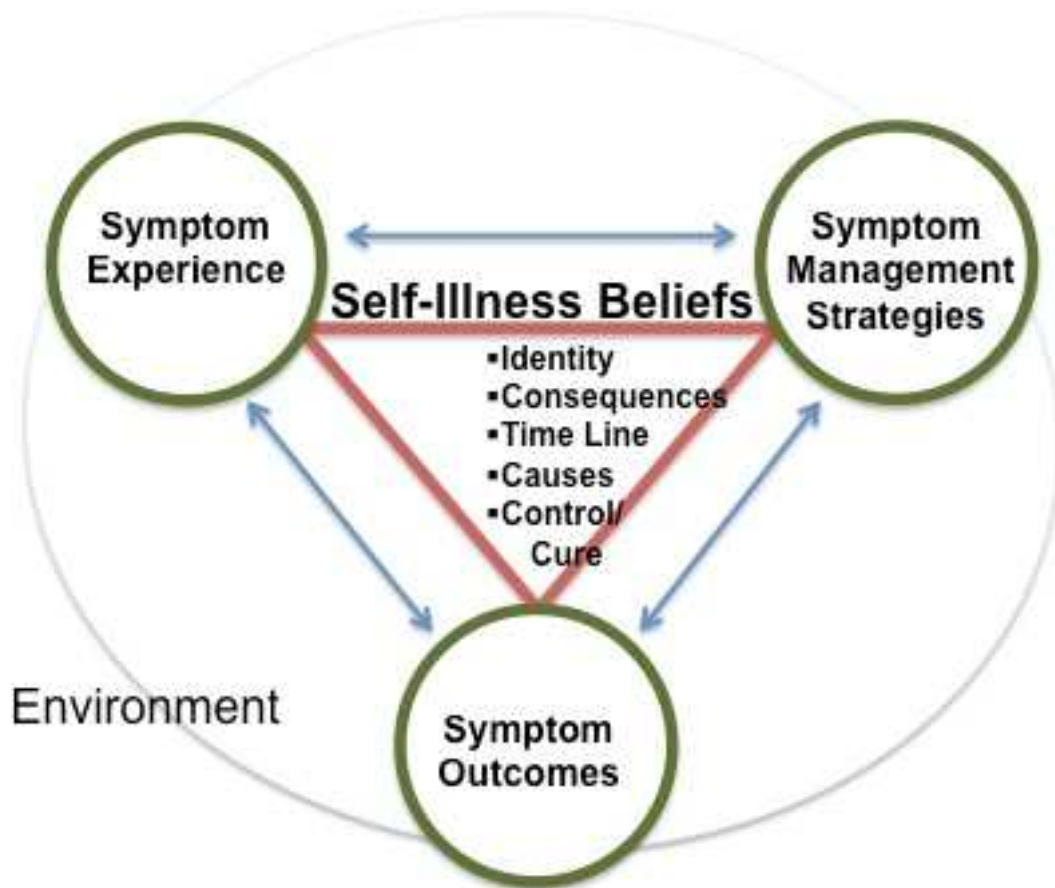


Figure 3.5. Conceptual Model of the Self-Regulation Symptom Management Model

The three concepts from the symptom management theory: symptom experience, symptom management, and symptom outcomes, but are impacted by the self- illness beliefs or five domains of illness representation borrowed from the Self-Regulation Model: identity, consequences, time line, causes, control, and cure. The environment is influential to all of them as when it is, where you are, and whom you are with can change the entire experience.

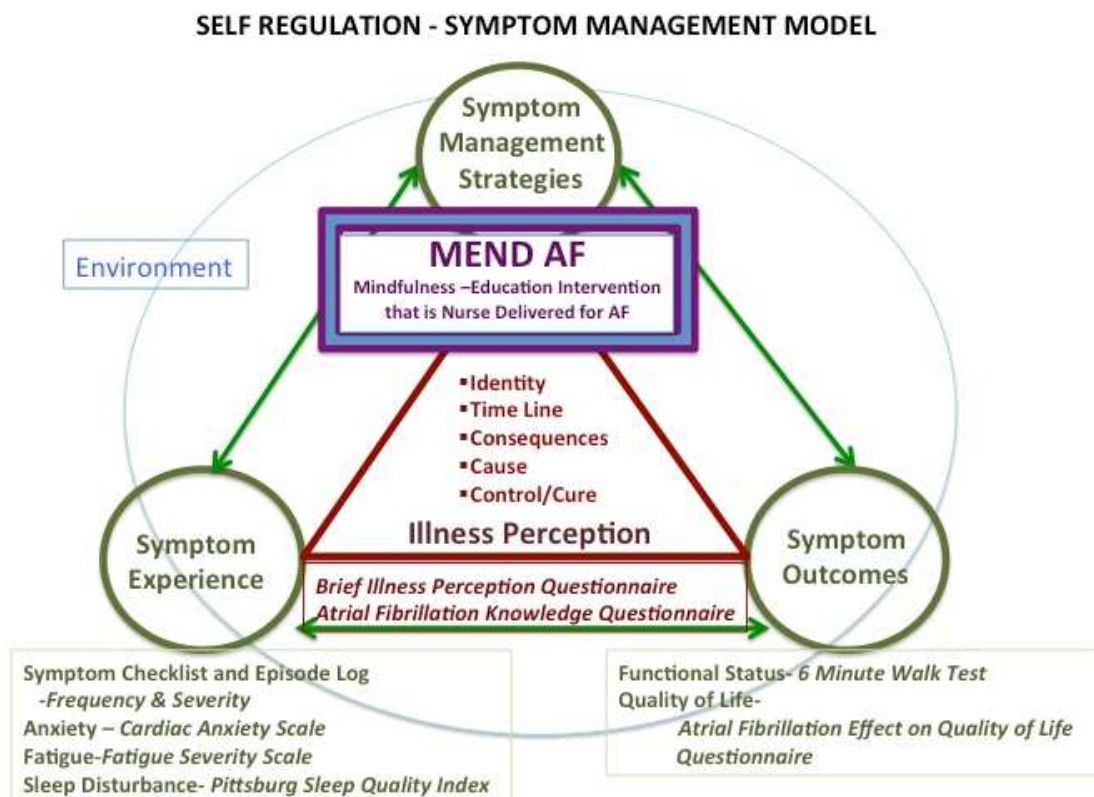


Figure 3.6. The Self-Regulation Symptom Management Model for the evaluation of a Mindfulness-Education Intervention that is Nurse Delivered for PAF (MEND AF).

Symptom Management Strategies represent the strategies includes the prescribed plan of medications and procedures along with MEND AF. Symptom Experience represents the actual symptoms experienced due to PAF and included the evaluation of the overall symptoms (Symptom Checklist-Frequency and Severity Scale); and the specific symptoms of anxiety (Cardiac Anxiety Questionnaire), fatigue (Fatigue Severity Scale), and sleep disturbance (Pittsburgh Sleep Quality Index). Symptom Outcomes represent the overall outcomes of PAF and was evaluated with the Atrial Fibrillation Effect on Quality of Life Questionnaire, the 6-Minute Walk Test, and the Leisure-Time Activity Categorical Item. Illness Perception represents the perception of health associated with PAF and was evaluated using the Brief Illness Perception Questionnaire and the Atrial Fibrillation Knowledge Scale was used to evaluate the impact of the education on AF knowledge.

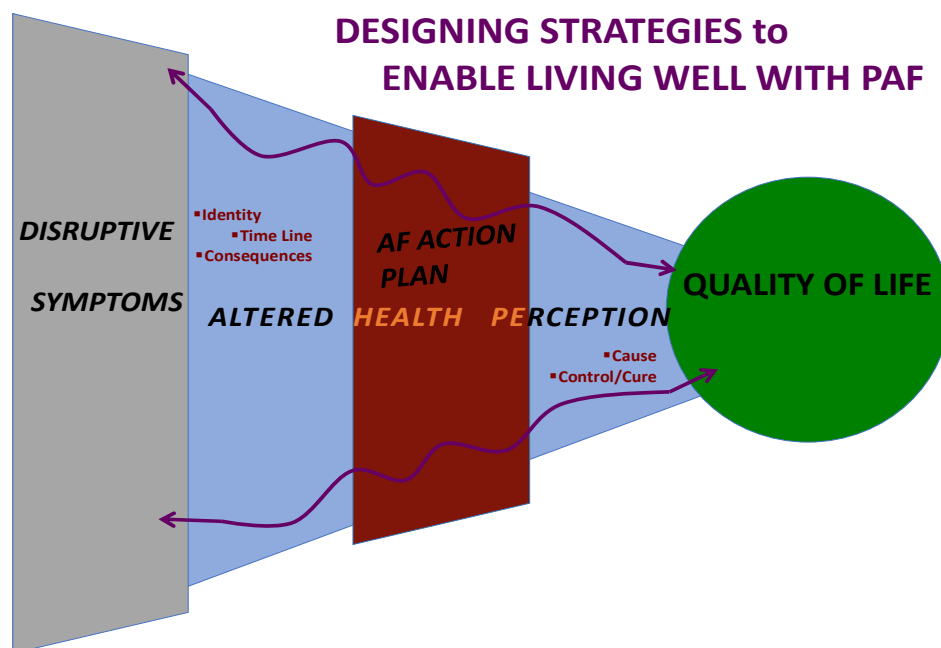


Figure 3.7. Theoretical Framework for Designing and Evaluating Interventions for Individuals with Paroxysmal Atrial Fibrillation.

The conceptual model, *Designing Strategies to Enable Living Well with PAF*, resulted from a grounded theory qualitative study (Author, 2017) and provides a theoretical framework for the examination and evaluation of a symptom management intervention. Disruptive Symptoms represents the symptoms that are confusing and disruptive to normal life. Altered Health Perception represents the dynamic perception of health associated with PAF. AF Action Plan represents the treatment strategies that are used and includes the prescribed plan that includes usual care of medication and procedures along with self-management strategies. Quality of Life represents the overall outcomes of PAF.

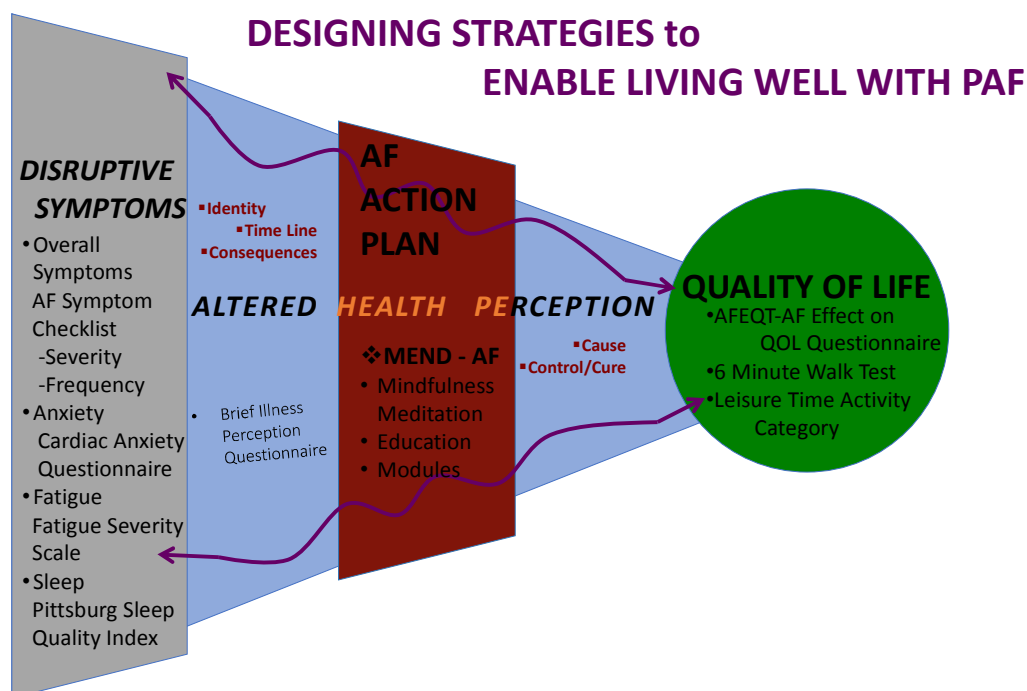


Figure 3.8. The New Conceptual Model to Evaluate MEND AF

The conceptual model, *Designing Strategies to Enable Living Well with PAF*, resulted from a grounded theory qualitative study (Author, submitted, 2017) and provides a theoretical framework for the examination and evaluation of a symptom management intervention.

Disruptive Symptoms represents the symptoms that cause confusion and are disruptive to normal life. The four measures used to evaluate Disruptive Symptoms were (a) Symptom Checklist-Frequency and Severity Scale, (b) Cardiac Anxiety Questionnaire, (c) Fatigue Severity Scale, and (d) Pittsburgh Sleep Quality Index. *Altered Health Perception* represents the permeable change in health perception associated with onset of PAF and was evaluated using the Brief Illness Perception Questionnaire. An *AF Action Plan* represents the treatment strategies that are used in conjunction with the prescribed plan, medication and procedures. In this study, the AF Action plan includes MEND AF, a mindfulness and education intervention. *Quality of Life* represents the overall outcomes of PAF and was evaluated with the following measures: Atrial Fibrillation Effect on Quality of Life, 6-Minute Walk Test, and Leisure-Time Activity Categorical Item.

Chapter 4

A Mindfulness-Education Intervention that is Nurse Delivered to Reduce Symptoms and Improve Quality of Life in Patients with Paroxysmal Atrial Fibrillation: the MEND-AF Study

REQUIRED SHORT TITLE: Mindfulness-Education for Atrial Fibrillation: MEND AF

Authors: Linda K. Ottoboni, PhD(c), CNS_{1,2}

Frederick M. Hecht, MD₃

Mintu Turakhia, MD, MAS_{1,4}

Jill Howie-Esquivel, PhD, ACNP₅

Janine Cataldo, PhD, RN₂

₁Stanford Healthcare, 300 Pasteur Drive, Stanford, CA 94305

₂ Department of Physiological Nursing, University of California, San Francisco, CA

₃ Osher Center for Integrative Medicine, University of California, San Francisco, CA

₄ Palo Alto Veterans Administration Medical Center, Palo Alto, California

₅ University of Virginia, Virginia

Corresponding Author: Linda K. Ottoboni, 1435 Enchanted Way, San Mateo, CA 94402

Phone: 650-498-5914; Fax: 650-725-7568

Journal of interest: Heart Rhythm Journal

Word count: (GOAL is 5000: includes ALL text in the submission,)

Number of figures/tables: 8 (Limit 8)

Conflict of Interest: None-any of the authors

Source of Funding: Sigma Theta Tau

Key words: atrial fibrillation, symptoms, mindfulness meditation, education, quality of life

Abstract

Background: Atrial fibrillation (AF) currently affects up to 2% of the US population. Episodic or paroxysmal atrial fibrillation (PAF) increases stroke risk and often results in debilitating symptoms. Symptoms contribute to increased hospitalizations and decreased quality of life (QOL). Despite improved treatment outcomes with catheter ablation procedures, symptoms may persist and QOL can be compromised. Therefore, additional interventions aimed at symptom reduction and increased QOL are needed.

Objective: This study was done to examine the effects of a nurse delivered, mindfulness-education intervention (MEND AF) on symptoms and QOL in patients with PAF.

Methods: Symptomatic PAF patients were enrolled in the intervention in a single center with a prospective, pre-posttest design. MEND AF provided six weeks of assigned guided meditation practice and educational module review. Efficacy was evaluated using initial and final assessment measures: Symptom Frequency/Severity Checklist, Cardiac Anxiety Questionnaire, Fatigue Severity Scale, the Pittsburg Sleep Quality Index, and Atrial Fibrillation Effect on QOL Questionnaire.

Results: A significant reduction in AF symptom frequency (19.71 to 13.14; $p=0.004$) and severity (15.46 to 11.04; $p=0.001$) was found. Anxiety, fatigue and sleep disturbance scores were decreased; but not significantly. A significant improvement in QOL (89.09 to 90.47; $p=0.011$) and subscales, Treatment Concern (89.50 to 91.34; $p=0.007$) and Symptom Severity (89.23 to 90.84; $p=0.003$).

Conclusions: This is the first study to examine the efficacy of a mindfulness meditation and AF education intervention for PAF patients. Results suggest that individuals who struggle with symptoms and reduced QOL from PAF could benefit from the MEND AF intervention.

Introduction

Atrial fibrillation (AF) is the most common cardiac arrhythmia disorder in the United States, and the incidence is expected to increase from five to fifteen million people by the year 2050^{1,2}. The estimated annual healthcare costs of specialized AF treatments and treatments associated with comorbidities (e.g., stroke and cardiac dysfunction) are 26 billion dollars³.

Symptoms associated with AF contribute to an increased risk of hospitalizations⁴ and a decreased health related quality of life⁵. Increased symptoms and diminished QOL are associated with increased mortality and higher rates of hospitalizations⁶. Compared to those with persistent or chronic AF, patients with episodic or paroxysmal atrial fibrillation (PAF) have more debilitating symptoms and a lower level of QOL⁷. Affordable and effective symptom management are needed to improve the health and QOL of patients with PAF.

Overall AF symptoms include palpitations, shortness of breath, chest pain, dizziness, anxiety, fatigue, and sleep disturbance^{8,9,10}. Most studies report on cumulative or overall AF symptom frequency and severity, but there is a dearth of information on specific symptoms^{11,12}. Anxiety was found to be significantly greater in patients with PAF and persistent AF, when compared to non-AF matched controls, and associated with increased frequency and severity of overall symptoms and decreased QOL^{9,11}. Fatigue is the most frequently reported symptom in AF patients that classify their symptoms as severe (57%; n=840) or disabling (63.4%; n=118) and consistently associated with decreased quality of life (QOL) and an increased hospitalizations⁷. Insomnia, a specific sleep disturbance, was significantly more prevalent ($p<0.05$) in AF patients compared to a non-AF matched control group¹⁰. Obstructive sleep apnea (OSA) has been associated with an increased incidence of AF¹³, but more recent evidence indicates that OSA may increase symptoms without altering AF prevalence or progression¹⁴.

The impact of sleep disturbances without OSA has not been examined in this population.

Therefore, in addition to overall symptom frequency and severity, the current study will examine three specific symptoms of anxiety, fatigue, and sleep disturbance to increase our knowledge relative to these impactful symptoms.

Current AF Management Guidelines focus on the reduction of stroke risk, restoration of normal sinus rhythm, and achievement of heart rate control. Lesser emphasis is often placed on the alleviation of AF symptoms¹⁵. Because of the morbidity and mortality associated with AF, rhythm restoration with ablation procedures are currently the preferred treatment^{2,16}. Patients having catheter ablation procedures report greater symptom reduction and QOL than those receiving medications for rhythm restoration or rate control^{17,18,19}. Efforts to maintain sinus rhythm are costly and challenging, yet, AF may recur and symptoms may persist^{20,21}. Alternative interventions aimed at symptom reduction and QOL improvement are limited; effective non-invasive interventions that target AF symptom reduction are needed.

Recently, along with more traditional treatments, management of PAF has included the integration of mind-body practices for the improvement of physical, mental, emotional, and spiritual well-being²². Yoga has been associated with a reduced number of PAF occurrences, decreased anxiety levels, and improved QOL^{23,24}. Meditation, a component of yoga, but done independent of movement, has been found to reduce symptom frequency and severity in patients with coronary artery disease^{25,26,27}. There is evidence that mindfulness meditation, a specific meditation practice that supports individuals to develop the skills to be more “mindful” or present in the moment as opposed to contemplating past events or anticipating possible future events, is effective for the reduction of anxiety in people with cardiac conditions²⁸.

Mindfulness based stress reduction (MBSR) is an eight week, structured program on the practice of mindfulness using meditation, body awareness, and movement²⁹. MBSR has been effective for anxiety and stress reduction in patients with cancer and diabetes^{30,31,32}. However, there are limited studies on the effect of MBSR for people with cardiac conditions²⁸ and to date there are no known studies with PAF patients.

Patient education that includes AF etiology, disease process and treatment has been described by patients as essential to their success in AF self-management and ability to effectively participate in treatment decisions. However, there are few studies to evaluate the specific impact AF education has on outcomes or knowledge³³⁻³⁶. Providing patient education to this patient population is supported, but there is no standard on timing or content delivered³⁷⁻³⁹. The provision of a comprehensive AF education program in conjunction with a mindfulness meditation intervention could increase comprehension related to AF, which in turn, could impact AF symptoms and QOL. To date, an intervention for PAF patients that provides both mindfulness meditation and AF education has not been examined.

Therefore, the specific aims of this study were to determine among PF patients, the effect size of MEND AF on:

- 1) the frequency and severity of overall symptoms and specific AF symptoms (anxiety, fatigue, and sleep disturbance); and
- 2) QOL.

Methods

Study Design

The efficacy of a six-week mindfulness meditation and education intervention (MEND AF) was evaluated with a prospective, pre-post cohort design in a single site, academic medical

center. The Institutional Review Boards of the recruitment site approved the study and informed consent.

Individuals were *included* if they: (a) had a symptomatic PAF episode in the prior six months; (b) were ≥ 18 years old; (c) could speak, read and write English; (d) were able to ambulate independently; (e) were able to attend two 90-minute sessions six weeks apart; and (f) were able to participate in weekly telephone follow-up sessions. Individuals were *excluded* if they had: (a) a New York Heart Association (NYHA) Functional Class IV diagnosis; (b) life expectancy of less than six months; (c) been hospitalized in the prior three months for a diagnosis unrelated to PAF; (d) previous experience practicing mindfulness; (e) cognitive impairment determined with Mini-Cog screening; (f) were scheduled for PAF procedure or treatment during the six-week intervention.

Patients were recruited between October 2016 to February 2017 from the list of patients scheduled for treatment in the outpatient setting. Of the 466 scheduled clinic patients, seventy were eligible and 32 (46%) were recruited (Figure 1).

Measures

The *Mini Cognitive Screening* assessment tool was used to (*Mini-Cog*) screen for cognitive impairment based on a scoring algorithm (e.g. unable to draw a clock face correctly and one or two words recalled out of three; OR unable to recall any of the three words)⁴⁰.

The *Symptom Checklist-Frequency and Severity Scale (SCL)* measured overall symptom frequency and severity of PAF-related symptoms over the prior four weeks. Participants rated the frequency (0-4) and severity (0-3) of 16 symptoms with possible scores for symptom frequency (0-64) and symptom severity (0-48), with higher scores representing higher frequency/severity⁴¹.

The *Cardiac Anxiety Questionnaire (CAQ)* measured the specific symptom, cardiac-specific or heart focused anxiety and three subscales: cardiac fear, avoidance, and heart-focused attention⁴². Eighteen behaviors were rated by frequency of occurrence on 5-point Likert scale (0-never to 4-always) with higher scores indicating greater heart focused anxiety.

The *Fatigue Severity Score (FSS)* measured the specific symptom, fatigue severity, for the prior week. Participants ranked nine items on whether they had interfered with their daytime function along a Likert scale from 1(strongly disagree) to 7(strongly agree); with higher score indicating more fatigue⁴³.

The *Pittsburgh Sleep Quality Index (PSQI)* assessed the specific symptom, sleep disturbance⁴⁴. Nineteen items were scored resulting in a single score (0-21) with a higher score indicating greater sleep disturbance and poorer sleep quality.

The *Atrial Fibrillation Effect on Quality of Life Questionnaire (AFEQT)* measured AF-related QOL including the dimensions of activity, symptoms, and treatment concerns over the prior four weeks. Twenty items are scored on a 1-7 Likert scale (not at all to extreme). The AFEQT Global Measure Score is a combined score of all dimensions (0-100) with a higher score representing greater QOL and there is a subscale score for each dimension⁴⁵.

The *Atrial Fibrillation Knowledge Scale (AFKS)* was used to determine the effectiveness of the AF education portion of the intervention by evaluating the change in AF knowledge from initial to final session⁴⁶. The *AFKS* is a self-administered multiple-choice test that includes 11 items related to AF disease trajectory, symptom recognition, and treatment scored by number of correct answers (0-11), with a higher score representing greater understanding of AF.

Protocol

After being consented, patients were screened for cognitive impairment, if negative, they received (1) an initial session; (2) a six-week intervention of mindfulness meditation practice, education modules, and weekly phone calls; and (3) a final session (See Table 1).

In the initial session, each patient completed all measures, discussed their current PAF treatment, and viewed a video introducing meditation practice. Details of the intervention were reviewed and participants received a packet that included: (1) a USB drive with six weekly guided meditation audios developed and narrated by a trained MBSR instructor; (2) Printed AF education modules that included information about PAF: etiology, treatment, stroke and anticoagulation, triggers, arrhythmia occurrence management, and associated cardiovascular risk factors; (3) a meditation workbook for optional reading; and (4) a meditation/symptom log.

Weekly, for the next six weeks, they were assigned a specific guided meditation to practice for 10-15 minutes six days per week and an education module to read (Table 2). They were asked to record the number of minutes of daily meditation practice and symptoms they experienced each week. Participation in a weekly telephone call with the researcher provided a time to discuss questions, concerns, or challenges related to the intervention (Figure 2).

In the final session at the completion of six weeks, retesting of all measures was done and an interview with the researcher was completed to determine the participants' overall experience with the intervention.

Data Analysis

Demographic data were analyzed using descriptive statistics for continuous data and frequencies and percentages for categorical data.

Efficacy potential was evaluated using initial and final scores on all study measures. Matched pair t-tests were performed to determine changes in symptom frequency and severity, anxiety, fatigue, sleep disturbance, QOL, and AF knowledge. Effect sizes (ES) were calculated by dividing the differences of the means between the initial and final tests by the standard deviation of the differences. Effect size guidelines included small ES=. 20, medium ES =. 50, and large ES=. 80⁴⁷. When appropriate, internal consistency was evaluated on measures, using Cronbach's alpha.

Results

Sample

Thirty-one participants were enrolled in the MEND AF intervention, and no participants were excluded based on the cognitive screening results. As shown in Table 3, the mean age of participants was 63.16 (SD \pm 10.73), slightly over one third were women, most were Caucasian with an education beyond high school they were varied across economic levels.

Clinical data are presented in Table 4. Time since diagnosis varied from less than one year to greater than 10 years. A third of the group with echocardiogram data, had an abnormal ejection fraction, but only one reported being diagnosed with heart failure. Over half of the group reported having atrial arrhythmias. Hypercholesterolemia, hypertension, CAD, and depression were the most prevalent reported comorbidities.

The PAF treatment experiences varied among the participants, but over half of them had been treated in the emergency room. A third of the participants had received at least one cardioversion and a third of the group had undergone a previous ablation (see Table 5). Majority were receiving medications for rate control, rhythm control, and anticoagulation (i.e., either warfarin or novel anticoagulant).

Twenty six of the 31 participants that began the intervention, completed the six-week intervention and attended the final session. There were no significant differences between the group of participants that completed the intervention and the five that withdrew (three males and three females). Of the 26 participants that completed the intervention, 84% reported practicing the recommended number of minutes of meditation, and 100% reported completion of the six weekly education modules; these results suggest high engagement with the intervention.

The primary aims for this study were to determine, among PF patients, the effect size of MEND AF on the frequency and severity of overall symptoms and specific AF symptoms (anxiety, fatigue, and sleep disturbance); and QOL.

Efficacy potential was evaluated using matched paired t-tests between the initial and final assessment scores in overall and specific symptom frequency and severity, and QOL (Table 6.) A significant decrease in overall AF symptom frequency scores, (19.71 to 13.14; $p=0.004$; $ES=0.617$) and severity scores (15.46 to 11.04; $p=0.001$; $ES=0.771$) were found.

Although there were noted decreases in the total scores for specific symptoms (anxiety, fatigue and sleep disturbance), they were not statistically significant. However, a significant decrease was found on one anxiety subscale score (heart related attention) (1.94 to 1.61; $p=0.017$; $ES=0.503$). The mean score change on the PSQI scores exceeded 5, suggesting the presence of sleep disturbances throughout the intervention for this sample.

As seen in Table 6, a significant improvement for QOL was found, (89.09 to 90.47; $p=0.011$, $ES=0.536$). In addition, significant improvements in the AFEQT subscales were found, Treatment Concern (89.50 to 91.34; $p=0.007$, $ES=0.316$) and Symptom Severity (89.23 to 90.84; $p=0.003$; $ES=0.659$).

In a secondary exploratory analysis of patient knowledge related to AF, a statistically significant higher final score of 8.35 compared to the initial score of 7.54 ($p = 0.03$; ES = 0.452). Another single scored item, “How well do you feel you understand your illness?” also showed significant improvement (2.50 to 3.57, $p=0.012$, ES 0.525), further supporting that participants had an improved understanding of AF.

Discussion

This is the first study to examine the efficacy of an intervention that includes mindfulness meditation and AF education for PAF patients. Results from this study suggest that individuals with PAF who struggle with symptoms and reduced QOL from PAF could benefit from the MEND AF intervention, especially for those whose symptoms persist following catheter ablation. The study results of MEND AF support previous findings that have associated greater symptom frequency and severity with lower QOL^{48,49}.

This study provides additional support for the use of integrative interventions for symptom reduction in PAF patients. Yoga was previously shown to improve QOL and reduce anxiety and depression in PAF patients²⁴. A greater reduction in symptomatic PAF recurrence was found in those patients who received acupuncture treatments compared to those who received antiarrhythmic medications⁵⁰. Biofeedback has been found to be effective in reducing arrhythmias by manipulating heart rate variability, but is unlikely to have a significant impact in patients with AF due to the inaccessibility of the sinus node⁵¹. One of the five patients that withdrew from the intervention found the meditation practice to be “disturbing”, so the potential negative impact of meditation on this patient population needs further evaluation.

In one study, no improvement in AF awareness or overall health was found for patients who received an AF educational presentation supplemented with written materials³³. However, a

significant improvement in patients' knowledge related to anticoagulation ($p=0.014$), and target anticoagulation levels ($p=0.001$) was shown. Several education intervention studies, have reported no significant improvement in AF knowledge^{52,53}. The results of this study, although not generalizable beyond this group, do suggest a possibility that the education provided could promote learning. A new measure that includes comprehension on all oral anticoagulants, as opposed to only warfarin, should be considered to replace the AFKS to evaluate AF knowledge in future studies⁵⁴. In addition, a "teach back" strategy that emphasizes content areas of importance will be considered in future MEND AF interventions, as this method has been effective in teaching complex concepts to heart failure patients⁵⁵.

The contribution of the weekly phone calls to the intervention is difficult to measure. The phone call was intended to allow participants to ask questions or express concerns about the medication or the education content, but resulted in discussions on a variety of topics (e.g., symptoms, medication questions). Because fear and uncertainty are drivers for emergency room visits⁵⁶, it is possible that the weekly phone intervals decreased emergency room and clinic visits and physician calls, but due to the limited scope and resources of this study, data on health care utilization could not be collected. In terms of feasibility, the cost of the intervention needs to be evaluated to determine if direct contact with a clinical provider for the initial and final sessions and the weekly calls are necessary and cost effective. The inclusion of a revenue-generating provider to deliver the intervention (e.g., advanced practice provider) and utilization of additional technology (e.g., electronic data entry, structured times for group sessions) could be explored to potentially reduce the resources required to provide MEND AF.

Because MEND AF is a multifaceted intervention it is unclear if the entire intervention is better than a minimal, single or no intervention for the treatment of PAF patients. However, this

study supports the findings of several previous studies that have evaluated the effectiveness of multifaceted interventions for AF patients. One study found a significant reduction in symptoms ($p < 0.001$) and reduction in AF recurrence (dependent on % weight loss) with a primary focus on cardiovascular risk factor reduction, particularly weight management⁵⁷. Another study that included a face to face education/risk reduction goal setting session followed by three monthly coaching/goal setting phone sessions failed to reach the primary endpoint of weight loss, yet, noted significant symptom reduction, $p = 0.005$ ⁵⁸. A third intervention study included an integrated nurse-led care model aided by computer software and resource coordination to improve adherence to AF guideline therapy⁵⁹. This nurse-led intervention, not only improved adherence of AF guideline therapy, but also showed a larger decrease in hospitalizations (13.5 vs. 19.1%, $p = 0.029$) and deaths (3.9% vs. 1.1%, $p = 0.025$), when compared to the usual care group. Although the number of studies to test the effectiveness of multifaceted interventions is limited, the current study adds the possibility that a multi-faceted intervention could be effective for AF patients. However, the difficulty teasing out the individual contributions of each facet to the effectiveness of an intervention has been well documented.

Limitations

This study is limited by the study design. This is a feasibility study and did not include a control group. No causal inferences can be made because of the single time, pre-post design and the small sample size. The sustained effect of the intervention is unknown and requires further evaluation. The impact of meditation on heart rhythm, heart rate, and blood pressure were not included in this study, so it is unknown if meditation had any effect on PAF recurrence. Adherence to prescribed medical regimens was not measured and could have impacted symptoms.

Future Directions

Future trials with a control group and inclusion of larger, more diverse samples at multiple sites are needed to identify the essential components of the MEND-AF intervention. The results from this study are encouraging, but future comparative studies are needed to provide evidence that the implementation of MEND AF can effectively support symptom management in PAF patients. Therefore, future development and testing of MEND AF will be required as it moves beyond a small sample size at a single site to being tested in varied settings with larger, more diverse populations and implemented in different practice settings.

Conclusion

Current treatments for PAF are focused on arrhythmia elimination, with less attention placed on the patient's response to managing the arrhythmia. The nurse led intervention in this study, MEND AF, is patient focused and provides a treatment option that can be easily used in conjunction with standard arrhythmia management practices. MEND AF allows the patient to remain at the forefront of care delivery and suitably augments standard treatments.

Combining the integrative strategy of mindfulness meditation with traditional, patient educational resources is novel and the results of the intervention on symptom reduction and improved QOL are positive. As is, MEND AF can be easily replicated, but may require modification depending on available resources. However, prior to its broader implementation as an evidenced-based health care intervention, it is essential that the intervention be rigorously evaluated for feasibility, efficiency and effectiveness.

References

1. Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., others. (2016). Heart Disease and Stroke Statistics—2016 Update A Report From the American Heart Association. *Circulation*, CIR-0000000000000350.
2. Miyasaka, Y., Barnes, M. E., Gersh, B. J., Cha, S. S., Bailey, K. R., Abhayaratna, W. P., Tsang, T. S. M. (2006). Secular Trends in Incidence of Atrial Fibrillation in Olmsted County, Minnesota, 1980 to 2000, and Implications on the Projections for Future Prevalence. *Circulation July 11, 2006, 114(2)*, 119–125.
<https://doi.org/10.1161/CIRCULATIONAHA.105.595140>
3. Kim, M. H., Johnston, S. S., Chu, B.-C., Dalal, M. R., & Schulman, K. L. (2011). Estimation of Total Incremental Health Care Costs in Patients With Atrial Fibrillation in the United States. *Circulation: Cardiovascular Quality and Outcomes*, 4(3), 313–320.
<https://doi.org/10.1161/CIRCOUTCOMES.110.958165>
4. Turakhia, T., Solomon, M.D., Jhaveri, M., Davis, P., Eber, (2015). Burden, timing, and relationship of cardiovascular hospitalization to mortality among Medicare beneficiaries with newly diagnosed atrial fibrillation, *American Heart Journal*, 2013; 166:573-80.
5. Dorian, P., Jung, W., Newman, D., Paquette, M., Wood, K., Ayers, G. M., ... Luderitz, B. (2000). The impairment of health-related quality of life in patients with intermittent atrial fibrillation: implications for the assessment of investigational therapy. *Journal of the American College of Cardiology*, 36(4), 1303–1309.
6. Schron, E., Friedmann, E., & Thomas, S. A. (2014). Does Health-Related Quality of Life Predict Hospitalization or Mortality in Patients with Atrial Fibrillation? *Journal of Cardiovascular Electrophysiology*, 25(1), 23–28. <https://doi.org/10.1111/jce.12266>
7. Freeman, J. V., Simon, D. N., Go, A. S., Spertus, J., Fonarow, G. C., Gersh, B. J., ... others. (2015). Association Between Atrial Fibrillation Symptoms, Quality of Life, and Patient Outcomes. *Circulation: Cardiovascular Quality and Outcomes*, CIRCUITCOMES-114.
8. Rienstra, M., Lubitz, S. A., Mahida, S., Magnani, J. W., Fontes, J. D., Sinner, M. F., ... Benjamin, E. J. (2012). Symptoms and Functional Status of Patients With Atrial Fibrillation: State of the Art and Future Research Opportunities. *Circulation*, 125(23), 2933–2943.
<https://doi.org/10.1161/CIRCULATIONAHA.111.069450>
9. Thrall, G., Lip, G., Carroll, D., & Lane, D. (2007). Depression, Anxiety, and Quality of Life in Patients With Atrial Fibrillation. *CHEST Journal*, 132(4), 1259.
<https://doi.org/10.1378/chest.07-0036>

10. Goren, A., Liu, X., Gupta, S., Simon, T. A., & Phatak, H. (2013). Quality of Life, Activity Impairment, and Healthcare Resource Utilization Associated with Atrial Fibrillation in the US National Health and Wellness Survey. *PLoS ONE*, 8(8), e71264. <https://doi.org/10.1371/journal.pone.0071264>
11. Kupper, N., van den Broek, K. C., Widdershoven, J., & Denollet, J. (2013). Subjectively Reported Symptoms in Patients with Persistent Atrial Fibrillation and Emotional Distress. *Frontiers in Psychology*, 4. <https://doi.org/10.3389/fpsyg.2013.00192>
12. Sears, S. F., Serber, E. R., Alvarez, L. G., Schwartzman, D. S., Hoyt, R. H., & Ujhelyi, M. R. (2005). Understanding atrial symptom reports: objective versus subjective predictors. *Pacing and Clinical Electrophysiology*, 28(8), 801–807.
13. Gami, A. S., Hodge, D. O., Herges, R. M., Olson, E. J., Nykodym, J., Kara, T., & Somers, V. K. (2007). Obstructive Sleep Apnea, Obesity, and the Risk of Incident Atrial Fibrillation. *Journal of the American College of Cardiology*, 49(5), 565–571. <https://doi.org/10.1016/j.jacc.2006.08.060>
14. Holmqvist, F., Guan, N., Zhu, Z., Kowey, P. R., Allen, L. A., Fonarow, G. C., ... ORBIT-AF Investigators. (2015). Impact of obstructive sleep apnea and continuous positive airway pressure therapy on outcomes in patients with atrial fibrillation-Results from the Outcomes Registry for Better Informed Treatment of Atrial Fibrillation (ORBIT-AF). *American Heart Journal*, 169(5), 647–654.e2. <https://doi.org/10.1016/j.ahj.2014.12.024>
15. Kirchhof, P., Benussi, S., Kotecha, D., Ahlsson, A., Atar, D., Casadei, B., ... Zeppenfeld, K. (2016). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *European Heart Journal*, 37(38), 2893–2962. <https://doi.org/10.1093/eurheartj/ehw210>
16. Chyou, J. Y., Hunter, T. D., Mollenkopf, S. A., Turakhia, M. P., & Reynolds, M. R. (2015). Individual and Combined Risk Factors for Incident Atrial Fibrillation and Incident Stroke: An Analysis of 3 Million At-Risk US Patients. *Journal of the American Heart Association*, 4(7), e001723. <https://doi.org/10.1161/JAHA.114.001723>
17. Brachmann, J., Lewalter, T., Kuck, K.-H., Andresen, D., Willems, S., Spitzer, S. G., ... Senges, J. (2017). Long-term symptom improvement and patient satisfaction following catheter ablation of supraventricular tachycardia: insights from the German ablation registry. *European Heart Journal*, 0, 1–10. <https://doi.org/10.1093/eurheartj/ehx101>
18. Calkins, H., Hindricks, G., Cappato, R., Kim, Y.-H., Saad, E. B., Aguinaga, L., ... Yamane, T. (2017). 2017 HRS/EHRA/ECAS/APHRS/SOLAECE Expert Consensus Statement on Catheter and Surgical Ablation of Atrial Fibrillation. *Heart Rhythm*. <https://doi.org/10.1016/j.hrthm.2017.05.012>

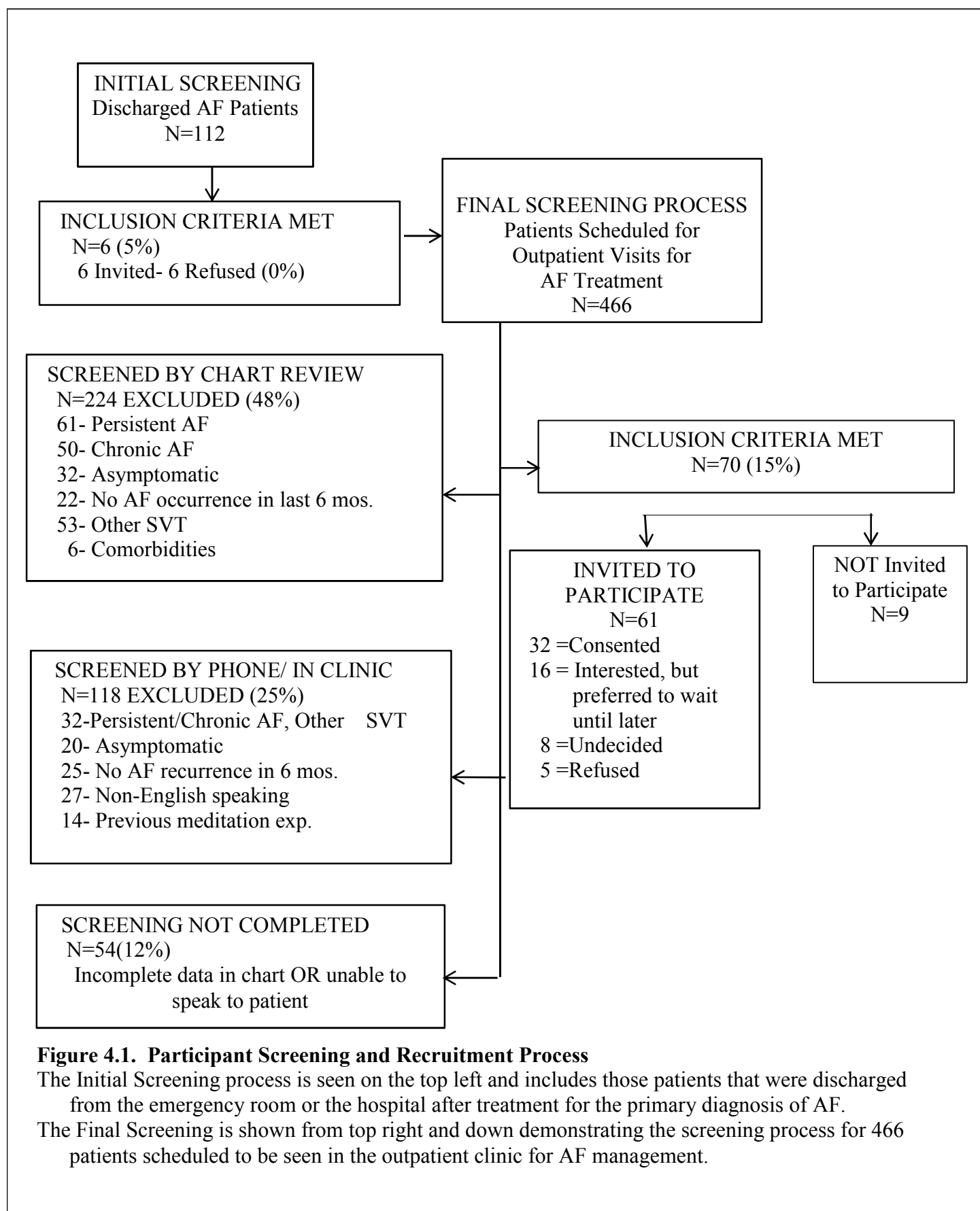
19. Takigawa, M., Takahashi, A., Kuwahara, T., Okubo, K., Takahashi, Y., Watari, Y., ... Isobe, M. (2014). Long-Term Follow-Up After Catheter Ablation of Paroxysmal Atrial Fibrillation: CLINICAL PERSPECTIVE. *Circulation: Arrhythmia and Electrophysiology*, 7(2), 267–273. <https://doi.org/10.1161/CIRCEP.113.000471>
20. Gehi, A. K., Sears, S., Goli, N., Walker, T. J., Chung, E., Schwartz, J., ... Mounsey, J. P. (2012). Psychopathology and Symptoms of Atrial Fibrillation: Implications for Therapy: Gehi et al. Psychopathology and Symptoms of Atrial Fibrillation. *Journal of Cardiovascular Electrophysiology*, 23(5), 473–478. <https://doi.org/10.1111/j.1540-8167.2011.02264.x>
21. Thompson, T. S., Barksdale, D. J., Sears, S. F., Mounsey, J. P., Pursell, I., & Gehi, A. K. (2014). The Effect of Anxiety and Depression on Symptoms Attributed to Atrial Fibrillation: DEPRESSION, ANXIETY, AND ATRIAL FIBRILLATION. *Pacing and Clinical Electrophysiology*, 37(4), 439–446. <https://doi.org/10.1111/pace.12292>
22. Kanmanthareddy, A., Reddy, M., Ponnaganti, G., Sanjani, H. P., Koripalli, S., Adabala, N., ... others. (2015). Alternative medicine in atrial fibrillation treatment—Yoga, acupuncture, biofeedback and more. *Journal of Thoracic Disease*, 7(2), 185.
23. Doliwa, P. S., Rosenqvist, M., & Frykman, V. (2012). Paroxysmal atrial fibrillation with silent episodes: Intermittent versus continuous monitoring. *Scandinavian Cardiovascular Journal*, 46(3), 144–148. <https://doi.org/10.3109/14017431.2012.661873>
24. Lakkireddy, D., Atkins, D., Pillarisetti, J., Ryschon, K., Bommana, S., Drisko, J., ... Dawn, B. (2013). Effect of Yoga on Arrhythmia Burden, Anxiety, Depression, and Quality of Life in Paroxysmal Atrial Fibrillation. *Journal of the American College of Cardiology*, 61(11), 1177–1182. <https://doi.org/10.1016/j.jacc.2012.11.060>
25. Olivo, E. L., Dodson-Lavelle, B., Wren, A., Fang, Y., & Oz, M. C. (2009). Feasibility and effectiveness of a brief meditation-based stress management intervention for patients diagnosed with or at risk for coronary heart disease: A pilot study. *Psychology, Health & Medicine*, 14(5), 513–523. <https://doi.org/10.1080/13548500902890087>
26. Ray, I. B., Menezes, A. R., Malur, P., Hiltbold, A. E., Reilly, J. P., & Lavie, C. J. (2014). Meditation and Coronary Heart Disease: A Review of the Current Clinical Evidence. *The Ochsner Journal*, 14(4), 696–703.
27. Schneider, R. H., Grim, C. E., Rainforth, M. V., Kotchen, T., Nidich, S. I., Gaylord-King, C., ... Alexander, C. N. (2012). Stress Reduction in the Secondary Prevention of Cardiovascular Disease: Randomized, Controlled Trial of Transcendental Meditation and Health Education in Blacks. *Circulation: Cardiovascular Quality and Outcomes*, 5(6), 750–758. <https://doi.org/10.1161/CIRCOUTCOMES.112.967406>
28. Parswani, M. J., Sharma, M. P., & Iyengar, S. (2013). Mindfulness-based stress reduction program in coronary heart disease: A randomized control trial. *International Journal of Yoga*, 6(2), 111–117. <https://doi.org/10.4103/0973-6131.113405>

29. Kabat-Zinn, J. (1990). *Full Catastrophe Living* (15th anniversary edition). New York, NY: Bantam Dell.
30. Garland, S. N., Tamagawa, R., Todd, S. C., Specia, M., & Carlson, L. E. (2013). Increased Mindfulness Is Related to Improved Stress and Mood Following Participation in a Mindfulness-Based Stress Reduction Program in Individuals With Cancer. *Integrative Cancer Therapies*, 12(1), 31–40. <https://doi.org/10.1177/1534735412442370>
31. Hartmann, M., Kopf, S., Kircher, C., Faude-Lang, V., Djuric, Z., Augstein, F., ... Nawroth, P. P. (2012). Sustained Effects of a Mindfulness-Based Stress-Reduction Intervention in Type 2 Diabetic Patients: Design and first results of a randomized controlled trial (the Heidelberg Diabetes and Stress-Study). *Diabetes Care*, 35(5), 945–947. <https://doi.org/10.2337/dc11-1343>
32. Kopf, S., Oikonomou, D., Hartmann, M., Humpert, P., Herzog, W., & Nawroth, P. (2014). Mindfulness based stress reduction training was able to improve stress, depression and health status in patients with type 2 diabetes over 3 years. – Results of the Heidelberg Diabetes and Stress Study (HEIDIS). *Experimental and Clinical Endocrinology & Diabetes*, 122(03). <https://doi.org/10.1055/s-0034-1372181>
33. Lane, D. A., Ponsford, J., Shelley, A., Sirpal, A., & Lip, G. Y. H. (2006). Patient knowledge and perceptions of atrial fibrillation and anticoagulant therapy: Effects of an educational intervention programme. *International Journal of Cardiology*, 110(3), 354–358. <https://doi.org/10.1016/j.ijcard.2005.07.031>
34. Clarkesmith, D. E., Lip, G. Y. H., & Lane, D. A. (2017). Patients' experiences of atrial fibrillation and non-vitamin K antagonist oral anticoagulants (NOACs), and their educational needs: A qualitative study. *Thrombosis Research*, 153, 19–27. <https://doi.org/10.1016/j.thromres.2017.03.002>
35. Clarkesmith, D. E., Pattison, H. M., Lip, G. Y. H., & Lane, D. A. (2013). Educational Intervention Improves Anticoagulation Control in Atrial Fibrillation Patients: The TREAT Randomised Trial. *PLoS ONE*, 8(9). <https://doi.org/10.1371/journal.pone.0074037>
36. Hernández Madrid, A., Potpara, T. S., Dagres, N., Chen, J., Larsen, T. B., Estner, H., ... Blomstrom-Lundqvist, C. (2016). Differences in attitude, education, and knowledge about oral anticoagulation therapy among patients with atrial fibrillation in Europe: result of a self-assessment patient survey conducted by the European Heart Rhythm Association. *EP Europace*, 18(3), 463–467. <https://doi.org/10.1093/europace/euv448>
37. Angaran, P., Mariano, Z., Dragan, V., Zou, L., Atzema, C., Mangat, I., & Dorian, P. (2015). AF therapies after ER visit -AFTER 3.pdf. *Journal of Atrial Fibrillation*, 7(5), 20–25.
38. McCabe, P. J., Schumacher, K., & Barnason, S. A. (2011). Living with atrial fibrillation: a qualitative study. *Journal of Cardiovascular Nursing*, 26(4), 336–344.

- 38.Kang, Y., & Bahler, R. (2004). Health-related quality of life in patients newly diagnosed with atrial fibrillation. *European Journal of Cardiovascular Nursing*, 3(1), 71–76.
<https://doi.org/10.1016/j.ejcnurse.2003.12.002>
- 39.McCabe, P. (2011). What patients want and need to know about atrial fibrillation. *Journal of Multidisciplinary Healthcare*, 413. <https://doi.org/10.2147/JMDH.S1931>
- 40.Doerflinger, D. M. C. (2007). Mini-Cog. *American Journal of Nursing*, 107(12), 62–71
- 41.Bubien, R., & Jenkins, L. S. (1993). *Test specifications for Symptoms Checklist: Frequency and Severity*. University of Wisconsin, Milwaukee, WI.
- 42.Eifert, G. H., Thompson, R. N., Zvolensky, M. J., Edwards, K., Frazer, N. L., Haddad, J. W., & Davig, J. (2000). The Cardiac Anxiety Questionnaire: development and preliminary validity. *Behaviour Research and Therapy*, 38(10), 1039–1053.
[https://doi.org/10.1016/S0005-7967\(99\)00132-1](https://doi.org/10.1016/S0005-7967(99)00132-1)
- 43.Krupp, L. B., LaRocca, N. G., Muir-Nash, J., & Steinberg, A. D. (1989). The fatigue severity scale: application to patients with multiple sclerosis and systemic lupus erythematosus. *Archives of Neurology*, 46(10), 1121–1123.
- 44.Buysse, D. J., Reynolds III, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A New Instrument for Psychiatric Practice and Research. *Psychiatric Research*, 28, 193–213.
- 45.Spertus, J., Dorian, P., Bubien, R., Lewis, S., Godejohn, D., Reynolds, M. R., ... Burk, C. (2011). Development and Validation of the Atrial Fibrillation Effect on QualiTy-of-Life (AFEQT) Questionnaire in Patients With Atrial Fibrillation. *Circulation: Arrhythmia and Electrophysiology*, 4(1), 15–25. <https://doi.org/10.1161/CIRCEP.110.958033>
- 46.Hendriks, J. M., Crijns, H. J. G. M., Tieleman, R. G., & Vrijhoef, H. J. M. (2013). The atrial fibrillation knowledge scale: Development, validation and results. *International Journal of Cardiology*, 168(2), 1422–1428. <https://doi.org/10.1016/j.ijcard.2012.12.047>
- 47.Cohen, S., Gaddam, S., Gemignani, A., Wu, W.-C., Sharma, S., & Choudhary, G. (2013). Right Ventricular Function Relates to Functional Capacity in Men with Atrial Fibrillation and Preserved Left Ventricular Ejection Fraction. *Echocardiography*, 30(5), 542–550.
<https://doi.org/10.1111/echo.12099>
- 49.Lane, D. A., Langman, C. M., Lip, G. Y. H., & Nouwen, A. (2009). Illness perceptions, affective response, and health-related quality of life in patients with atrial fibrillation. *Journal of Psychosomatic Research*, 66(3), 203–210.
<https://doi.org/10.1016/j.jpsychores.2008.10.007>

49. McCabe, P. J., & Barnason, S. A. (2012). Illness Perceptions, Coping Strategies, and Symptoms Contribute to Psychological Distress in Patients With Recurrent Symptomatic Atrial Fibrillation: *The Journal of Cardiovascular Nursing*, 27(5), 431–444. <https://doi.org/10.1097/JCN.0b013e31821e7ab1>
50. Lombardi, F., Belletti, S., Battezzati, P. M., & Lomuscio, A. (2012). Acupuncture for paroxysmal and persistent atrial fibrillation: An effective non-pharmacological tool? *World Journal of Cardiology*, 4(3), 60. <https://doi.org/10.4330/wjc.v4.i3.60>
51. Engel, B.T. 1973 Clinical applications of operant conditioning techniques in the control of cardiac arrhythmias. *Semin Psychiatry* 1973;5:433-8.
52. McCabe, P. J., Schad, S., Hampton, A., & Holland, D. E. (2008). Knowledge and self-management behaviors of patients with recently detected atrial fibrillation. *Heart & Lung: The Journal of Acute and Critical Care*, 37(2), 79–90. <https://doi.org/10.1016/j.hrtlng.2007.02.006>
53. Xu, W., Sun, G., Lin, Z., Chen, M., Yang, B., Chen, H., & Cao, K. (2010). Knowledge, attitude, and behavior in patients with atrial fibrillation undergoing radiofrequency catheter ablation. *Journal of Interventional Cardiac Electrophysiology*, 28(3), 199. <https://doi.org/10.1007/s10840-010-9496-2>
54. Desteghe, L., Engelhard, L., Raymaekers, Z., Kluts, K., Vijgen, J., Dilling-Boer, D., ... Heidbuchel, H. (2016). Knowledge gaps in patients with atrial fibrillation revealed by a new validated knowledge questionnaire. *International Journal of Cardiology*, 223, 906–914. <https://doi.org/10.1016/j.ijcard.2016.08.303>
55. White, M., Garbez, R., Carroll, M., Brinker, E., & Howie-Esquivel, J. (2013). Is “Teach-Back” Associated With Knowledge Retention and Hospital Readmission in Hospitalized Heart Failure Patients?: *The Journal of Cardiovascular Nursing*, 28(2), 137–146. <https://doi.org/10.1097/JCN.0b013e31824987bd>
56. Rising, K. L., Hudgins, A., Reigle, M., Hollander, J. E., & Carr, B. G. (2016). “I’m Just a Patient”: Fear and Uncertainty as Drivers of Emergency Department Use in Patients With Chronic Disease. *Annals of Emergency Medicine*, 68(5), 536–543. <https://doi.org/10.1016/j.annemergmed.2016.03.053>
57. Pathak, R. K., Middeldorp, M. E., Meredith, M., Mehta, A. B., Mahajan, R., Wong, C. X., ... Sanders, P. (2015). Long-Term Effect of Goal-Directed Weight Management in an Atrial Fibrillation Cohort: A Long-Term Follow-Up Study (LEGACY). *Journal of the American College of Cardiology*, 65(20), 2159–2169. <https://doi.org/10.1016/j.jacc.2015.03.002>
58. Lowres, N., Redfern, J., Freedman, S. B., Orchard, J., Bennett, A. A., Briffa, T., ... Neubeck, L. (2014). Choice of Health Options In prevention of Cardiovascular Events for people with49. Atrial Fibrillation (CHOICE-AF): A pilot study. *European Journal of Cardiovascular Nursing*, 1474515114549687.

59. Hendriks, J. M. L., de Wit, R., Crijns, H. J. G. M., Vrijhoef, H. J. M., Prins, M. H., Pisters, R., ... Tieleman, R. G. (2012). Nurse-led care vs. usual care for patients with atrial fibrillation: results of a randomized trial of integrated chronic care vs. routine clinical care in ambulatory patients with atrial fibrillation. *European Heart Journal*, 33(21), 2692–2699. <https://doi.org/10.1093/eurheartj/ehs071>
60. Squires, J. E., Sullivan, K., Eccles, M. P., Worswick, J., & Grimshaw, J. M. (2014). Are multifaceted interventions more effective than single-component interventions in changing health-care professionals' behaviours? An overview of systematic reviews. *Implementation Science*, 9, 152. <https://doi.org/10.1186/s13012-014-0152-6>



1. How are you doing overall?
2. Do you have any questions, comments, or concerns that came up for you when you reviewed the education content for this week?
3. Please share your experience if you had an atrial fibrillation episode within the last week? Did you have any unscheduled visits to the clinic, emergency room, or medication changes that you experienced over the last week?
4. If you had an AF occurrence within the last week, describe your experience completing the checklist and or symptom logs for those occurrences.
5. Do you have any questions related to the AF education that we covered today?
6. What has been your experience with the mindfulness practice this week?
7. Can you share your thoughts/feelings related to your experience during the mindfulness practice?
8. For those of you who have used the workbook, can you share what your experience with that resource has been like?
9. If anyone committed to modifying their risk factors, are you willing to share with us how that has been for you over the last week?
10. Do you have any specific questions related to the instructions for this next week?
11. What concerns do you have, if any, related to your ability to complete the intervention in the upcoming week?
12. Is there anything else that you would like to discuss before we conclude today...?
13. Will you be able to call in and join the weekly group call this week on (proposed date)_____?
14. If not, let's schedule a time to connect by phone

Figure 4.2. MEND AF Weekly Telephone Semi-Structured Interview Guide

Table 4.1.
MEND AF Study Procedures

	Screening	Initial Session	Weeks 1-2	Weeks 3-6	Final Session	Time to Complete in minutes	Time for MEND AF
Mini Cognitive Screening Test	X					2	2
Symptom Frequency/Severity Checklist(SCL)		X			X	4	8
Cardiac Anxiety Questionnaire		X			X	3	6
Fatigue Severity Scale		X			X	1	2
Pittsburg Sleep Quality Index		X			X	4	8
Atrial Fibrillation Effect on QOL Questionnaire		X			X	5	10
Atrial Fibrillation Knowledge Scale		X			X	3	6
Mindfulness Meditation Introduction		X				15	15
Weekly Mindfulness Practice 10 minutes 6 days/week (Week 1-2)			X			60 (x2)	120
15 minutes 6 days/week (Week 3-6)				X		90 (x4)	360
Weekly Education Module Read and Review a module per week			X	X		10 (x6)	60
Weekly Log of Mindfulness Practice and Symptoms						2	12
Weekly Telephone Call			X	X		8	48
TOTAL PARTICIPANT TIME							657

Note: This table includes all measures and interventions involved in the study intervention, along with time required for participant to complete each item and total time required for each participant.

Table 4.2.
MEND AF Weekly Assignments

<p>Week 1</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complete AF module 1 - <i>Understanding AF</i> <input type="checkbox"/> Practice AUDIO: <i>Awareness of Breath</i> (10 min)-Practice 6 days. <input type="checkbox"/> Complete daily meditation log/symptomatic episode log <input type="checkbox"/> Meditation workbook completion – Chapter 1 (optional) <input type="checkbox"/> Participate in a scheduled weekly phone call- individual or conference
<p>Week 2</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complete AF module 2 - <i>Understanding AF Treatment Options-Rhythm Control or Rate Control</i> <input type="checkbox"/> Practice AUDIO: <i>Body Scan Meditation</i> (10 min)-Practice 6 days. <input type="checkbox"/> Complete daily meditation log/symptomatic episode log <input type="checkbox"/> Meditation workbook completion – Chapter 2 (optional) <input type="checkbox"/> Participate in a scheduled weekly phone call- individual or conference
<p>Week 3</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complete AF module 3 -<i>Understanding Stroke Risk and its Management with Anticoagulation</i>) <input type="checkbox"/> Practice AUDIO: <i>Sitting Meditation</i> (15 min)-Practice 6 days <input type="checkbox"/> Complete daily meditation log/symptomatic episode log <input type="checkbox"/> Meditation workbook completion – Chapter 3 (optional) <input type="checkbox"/> Participate in a scheduled weekly phone call- individual or conference
<p>Week 4</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complete AF module 4 - <i>Identifying/Managing AF Triggers</i> <input type="checkbox"/> Practice AUDIO: <i>Combo Body Scan/Sitting Meditation</i> (15 min)-Practice 6 days. <input type="checkbox"/> Complete daily meditation log/symptomatic episode log <input type="checkbox"/> Meditation workbook completion – Chapter 4 (optional) <input type="checkbox"/> Participate in a scheduled weekly phone call- individual or conference
<p>Week 5</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complete AF module 5- <i>Managing an AF Arrhythmia Episode</i> <input type="checkbox"/> Practice AUDIO: <i>Bringing Awareness to Symptoms</i> (15 min)-Practice 6 days <input type="checkbox"/> Complete daily meditation log/symptomatic episode log <input type="checkbox"/> Meditation workbook completion – Chapter 6 (optional) <input type="checkbox"/> Participate in a scheduled weekly phone call- individual or conference
<p>Week 6</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complete AF module 5- <i>How Cardiovascular Risk Factors Impact AF</i> <input type="checkbox"/> Practice AUDIO: <i>Loving-Kindness Meditation</i> (15 min)-Practice 6 days <input type="checkbox"/> Complete daily meditation log/symptomatic episode log <input type="checkbox"/> Meditation workbook completion – Chapter 7 (optional) <input type="checkbox"/> Participate in a scheduled weekly phone call- individual or conference

Table 4.3.
MEND AF Demographic Data of Participants

	n	(%)
Enrolled	31	
Male gender	20	(64.5)
Age in years (range 37-83)	63.16(M)	10.73(SD)
< 60 years	10	(32.3)
60-70 years	13	(41.9)
> 70 years	8	(25.8)
Ethnicity		
Hispanic	2	(6.50)
Racial Identity		
African American	1	(3.2)
Asian	2	(6.5)
Caucasian	28	(90.3)
Education Level Completed		
High School	1	(3.3)
College without degree	4	(12.9)
Associate Degree	4	(12.9)
Bachelor's Degree	11	(35.5)
Graduate Degree	10	(32.3)
Employment Status		
Full Time	16	(52.6)
Part Time	1	(3.2)
Unemployed	1	(3.2)
Retired	13	(41.9)
Annual Household Income		
< \$50,000	3	(9.7)
\$ 50-100,000	9	(29.0)
\$100, 001-150,000	4	12.9)
\$150, 501-200,000	2	(6.5)
>\$200,001	7	(22.6)
Marital Status		
Single	1	(3.2)
Married	24	(77.4)
Separated/Divorced	5	(16.1)
Widowed	1	(3.2)

Table 4.4.
Medical History

	n (%)
Time Since PAF Diagnosis	
< 1 year	10 (32.2)
1-2 years	5 (16.1)
>5 years	12 (38.8)
Unable to recall	4 (12.9)
Other Arrhythmias	
Atrial Flutter	9 (29.0)
Atrial Tachycardia	8 (25.8)
AVNRT	1 (3.2)
Heart Block	2 (6.5)
Bradycardia	8 (25.8)
Ventricular Tachycardia	0 (0)
Left Atrial Volume Index	
<28 ml/m ² (normal)	4 (13.0)
29-39 ml/m ² (mild-mod)	6 (19.2)
>40 ml/m ² (severe)	5 (16.2)
Not measured	16 (51.6)
Ejection Fraction	
25-59	9 (29.0)
60-70	14 (45.0)
Not measured	8 (26.0)
Medical Comorbidities	
Coronary Artery Disease	6 (19.4)
Heart Failure	1 (3.2)
Valve Disease	4 (12.9)
Congenital Card Disease	1 (3.2)
Depression	5 (16.1)
Hypertension	7 (22.6)
Hypercholesterolemia	9 (29.0)
Diabetes	4 (12.9)

Table 4.5.
PAF Treatment History

	n (%)
Number of ER Visits for PAF	
Never	13 (41.9)
Once	8 (25.9)
Twice	5 (16.1)
≥ 3	5 (16.1)
Number of Cardioversions	
None	20 (64.5)
1-2	4 (12.9)
3-4	3 (9.7)
≥ 5	4 (12.9)
Prior Catheter Ablation	
None	22 (71.0)
1	6 (19.4)
2	1 (3.2)
≥ 3	2 (6.4)
Current Medications	
Rhythm Control	16 (51.6)
Rate Control	24 (77.4)
Anticoagulation	
Warfarin	3 (9.7)
NOAC	16 (51.6)
ASA	7 (22.6)
None	5 (16.1)

Table 4.6.**MEND AF t-Tests and Effect Sizes for Initial and Final Scores on Measured Variables**

MEASURED VARIABLES	t-test		Effect Size (SD of Differences)	CI	P
	Initial \bar{X} (SD)	Final \bar{X} (SD)			
OVERALL SYMPTOMS - AF Symptom Checklist					
Symptom Frequency	19.71 (11.31)	13.14 (7.24)	0.617 (10.66)	-2.27,-10.88	0.004
Symptom Severity	15.46 (6.91)	11.04 (6.20)	0.771(5.74)	-2.11,-6.74	0.001
SPECIFIC SYMPTOMS-ANXIETY, FATIGUE, and Sleep Disturbance					
Anxiety - Cardiac Anxiety Questionnaire (CAQ)					
CAQ Total Score	1.65 (0.68)	1.47 (0.54)	0.333(0.54)	-0.40, 0.04	ns
CAQ Subscales					
<i>Heart related fear</i>	1.69 (0.77)	1.56 (0.79)	0.191(0.71)	-0.42, 0.15	ns
<i>Heart related avoidance</i>	1.29 (0.95)	1.20 (0.78)	0.151(0.61)	-0.34, 0.15	ns
<i>Heart related attention</i>	1.94 (0.66)	1.61 (0.43)	0.503 (0.67)	0.07, 0.61	0.017
Fatigue - Fatigue Severity Scale (FSS)					
FSS Score	3.30 (1.54)	3.08 (1.45)	0.217 (1.05)	-0.20, 0.65	ns
Sleep Disturbance - Pittsburgh Sleep Quality Index (PSQI)					
PSQI Score	7.50 (3.88)	6.92 (3.66)	0.255 (2.27)	-1.49, 0.34	ns
SYMPTOM OUTCOMES- QOL and Functional Status					
QOL – Atrial Fibrillation Effect on Quality of Life (AFEQT)					
AFEQT Total score	89.09 (2.37)	90.47 (2.70)	0.536 (2.58)	0.34, 2.42	0.011
AFEQT Subscales					
<i>Symptom severity</i>	89.23 (2.07)	90.84 (2.66)	0.659 (2.44)	0.63, 2.60	0.003
<i>Daily activities</i>	89.68 (3.39)	91.02 (4.31)	0.290 (4.64)	-0.53, 3.21	ns
<i>Treatment concern</i>	89.50 (3.65)	91.34(4.03)	0.316 (3.17)	0.56, 3.12	0.007
<i>Treatment satisfaction</i>	88.67 (3.02)	89.92 (4.25)	0.300 (4.16)	-0.47, 2.97	ns

Note. This table includes initial and final scores for variables of Overall Symptom frequency and severity, Specific symptoms (anxiety, fatigue, and sleep disturbance), and Symptom Outcomes (QOL and functional status). CI = Confidence Interval, SD= Standard deviation, \bar{X} = Mean, Statistical significance is defined as $p < \text{or} = 0.05$, and ns is defined as $p > 0.05$

Chapter 5: Conclusion

The purpose of this dissertation was to: 1) Explore the experiences and perceived needs of those living with paroxysmal atrial fibrillation; 2) Develop a conceptual model to guide the design and evaluation of an intervention that enables individuals to live well with PAF, and 3) Determine the feasibility and efficacy potential of a nurse delivered intervention that includes mindfulness meditation and education to reduce symptoms, decrease negative illness perception and improve symptom outcomes (QOL and functional status).

This is the first study to present a novel conceptual model related to the clinical phenomenon of individuals with PAF that emerged from the findings of a grounded theory study. Additionally, this is the first study to examine the feasibility and effectiveness of a mindfulness meditation and education intervention that is nurse delivered to patients with PAF for the reduction of symptoms, improvement of QOL, and reduction of negative illness perceptions.

Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation

The narratives of participants in this study echoed many of the themes of participants in previous studies (McCabe and Barnason, 2012; Ekblad, Rönning, Fridlund, & Malm, 2015; Dalteg, Benzein, Sandgren, Fridlund, & Malm (2013), suggesting that the lived experience may be similar for PAF patients, regardless of culture or geographic location.

Reports of delays in the diagnosis and treatment for stroke risk reduction and rhythm restoration remain relatively unchanged from the reports of over five years ago (McCabe, 2012). With the increased availability of reliable, convenient ambulatory monitoring, a more expedient diagnosis is expected. But, in addition to the monitoring results, clinicians need to ascertain the basis of ill-defined symptoms. Particularly, among individuals with increased risk of PAF because of associated co-morbidities (e.g., obesity, elderly, hypertension). High-risk patients

need to be identified and then as part of their treatment, they need education on the signs and symptoms of AF and information on when to seek medical care.

According to current PAF/AF guidelines, clinicians must provide adequate education at optimal times to allow for the active and informed participation of patients in treatment decisions (Kirchhof, et al., 2016; Lane, Barker, & Lip, 2015). Unfortunately, the findings from this study suggest that many individuals feel that they do not achieve an adequate level of AF comprehension to effectively participate in treatment discussions. Participants described feeling overwhelmed while their clinician made attempts at engaging in crucial conversations related to prognosis and treatment options. This phenomenon has been previously described by others (Clarkesmith et al., 2017; Lane, Aguinaga, et al., 2015; McCabe, 2012; McCabe et al., 2015). Because AF education provided during the initial presentation of PAF can be overwhelming, a timeline needs to be established based on incremental building of complex concepts. This would promote a foundational understanding, potentiating an increased comprehension. Asking patients to describe their understanding of key concepts after presenting information has been successful in increasing knowledge in other specialties and needs to be utilized in AF education (White, Garbez, Carroll, Brinker, & Howie-Esquivel, 2013).

Reports of activity reduction due to fatigue or fear of recurrence among patients with AF needs to be addressed, particularly when there is evidence that inactivity and other cardiovascular risk factors contribute to increased AF symptom burden (Pathak et al., 2015). Exercise guidelines and discussions on lifestyle modifications to promote cardiovascular risk reduction need to be included in patient education. Other accommodations made by patients were felt to be more acceptable if they had voluntarily created their unique, individualized strategy, or AF Action Plan, to reduce symptoms and recurrences of PAF.

A Conceptual Model to Guide the Development and Evaluation of an Intervention that Enables Individuals to Live Well with PAF

The conceptual model from this dissertation, *Designing Strategies to Enable Living Well with Paroxysmal Atrial Fibrillation*, provides a foundation for future intervention studies for patients with PAF. This model can be used to advance knowledge related to the clinical phenomenon of living with PAF and to guide the design and evaluation of future interventions targeted at alleviating symptoms, improving QOL, and reducing a negative illness perception. Future feasibility and efficacy studies of symptom management interventions will allow for continued testing and validation of the defined concepts, their relationships between one another, and their “goodness of fit” within the entirety of the conceptual model.

A Mindfulness-Education Intervention that is Nurse Delivered to Reduce Symptoms and Improve Quality of Life in Patients with Paroxysmal Atrial Fibrillation: MEND-AF Study

This is the first study to examine the efficacy of an intervention that includes mindfulness meditation and AF education for PAF patients. The study results of MEND AF support previous findings that have associated greater symptom frequency and severity with lower QOL (Lane et al., 2009; McCabe & Barnason, 2012). This study provides additional support for the use of integrative interventions for symptom reduction in PAF patients. Although the results of this study are not generalizable beyond this group, this study can be replicated in other settings with various PAF samples. The positive effect of the intervention on symptom reduction is encouraging, but it is not possible to discern the impact of any single component of the multifaceted intervention. Results from this study suggest that individuals with PAF who struggle with symptoms and reduced QOL from PAF could benefit from the MEND AF intervention, especially for those whose symptoms persist following catheter ablation.

Limitations

This was a single site, pilot feasibility study and did not include a control group. The sample was predominantly Caucasian, and included only those who were English speaking, limiting generalizability. There were no controls for several possible confounding variables: prescribed medical regimens or adherence to those regimens, and several clinical indicators (e.g. heart rhythm and rate, blood pressure, and PAF recurrence). In addition, the sustained effect of the intervention is unknown and requires further evaluation. MEND AF is a multifaceted intervention that can be tailored for individual patient needs. Therefore, at this stage of development, additional testing using a factorial design is needed to determine the effectiveness of each individual component compared to the combination or no intervention. The small sample size of the intervention testing does not permit the testing of the conceptual model.

Strengths

This was an innovative study with the development of a conceptual model and the first study to evaluate the effects of meditation on symptomatic PAF patients. Theoretical sampling was used to support development of the conceptual model and assure theoretical saturation in the qualitative study, *Experiences and Perceived Needs of Individuals Living with Paroxysmal Atrial Fibrillation*.

The clinical implementation of the intervention was deemed feasible and the intervention is easily replicated. The meditation series over the six weeks was modeled after an MBSR course, so this modification in the meditation practice was found to be acceptable to the patients and effective in reducing symptoms and increasing QOL.

Summary

In conclusion, patients with PAF are challenged by disruptive symptoms. Symptoms are influenced by health and illness perceptions. An altered health perception defies those with PAF who struggle to re-establish their sense of health once it becomes more aligned with illness than wellness is difficult. Negative illness perception is not unique to PAF patients but may be more dominant because PAF is often the first medical diagnosis and often unexpected, so their previous good state of health is shaken.

The conceptual model developed in this study is a contribution to nursing science, as it can be used to advance the understanding of the relationships among the concepts related to PAF patients: disruptive symptoms, altered health perception, quality of life and an AF action plan. The model is iterative and can be further tested to promote the advancement of knowledge about the needs of individuals with PAF.

The treatment focus for PAF is predominantly on procedures for arrhythmia elimination, with less emphasis on support for patients to improve their health and QOL. Therefore, a team approach is ideal for the provision of comprehensive patient care delivery. Recognizing and acknowledging the disruption that is potentially experienced by patients with PAF, nurses are well positioned to create strategies for managing an arrhythmia recurrence if it were to occur, eliminating the need for avoidance of these situations and activities. Providing the education that is needed by patients, so that they can competently engage in treatment decisions is essential. Additionally, the relationship of the nurse provider can promote adherence to the prescribed treatment plan while advocating and promoting strategies for improved self-care. Restoring the unique contributors within each patient's lives can be utilized to empower them and regain their sense of good health.

This study provides a unique, innovative intervention aimed at symptom reduction and QOL improvement. With this intervention, PAF patients can have the opportunity to increase their AF knowledge and develop an achievable skill set to support the reduction of their symptoms, improve their health, and improve their QOL. Many patients prefer to trial noninvasive treatments prior to procedures, so interventions beyond medications need to be explored as integrative treatment options. There are few evidenced based interventions currently available to offer patients. Therefore, this study provides a timely and unique nurse-delivered intervention that contributes to the advancement of evidence-based clinical practice for individuals with PAF.

References

- Dalteg, T., Benzein, E., Sandgren, A., Fridlund, B., & Malm, D. (2013). Managing Uncertainty in Couples Living With Atrial Fibrillation: *The Journal of Cardiovascular Nursing*, 1. <https://doi.org/10.1097/JCN.0b013e3182a180da>
- Ekblad, H., Rönning, H., Fridlund, B., & Malm, D. (2013). Patients' well-being: experience and actions in their preventing and handling of atrial fibrillation. *European Journal of Cardiovascular Nursing*, 12(2), 132–139. <https://doi.org/10.1177/1474515112457132>
- Kirchhof, P., Benussi, S., Kotecha, D., Ahlsson, A., Atar, D., Casadei, B., ... Zeppenfeld, K. (2016). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *European Heart Journal*, 37(38), 2893–2962. <https://doi.org/10.1093/eurheartj/ehw210>
- Lane, D. A., Langman, C. M., Lip, G. Y. H., & Nouwen, A. (2009). Illness perceptions, affective response, and health-related quality of life in patients with atrial fibrillation. *Journal of Psychosomatic Research*, 66(3), 203–210. <https://doi.org/10.1016/j.jpsychores.2008.10.007>
- Lane, D. A., Barker, R., & Lip, G. Y. H. (2015). Best Practice for Atrial Fibrillation Patient Education. *Current Pharmaceutical Design*, 21(5), 533–543.
- Lane, D. A., Aguinaga, L., Blomström-Lundqvist, C., Boriani, G., Dan, G.-A., Hills, M. T., ... Hurwitz, J. (2015). Cardiac tachyarrhythmias and patient values and preferences for their management: the European Heart Rhythm Association (EHRA) consensus document endorsed by the Heart Rhythm Society (HRS), Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE). *EP Europace*, 17(12), 1747–1769. <https://doi.org/10.1093/europace/euv233>
- McCabe, P. J., Rhudy, L. M., & DeVon, H. A. (2015). Patients' experiences from symptom onset to initial treatment for atrial fibrillation. *Journal of Clinical Nursing*, 24(5–6), 786–796. <https://doi.org/10.1111/jocn.12708>
- Pathak, R. K., Middeldorp, M. E., Meredith, M., Mehta, A. B., Mahajan, R., Wong, C. X., ... Sanders, P. (2015). Long-Term Effect of Goal-Directed Weight Management in an Atrial Fibrillation Cohort: A Long-Term Follow-Up Study (LEGACY). *Journal of the American College of Cardiology*, 65(20), 2159–2169. <https://doi.org/10.1016/j.jacc.2015.03.002>
- White, M., Garbez, R., Carroll, M., Brinker, E., & Howie-Esquivel, J. (2013). Is “Teach-Back” Associated With Knowledge Retention and Hospital Readmission in Hospitalized Heart Failure Patients?: *The Journal of Cardiovascular Nursing*, 28(2), 137–146. <https://doi.org/10.1097/JCN.0b013e31824987b>

Publishing Agreement

It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

Please sign the following statement:

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Jinda K. Ottoboni

Author Signature

12/12/2017

Date