

PATIENT COMMUNICATION IN AN ONLINE PEER-TO-PEER FORUM FOR ATRIAL
FIBRILLATION: AN INTERPRETIVE DESCRIPTION

by

KIRSTEN REDMAN
BSN, The University of British Columbia, 2004

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Abstract

Atrial fibrillation (AF) is the most common heart arrhythmia. For people who experience symptomatic episodes, trying to identify triggers and maintain control can cause significant distress. While the sharing of personal experiences and stories occurs routinely on the Internet, the impact of having access to online AF-related information is unknown. The purpose of this study was to explore anecdotal and experiential knowledge about AF created online and elucidate information and support needs from a patient perspective. I employed a non-participant, observational design to tap into a uniquely patient-centred perspective by analyzing messages on a commonly available electronic message board used by AF patients. My analysis was guided by the Interpretive Description qualitative approach, and informed by the Experiential Health Information Processing model. In my analysis, I conceptualized four component parts to describe how participants interacted on the message board to take command of their AF: 1) sharing experiences and values, 2) searching for sense, 3) managing the complexities of information, and 4) acting as a wise consumer. The results demonstrated that many of the participants entered the message board with a common sense of mistrust in the pharmaceutical industry and desired non-pharmacologic approaches to AF treatment. The opinions of lay experts on the message board, anecdotal stories, and hyperlinked Internet data were all highly valued sources of information in the messages. Notable actions described by participants included manipulating anti-arrhythmic drugs and nutritional supplements to perceived symptoms of arrhythmia and using the board to select an ablation operator. I propose that there is an unmet need in the AF population for patient education regarding non-pharmacologic approaches to AF. Further research is suggested to examine the prevalence of

complementary and alternative medicine use in the AF population and to support nurses encountering patients who present with information gained online.

Preface

With the guidance of my supervisor Dr. Sally Thorne and committee members Dr. Sandra Lauck, and Dr. Tarnia Taverner, I conducted all aspects of this research study. No portions of this thesis have been previously published.

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List of Abbreviations

AAD	Anti-arrhythmic drug
AF	Atrial fibrillation
afib	Atrial fibrillation
AoIR	Association of Internet researchers
bpm	Beats per minute
CAM	Complementary and alternative medicine
EKG	Electrocardiogram
EP	Electrophysiologist
EPP	Expert patients program
HIPM	Health information processing model
HISB	Health information searching behaviour
HON	Health on the Net
HR	Heart rate
ID	Interpretive description
IPQ	Illness Perception Questionnaire
IPQ-R	Illness Perceptions Questionnaire- Revised
NSR	Normal sinus rhythm
PACs	Premature atrial contractions
PVCs	Premature ventricular contractions
SEO	Search engine optimization
PIP	Pill in the pocket

Glossary: Key Clinical Terms

Key Clinical Term	Description
Ablation	An invasive procedure in which specialized catheters placed in the heart burn or freeze cardiac cells believed to be contributing to arrhythmia.
Atrial fibrillation (AF)	Abnormal, irregular heart rhythm based in the atria of the heart.
Complementary and alternative medicine (CAM)	An umbrella term to describe approaches to healthcare that reside outside of mainstream medicine.
Electrocardiogram (ECG)	A clinical test which shows the electrical signals from the heart.
Electrophysiologist (EP)	A cardiologist who specializes in the electrical rhythms of the heart.
Flecainide	A medication used to control abnormal heart rhythms.
Health information processing model (HIPM)	A research framework put forward by O'Grady et al. 2008 to describe collaborative learning in online forums.
Health information searching behaviour (HISB)	The ways in which individuals obtain health information.

Key Clinical Term	Description
Interpretive description (ID)	An approach to qualitative research focused on accessing knowledge from a clinically relevant pattern of observations for the purpose of furthering clinical knowledge.
Normal sinus rhythm (NSR)	The normal rhythm of the heart.

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Chapter One: Introduction and Background to the Problem

People worldwide are seeking health information online. Little is known about how patients with atrial fibrillation (AF), the most common adult heart arrhythmia, engage in online information seeking behaviours. AF research has shown that illness representations contribute greatly to psychological adjustment. However, the influence of computer-mediated communication on AF illness representations is unknown. Given the high degree of psychological distress and uncertainty experienced by persons with AF, one may expect them to be susceptible to both the benefits and harms of online information sharing. Nurses play a valuable role in supporting patients with AF by providing anticipatory guidance and emotional support. Further exploration is needed to determine at what points in the AF illness trajectory patients use computer-mediated communication and the nature of dialogue exchanged. This data may contribute to patient safety by identifying areas of misinformation in knowledge shared online. Additionally, the data may provide insight as to whether there is a role for nurses facilitating patient support online.

Social Context

Over the last few decades, the role of the patient has changed from passive recipient of care to active participant (Nelson, Joos, & Wolf, 2013). The shift away from paternalistic underpinnings in healthcare, coupled with fiscal constraint pressures, contribute to an increased recognition of the individual's responsibility for health (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Nelson et al., 2013). This recognition is clearly espoused in the strategic planning of the British Columbia Ministry of Health. For example, priorities for the BC health system include a patient-centered framework that specifically highlights the importance of patients having increased presence in healthcare delivery and shared decision-making (British

Columbia Ministry of Health, 2015). At the same time, information technology is rapidly evolving and, with fewer barriers to accessing information, patients become active contributors to knowledge and support for other patients (O'Grady, Witteman, & Wathen, 2008).

The 2010 *Canadian Internet Use Survey* by Statistics Canada reported that 80 percent of Canadian households have access to the Internet (Statistics Canada, 2011) and 97 percent of Internet users have reported using the Internet to search for information, including health information (Middleton, Veenhof, & Leith, 2010). Whether intended or not, stories and experiences shared may become like fact and contribute to the emergence of the person with illness as an authoritative source of information (O'Grady et al., 2008). Regardless of legitimacy, this kind of information can have a significant impact on how patients both learn and feel about AF.

Illness Context: Atrial Fibrillation

AF is the most common abnormal heart rhythm and its prevalence increases with age (Healey et al., 2011; Kannel, Wolf, Benjamin, & Levy, 1998). At age 50 years, the prevalence of AF is estimated to be 0.5 percent; after age 80 years the prevalence increases to over 10 percent (Kannel et al., 1998). AF carries both physical and psychological burdens. The risk of stroke is over five times higher in AF patients than age and blood pressure matched control groups (Wolf, Dawber, Thomas, & Kannel, 1978). Outcomes for persons with stroke who have AF are also more severe than those who don't have AF (Marini et al., 2005). Moreover, AF is associated with heart failure, dementia, and increased total mortality (Benjamin et al., 1998; Jacobs, Cutler, Day, & Bunch, 2015; Wang et al., 2003).

Studies have repeatedly shown that patients with AF experience psychological distress, including high levels of anxiety, depression, and reduced quality of life (Dorian et al., 2000;

Healey et al., 2011; McCabe, Schumacher, & Barnason, 2011; Suzuki & Kasanuki, 2004). In fact, AF patients experience similar impairment to quality of life as compared to patients with greater degrees of structural disease, including patients with heart failure and patients post myocardial infarction (Dorian et al., 2000). The impairment in quality of life does not correlate well to traditional measures of disease severity (Dorian et al., 2000). This may be because the subjective symptoms experienced by patients do not always correlate to electrocardiographic evidence of the arrhythmia (Mehall, Kohut, Schneeberger, Merrill, & Wolf, 2007). For instance, a patient may report AF symptoms but in fact be in a normal rhythm.

In a susceptible person, triggers, including excessive alcohol intake or aerobic exercise, can induce an AF episode¹. However, the pattern may change over time and for many people there is no trigger at all (Healey et al., 2011). Trying to find a trigger and maintain control can cause patients to avoid any situation that may be stressful, changing social commitments and communication styles (McCabe, Schumacher, et al., 2011). While stress is not a documented risk factor, McCabe, Barnason, and Houfek (2011) found that patients with AF held strong beliefs attributing AF to psychological causes. The focus on a psychological cause can become maladaptive. Suzuki and Kasanuki (2004) found AF patients were significantly more likely to meet clinical criteria for agoraphobia than the general population. One explanation may be that the experience of unpredictable symptoms influences patients to stay at home rather than risk having an attack in public (Suzuki & Kasanuki, 2004).

Unlike other cardiac conditions such as coronary artery disease, the exact pathophysiology of AF is unknown (Schnabel, 2012). Large clinical trials have evaluated novel anticoagulants to prevent stroke and compared procedures (e.g. catheter ablation) to

¹ Identification of a trigger is only relevant to non-continuous forms of AF.

pharmacological management (anti-arrhythmic drugs) to determine safety and efficacy of treatment². However, little research has been conducted about preventing the disease itself (Schnabel, 2012). Consistently reported risk factors include: advancing age, genetic predisposition, underlying heart disease, obesity, sleep apnea, excessive alcohol intake and hypertension (Healey et al., 2011; Schnabel, 2012). While all types of AF are chronic, the condition is categorized as paroxysmal (episodes last less than seven days), persistent (lasting more than 7 days but amendable to treatment) or permanent³. AF can be symptomatic or asymptomatic, regardless of duration.

Diagnosis and treatment of AF is complex. Patients often initially present with vague symptoms and/or abrupt episodes that are not caught electrocardiographically, contributing to frustration and a lack of support when diagnosis is delayed (McCabe, Schumacher, et al. 2011). Medical treatment is highly personalized and can vary considerably between patients based on the pattern of AF, severity of symptoms reported, overall heart function and presence of co-morbidities (Healey et al., 2011). The diversity in treatment options can contribute to uncertainty for patients (Kang, Daly, & Kim, 2004) and has the potential to be confusing for patients with limited health literacy.

Problem Statement

Given that computers and Internet use in the home are increasing, and that there exists a socio-political trend towards individual responsibility for health, I anticipate patients with AF are

² Catheter ablation is an invasive cardiac procedure. A catheter wire is inserted (percutaneously) into the left atrium where specialized electrical mapping is performed to isolate and ablate aberrant electrical pathways. The procedure has yet to show a mortality benefit, however, studies consistently show an improvement in quality of life in comparison to pharmacologic management in a select group of patients.

³ The risk for stroke is similar amongst paroxysmal and permanent forms in patients with comparable risk factors (Schnabel, 2012).

using the Internet for information and support needs. Paroxysmal AF is a condition characterized by uncertainty and high levels of psychological distress. In contrast to other cardiac conditions, there is little research regarding prevention of this illness. However, patients have a strong need to limit the frequency and severity of their attacks, and look to lifestyle and psychological factors as a means for control (McCabe, Schumacher et al., 2011). Informational and emotional support has been shown to reduce uncertainty among patients with atrial fibrillation (Kang et al., 2004). However, the incongruence between subjective symptoms and actual illness burden places patients at unique risk for misunderstandings. Based on my literature review, there are no studies examining the content patients view on the Internet related to AF. Research is needed to examine the type and nature of information exchanged online. A better understanding of the nature of experiential and anecdotal information shared online will assist health care providers who are looking for additional support resources for their patients. Additionally, the potential to identify common misperceptions of events may ultimately contribute to patient safety. Lastly, illuminating the illness experience from a previously unstudied context may contribute to a better understanding of the illness experience for health care providers.

Research Purpose

The purpose of this study was to expand our understanding of how patients with AF engage in online information seeking. Toward this end, this study explored anecdotal and experiential knowledge created online regarding AF and elucidated information and support needs from a patient perspective. The intention of this exploration was to form the beginnings of a premise that health care professionals could use to begin to identify gaps in their provision of education and support to these patients. Additionally, I felt a critical examination for the

presence of biased or promotional material, as well as, common misunderstandings of ordinary illness events, could contribute to patient safety.

Research Question

The primary research question to be answered by this study was: What is the nature of content and dialogue exchanged between patients in online forums about AF?

Conclusion

The sharing of personal experiences and stories occurs daily on the Internet yet the impact of AF patients having access to this information is unknown. It is possible that online forums offer information and support of a different nature than that of medical websites. This initial study aims to expand knowledge of the online peer-to-peer communication experience for these patients. Utilizing commonly available data online is offered as a way to tap into a uniquely patient-centered perspective. I continue this thesis with a literature review in chapter two to discuss what is currently known about online health information searching behaviours and in particular peer-to-peer computer-mediated communication. I also review what is currently known about learning needs of people with AF and their illness beliefs. In chapter three I discuss and defend the choice of study design, as well as highlight some of the strengths and limitations to conducting Internet research. Chapter four presents the research findings, chapter five includes a discussion of those findings, and chapter six concludes the thesis.

Chapter Two: Literature Review

Prior to embarking on the research described in the thesis, I sought to understand the existing literature related to AF patients and online modalities. This led me to explore the research literature related to computer-mediated communication, health literacy, and health information searching behaviour; as well as literature relating to the characteristics of message boards, their users, and the content discussed online. With an understanding of the context of studying patients online I looked to the AF literature to find a significant knowledge gap. Thus, in this chapter I first provide an overview of online health information searching behaviour and follow with an overview of the literature on the educational needs of AF patients and their illness beliefs.

Health Literacy and Prevalence of Internet Use

Atrial fibrillation is a complex arrhythmia. Treatment recommendations vary, based on an individual's current medical status and medical history, as well as the preferences of the patient and physician (Stiell & Macle, 2011). Additionally, professional AF guidelines differ between Canada, America, and Europe for a number of reasons including regional regulations, resource availability, and the timing of publication (Camm & Camm, 2014). Individuals searching online may encounter contradictory information and they require critical thinking skills to apply the insights gained from personal stories shared online. These skills involve what is called health literacy. There are many broad definitions of health literacy. The Canadian Council on Learning⁴ (2008a) summarizes that "health literacy appears to involve more than the ability to read or understand numbers. Context matters, as does the ability to find, understand, evaluate and communicate health-related information" (p. 9).

⁴ The Canadian Council on Learning is a non-profit, independent organization that receives federal government funding

Both health literacy and Internet access are tied into socioeconomic status. Studies have consistently shown that individuals with higher education levels and income are significantly more likely to use the Internet (Canadian Council on Learning, 2008b; Diaz et al., 2002; Dickerson et al., 2004; Statistics Canada, 2011). According to the International Adult Literacy and Skills Survey, 60 percent of Canadians lack enough health literacy to make appropriate medical decisions on their own (Canadian Council on Learning, 2008a). Higher education levels are associated with higher health literacy scores and health status (Canadian Council on Learning, 2008a). Those with the lowest health literacy scores are 2.5 times as likely to be on income assistance (Canadian Council on Learning, 2008a). In Canada, age is also predictive of Internet use, with seniors over age 75 years being the smallest but fastest growing group of Internet users (Statistics Canada, 2011).

Online Health Information Seeking

While there is no agreed upon standard definition of health information seeking behaviour (HISB), it can be “broadly viewed as ways individuals obtain information about health, illness, health promotion, and risks to health” (Cutilli, 2010, p. 214). A review of theories that exist to describe and explain HISB noted that the information-seeking patterns on the web are in fact the same as those seen offline (O’Grady et al., 2008). However, with the Internet, people are now able to interact with others going through the same experiences faster and more easily (O’Grady et al., 2008). Collective knowledge sharing of health and illness is supported through a variety of formats on the Internet including forums for information and anecdotal story exchange, blogs that diarize illness experiences, and wikis where groups of people generate a collaborative knowledge repository (Boulos, Maramba, & Wheeler, 2006; O’Grady et al., 2008).

For-profit websites also exist for health information sharing. For example, the website *patientslikeme.com* enables individuals to share their health conditions, symptoms and treatments, to create a common knowledge base. Search features enable individuals to see how many other website users have the same condition or are using the same treatment. The website tracks side effects, perceived effectiveness, advice, burden, dosages and cost of treatments reported by their members. Patientslikeme.com discloses that they sell non-personally identifiable information to companies developing or selling products to patients.

HISB prior to seeing a practitioner. Dickerson et al. (2004) sought to understand health information-seeking behaviours by interviewing patients attending primary care clinics in Buffalo. Only 53 percent of their subjects used the Internet but of those 53 percent, 68 percent used it to search for health information. They noted patients most frequently stated they looked for information pertaining to a physical illness, followed by nutrition and fitness. Al-Shammary, Awan, Butt, and Yoo (2007) gave questionnaires to patients waiting to see general practitioners in the United Kingdom. Almost half the sample reported using the Internet to search for health information, and 36 percent reported self-diagnosis as the reason for use. Limitations of the studies sampling from physician offices included not reaching patients who chose to consult the Internet but not visit a practitioner.

HISB after seeing a practitioner. Bell, Hu, Orrange and Kravitz (2011) recruited a sample of 274 individuals from an online health forum to study information-seeking behaviour after seeing a physician. Sixty-eight percent of the sample reported going online after their medical appointment. Of the portion going online, 86 percent used a search engine such as Google, 82 percent consulted the online forum they were recruited from, and 52 percent reported reading an online medical journal article. The majority (70 percent) reported going online because they were curious to learn more about their health; the remaining 30 percent went online due to dissatisfaction with their medical visit (Bell et al., 2011).

The Business of Web Searching

When Eysenbach and Kohler (2002) observed health related web searches, the vast majority of participants looked only at the first few results of a search engine and then re-phrased the question rather than looking at the second page. Clearly it is advantageous for business and health websites to appear in the top of Google results. However, patients and consumers may not be aware that companies often employ search engine optimization (SEO) techniques as part of their marketing strategies. SEO involves attending to processes that impact the visibility of a website on a search engine result page (Search Engine Optimization, Wikipedia). Software in this case acts as an invisible intermediary for health information with the ability to privilege or submerge information (Balka & Butt, 2008).

Google is an internationally popular search engine that indexes websites using a complex and confidential algorithm. However, there are many companies that specialize in SEO and sell services to help websites appear in the top of Google's natural search results. Additionally, Google profiles web users based on their search keywords, sites visited, and email content, to display personalized advertisements, as individuals browse the Internet (Google, 2013).

Businesses can also purchase sponsored search results. These advertisements look similar to the natural search results and appear at the very top of the page. There is twofold significance to industry crowding out search results: consumers may not realize websites are promotional and industry websites may be biased in nature towards an explanation of disease that supports the product being sold.

Quality of Health Information Online

Patient understanding of credibility. The literature indicates that patients claim to look for the source of the website to determine credibility (Diaz et al., 2002; Eysenbach & Kohler, 2002). Some authors have found that websites sponsored by medical associations are seen as the most credible health information sources (Diaz et al., 2002). However, when Eysenbach and Kohler (2002) observed online health searches, they noted that participants did not check for authorship and were unlikely to remember where information obtained came from. They reported that participants were more likely to obtain wrong answers due to misunderstanding the information than because of poor website quality.

Quality standards. The reliability of health related websites has been often studied and debated. Health on the Net (HON) (www.hon.ch), a European non-profit, non-governmental organization, accredited to the United Nations, provides basic ethical standards for website developers of health information. Despite these standards and other quality criteria measures for online material, implementation by website developers is dependent on their good will (Benigeri & Pluye, 2003). Khazaal, Chatton, Zullino and Khan (2012) noted that studies evaluating the value of the HON label to predict the content quality of health sites have been mixed. The authors analysed 388 mental health related websites and found that neither the origin of the sites nor the HON label was predictive of content quality. They suggested HON was likely a better ethical guide than actual content quality guide.

Analysing the quality or reliability of health information from end-user generated sites is difficult for several reasons. Textual data changes rapidly and can be altered once written (Adams, 2010). And, also as Lewis (2006) cautions, discussions of quality on the Internet open the debate as to what constitutes legitimate health information. Discussions should be

contextualized within the hegemony held by the medical profession towards the biomedical model (Lewis, 2006). Content analysis studies of online forums rarely report on the accuracy of the information shared. One study that did was Dickerson, Flaig, and Kennedy's (2000) study of a message board for patients with implantable defibrillators. Content deemed to be medical advice was reviewed for accuracy and only 7 percent was considered misleading and or confusing.

Adams (2010) reported most comments in the medical informatics literature about the quality of web 2.0 sites are in the form of editorials directed to health professionals and not patients. Common concerns highlighted by Adams' interdisciplinary literature and web review included: concerns related to authorship and informational quality, anonymity and privacy, as well as the skills required for users to apply insights to themselves. Boulos et al. (2006) argued the lack of attribution to specific authors on collaborative websites is a serious quality issue and the potential exists for charlatans to make dubious claims as content is unregulated.

Pharmaceutical companies can also market drugs through websites that consumers may not realize are promotional (Benigeri & Pluye, 2003). This can occur through non-disclosed sponsorship of social media sites such as blogs or moderated forums which portent to have neutral content (Liang & Mackey, 2011).

Marketing of Pharmaceuticals

Promoting the biomedical explanation for illness is a logical strategy for a company wanting consumers to purchase drug therapy. Read and Cain (2013) conducted a meta-analysis of studies comparing drug-company-owned and drug-company-funded mental health websites to non-profit sites. They found that with the exception of anorexia, the sites that disclosed drug company funding were more biased toward biogenic cause explanations and medical treatments.

The authors warned an overemphasis on biological explanations for mental health contributes to stigmatization of mental health problems and downplays the role of potential beneficial psychosocial treatments (Read & Cain, 2013).

The direct marketing of pharmaceuticals to consumers is regulated under the Food and Drugs Act by Health Canada (Health Canada, 2012). However, the Internet provides easy access to global companies and their marketing practices. Whereas, advertisements that include a brand name and make assertions of the drug's indication and efficacy are illegal in Canada, they are legal in the United States and New Zealand (Morgan, 2007). However, there is a notable lack of Internet examples in the Health Canada policy document "The distinction between advertising and other activities" (Health Canada, 2005). Lastly, the Internet also provides global access to rogue online pharmacies operating outside of conventional regulations (Liang & Mackey, 2011).

Computer-Mediated Communication

A complicating aspect of research about or within the Internet setting is a lack of consistency in terms used. As the World Wide Web started to change from static web pages to include social media such as blogs, wiki's, and message boards, the term web 2.0 began to be used (Adams, 2010; O'Grady et al., 2008). However, currently there is no consensus in definition of the term (Adams, 2010). Christopherson (2007) offers the definition that computer-mediated communication "refers to any interpersonal communication that occurs within the context of the Internet or intranet networks" (p. 3039). Regardless of the term or specific medium, end-user generated websites create a conduit for collective knowledge sharing. This study focused on asynchronous message boards (also called bulletin boards or online forums).

Asynchronous Message Boards

Asynchronous message boards are a type of computer-mediated communication. The boards provide a location for people to exchange anecdotal stories, information, questions, and answers. Messages posted to the forum can be answered (or not answered) at any time of day. Numerous illness-specific forums have been studied using content analysis with populations ranging from adolescents to older adults. Results consistently show similar helping mechanisms to that of face-to-face support groups, such as the sharing of personal experiences, empathy, support, and encouragement (Attard & Coulson, 2012; Coulson, 2005; Coulson, Buchanan, & Aubeeluck, 2007; Dickerson et al., 2000; Malik & Coulson, 2010; Radin, 2006; Ravert, Hancock, & Ingersoll, 2004)

Characteristics of Online Support Group Users

While many authors have studied the HISB of patients going online, there is a paucity of data about the characteristics of patients choosing to interact in online forums. A Dutch study that recruited random samples of patients with breast cancer, arthritis, and fibromyalgia from hospital databases noted they were unable to report on characteristics of online support group users because only eight of their 1013 patients reported posting online within the preceding four weeks (van Uden-Kraan et al., 2009). Darcy and Dooley (2007) recruited 40 percent of registered patients in an Irish online support group for anorexia. Correspondingly, their sample consisted mainly of young females; anorexia is estimated to occur more frequently in females and the gender skew is likely reflective of this fact. They found approximately 44 percent of participants came from rural areas and the clinical characteristics of anorexia were as severe, if not worse than, clinical comparison groups. Another study that recruited online (from 62 message boards on one website) noted their sample was predominantly female and white (Bell et

al., 2011). More recently, Muse, McManus, Leung, Meghreblian, and Williams (2012) compared responses to an Internet usage survey completed by university students based on their anxiety scores. The researchers noted the portion of the sample with higher health anxiety scores searched for health information online more often and for longer durations than the lower anxiety group. The higher anxiety group was significantly more likely to seek out descriptions of personal experience with illness and consult online message boards.

Active versus inactive users in online forums. In a case study of a successful breast cancer support and activism site Radin (2006) noted the website received five to six times as many visits as it did posts. This is not unusual and has been reported by a number of other researchers (Klemm, 2012; van Uden-Kraan et al., 2009; Weinberg, Schmale, Uken, & Wessel, 1996). Some of these visits were likely regulars who were simply checking up on the status of messages (Radin, 2006). However, the majority were likely people who never post and only read, often called “lurking” in the literature (Radin, 2006).

Studying inactive participants is by nature difficult. Two studies that randomly assigned women with breast cancer to a web-based group-support intervention noted that there were no differences in demographics between active and inactive participants (Klemm, 2012; Shaw et al., 2006). Malik and Coulson (2010) also found no differences in age, education, and employment levels between active and inactive users by surveying volunteers on infertility support message boards. These researchers found both active participants and lurkers went online to seek information and support from individuals going through the same experiences. However, the lurking group was more likely to report going online to access hope and reassurance, whereas the active posters were more likely to go online for empathy and emotional support. Overall, the lurkers visited the website less often and were significantly less satisfied with the site than active

participants. Limitations identified by the authors included a low portion of lurkers in the sample (only 15 percent). They were also unable to ascertain the true response rate for the lurking population.

Effect of a professional as moderator. A moderator is akin to a group leader in face-to-face support groups. Their role is to facilitate discussions, answer questions, follow up on persons who have stopped posting, (Klemm, 2012) and remove postings that don't meet the standards or rules of the message board. One random control study that evaluated the effects of online support group format, found that the moderated group read and posted significantly more than the peer led group, however, no significant differences in the outcome variable (depressive symptoms) were found (Klemm, 2012). It is generally agreed that the majority of Internet support forums are peer led rather than being moderated by a professional (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

Benefits and Disadvantages of Asynchronous Online Forums

Online forums have notable advantages to face-to-face support groups. In the pre-Internet era, peer support was limited by how many patients could get together at any one time (O'Grady et al., 2008). With online asynchronous communication participants can interact at any time of the day without the travel associated with meeting in person. Allowing more people in similar situations to interact than previously seen before (O'Grady et al., 2008).

Depending on viewpoint, much of the novel tenets to the Internet can be viewed positively or negatively. For instance, while the perception of anonymity may aid discussions of a personal nature, it may also facilitate the passage of questionable information by individuals who don't stand to suffer any recourse (Harris, Veinot, Bella, Rootman, & Krajnak, 2008). And while the visible barriers of social status are removed online, poor grammar and writing style

may hallmark the less educated online. For this reason, O'Grady et al. (2008) caution that the written format of the web still has the opportunity to reinforce existing power differentials.

Many users will reach an online forum through a search engine and this software is designed to deliver popular results⁵. A consequence of this is that the content surfacing about a topic represents the popular vote rather than the full information available (Gruhl, Meredith, Pieper, Cozzi, & Dill, 2006). Attard and Coulson (2012) studied message boards for Parkinson's disease and documented that some participants would be openly disappointed when they posted but received no replies. That some messages receive fewer or no replies at all speaks to the popularity-based format of the Internet. The written format of online support also has challenges, with several researchers noting misunderstandings happen, however, negative comments make up a very small minority of messages (Attard & Coulson, 2012; Malik & Coulson, 2010).

Outcomes of Participation

Several researchers have examined outcomes from participating in computer-mediated communication. Eysenbach, Powell, Englesakis, Rizo and Stern (2004) undertook a systematic review of quantitative literature to determine the effects of online peer-to-peer communication. They looked at intervention studies involving non-professionals communicating about health through any type of computer network. The authors conducted an extensive search strategy of multiple databases but did not use the keywords "computer-mediated communication". They searched instead for synonyms of 'support', 'computer network', and 'e-community-venue' in medical, social science and electronics literature. Despite their extensive search strategy, they found only six studies that solely examined peer-to-peer online communication. (Most of the

⁵ Earlier search engines were designed to perform searches based simply on keywords; however, commercial interests manipulated this software by duplicating key terms to deliver spam (Gruhl et al., 2006).

published studies included the peer-to-peer component as part of a larger intervention).

Electronic support groups studied included weight loss, diabetes and smoking cessation support. Wide variability in interventions, measurement tools and populations covered, as well as a lack of methodological rigor, prevented the authors from drawing conclusions about the effect of these support groups. Lieberman and Goldstein (2005) studied new members on a breast cancer forum and found statistically significant improvements in depression, personal growth, and psychological well-being scores at six months. However, without a control group the findings were limited, as participants could have improved over time without the online participation.

Healthcare professionals may worry patients will ignore their advice as a result of online information. In our modern society physicians have less cultural authority than in the past (Barker, 2008; Wathen, Wyatt, & Harris, 2008). Some patients may have a 'sceptical dependency' on their physicians, as they bring issues to their appointment, yet may be unwilling to hear medical opinions that differ from the views shared online. However, while laypersons may not accept everything a physician offers, they may find their health situation too complex to research on their own (Barker, 2008). In a study of healthcare non-adherence decisions, Weaver, Weaver, Thompson, and Hopkins (2009) showed that people who spent more time online searching for health information, and people who placed a higher value on mass media health information, were more likely to report non-adherence to medical advice based on Internet information. Barker (2008) offers that for patients with somatic illnesses such as fibromyalgia, the online environment offers little actual empowerment to a patient other than the option to seek out another physician.

Computer-mediated Communication and Cardiology

My literature review revealed only one study of an online community with a cardiac population and no studies related to AF⁶. Dickerson et al. (2000) studied an electronic message board for patients with implantable defibrillators and found results consistent with more contemporary research. Participants used the board to exchange practical information about living with their device, and shared personal stories and perspectives to support each other. The lack of content analyses relating to cardiology does not mean cardiology topics are not present in online forums. (The keywords atrial fibrillation and forum reveals over three million results in Google).

The Educational Needs of AF Patients

Currently there is very little information about what patients with AF understand about their condition and no data on what they look at online. Most of the published literature focuses on optimizing and improving adherence to anticoagulation treatment. Because recent pharmacologic advances have greatly changed the options for anticoagulation, I chose to exclude these prior studies as relevant to my literature review for the purpose of this study. This left eight studies relevant to the phenomenon in question, three that focused on measuring AF knowledge, three that focused on illness perceptions, one that focused on both areas, and one validation of a knowledge testing tool.

In Finland, Koponen et al. (2008) administered an author-developed AF knowledge test to 200 patients in the Emergency room. Just over one third of the sample was newly diagnosed

⁶ I searched “CINAHL”, “Medline”, “Academic Search Complete”, “Library, Information Science and Technology Abstracts”, and “PsycINFO” databases with the key words atrial fibrillation AND (computer mediated communication OR Internet OR online) which revealed 159 results, of which none related to patient communication online.

and all 200 patients repeated the survey three months later. Knowledge level regarding AF symptoms was generally good. However, only 44 percent were aware that AF could be asymptomatic, and only 29 percent understood it could reoccur while taking medications (Koponen et al., 2008). Although it is unclear how the authors measured coping, Koponen et al. noted patients who coped poorly were the most likely to answer questions regarding AF symptoms, detection of AF and treatment seeking, incorrectly. Knowledge levels did not statistically change over time.

In the United States, McCabe, Schad, Hampton, and Holland (2008) recruited hospitalized patients who had recently been diagnosed with AF and examined their knowledge and self-management behaviours. Two weeks after hospital discharge they asked patients structured, open-ended questions derived from the education material delivered in hospital. The authors found notable knowledge deficits related to AF and stroke symptoms. Only 47 percent of patients were able to identify AF as a stroke risk, and only 32 percent were able to identify greater than three symptoms of stroke. However, 80 percent reported taking their medications as prescribed and 91 percent kept follow up appointments with physicians.

Similarly, Xu et al. (2010) administered a knowledge test and behaviour questionnaire to hospitalized patients in China, however, these patients were waiting for ablation and needed to have had an AF diagnosis for over six months to participate. Overall, in line with previously published results, low mean scores for AF knowledge were found. Additionally, only 28% of the sample reported they knew the complications of the ablation procedure they were scheduled to undergo. The tool developed by the author was pilot tested and achieved acceptable scores of internal and content validity. While not addressed by the study authors, the published

questionnaire contains grammatical errors, however, this may have been the result of translating the material from a Chinese language.

Aliot et al. (2010) conducted an international survey to examine both knowledge and attitudes towards AF. The sample included 810 physicians and 825 patients from 11 countries, including Canada. Physicians were asked about their views of the risks of AF and its treatment compared to other cardiac illnesses, the quality of education material, the workload of AF patients, and their perception of how AF impacts quality of life. Patients were also asked to rate the risks of AF compared to other illnesses, as well as their level of satisfaction with information provided, and impact on daily life. While physicians were most concerned about stroke and potential for hospitalizations, the patients were most worried about death, sudden cardiac death and heart attack (Aliot et al., 2010). Over 35 percent of the patient sample preferred the Internet for information, the third choice next to specialists and general practitioners. Both physician and patient groups agreed AF had an adverse effect on quality of life, and over one third of the patient sample reported feeling worried or fearful about their AF.

Most recently, Hendriks, Crijns, Tieleman and Vrijhoef (2013) published their validation of an instrument to measure AF knowledge. The tool was developed from an intervention study about anticoagulation and was also based on scales used in the heart failure population. The eleven questions on the tool pertain to the disease, symptom recognition, treatment options and attitudes. However, weak internal validity was achieved with a Cronbach's alpha score of 0.58. As the authors note, the reliability score could be improved if more items, drawing on the same concept, were added to the scale. An unreliable instrument can limit statistical power in future studies, thus, as the authors acknowledge, further research into the reliability and validity of the scale is warranted. However, the scale is an important step towards future study of the

relationships between knowledge level, quality of life, self-management behaviours, and hospital admission rates (Hendriks et al., 2013).

Illness Representations

Health psychology research has shown that the cognitions individuals make about their illness, called illness representations (or sometimes illness beliefs), influence coping behaviours and health outcomes (Hagger & Orbell, 2003). Two published AF studies have used Leventhal's Common Sense Model in their research. In this model, individuals form illness representations by assimilating information from ingrained social and cultural knowledge of the illness and from external sources such as significant others and physicians, and compare it to their present experience (Hagger & Orbell, 2003). In a meta-analytic review of the Common Sense Model Hagger and Orbell (2003) described the content of illness representations as having dimensions of: cause, consequences, identity, and timeline. These four concepts are measured on the Illness Perception Questionnaire (IPQ) a commonly used tool in the literature. Cause relates to the factors an individual attributes as responsible for the illness, whereas, consequence represents the impact the illness has on functional capacity. Identity refers to self-reported symptoms and timeline relates to beliefs about the course of the illness (Hagger & Orbell, 2003).

Steed, Newman and Hardman (1999) studied a sample of 62 AF patients to determine the contribution of symptoms, illness representations, and coping to psychosocial adjustment. Symptomatic patients were compared based on whether they had paroxysmal or chronic AF to determine the effect of chronicity of symptoms; no significant differences were found. However, when symptomatic AF patients were compared to asymptomatic AF patients, the symptomatic group had significantly poorer psychosocial adjustment on four of the five subscales, including

psychological distress. This result was independent of disease severity. The authors did not report in detail about the illness beliefs collected by the IPQ scale.

However, McCabe, Barnason, et al. (2011) published details of illness beliefs from 207 symptomatic AF patients using the updated Illness Perceptions Questionnaire-Revised (IPQ-R). They found participants held the strongest beliefs for a psychological cause as opposed to external or lifestyle causes. Interestingly, 29 percent felt diet was an attributable cause to AF and 57 percent of those sampled felt AF caused difficulties for those close to them. While the IPQ-R does not measure AF symptoms such as palpitations specifically, of the symptoms measured, 81 percent identified fatigue as a symptom of AF. Forty-nine percent of the sample agreed or strongly agreed their AF was cyclical and unpredictable. When the authors looked for relationships between the beliefs they found patients who reported lower perceptions of understanding AF were significantly more likely to hold negative emotions toward it.

From what appears to be the same sample of 207 patients, McCabe and Barnason (2012) analyzed the IPQ and three additional scales to measure the extent illness perceptions, coping strategies, and symptom frequency and severity contribute to psychological distress. Variables such as gender, age, length of time since diagnosis and type of AF did not contribute to psychological distress. However, the perception of the illness having a psychological cause and great consequences contributed greatly to the explanatory model, more so than symptom frequency and severity.

Conclusion

Surveys of Internet use indicate the volume of patients using the Internet for information and support needs is rising. Additionally, with an aging population, the number of patients with AF is also expected to rise. Nurses regularly work with AF patients at decision-making points in

their illness and have a role to play in reducing uncertainty and supporting patient's psychosocial health. Internet options such as online forums provide a venue for anecdotal stories to be shared and viewed by limitless others. A better understanding of this collaborative information sharing online is needed as it potentially impacts illness perceptions and decision-making processes. Currently there are no published studies examining how patients with AF use Internet communication for education and support related to their condition. Examining content commonly viewed online is therefore, an important step towards developing patient-centered educational materials and psychosocial support services.

Chapter Three: Research Methodology

This study employed a naturalistic, non-participant, observational design to analyze messages on an electronic message board for AF. The study was guided by the qualitative approach, Interpretive Description, and informed by the Experiential Health Information Processing model. I next discuss each of these aspects of study design.

Qualitative Approach: Interpretive Description

Interpretive description (ID) is an approach to qualitative research, first described by Thorne, Kirkham and MacDonald-Emes (1997) for researchers who were not looking to test relationships and theories, but rather wished to inductively generate explanations and interpretations that could be applied in practice. ID was selected for its pragmatic nature and because ID studies, “explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of clinical insight” (Thorne, 2008, p. 74).

ID is underpinned by a constructivist epistemology; Thorne (2008) described this as an understanding that perceptions and experiences are socially constructed, and are in context with the cultural and social forces that shape them. Similar to the phenomenological hermeneutic tradition, the intent is to go beyond interpreting actions through motivations, and concentrate on the “lived experience” of the patient. However, with ID, the goal is to further clinical reasoning rather than generate generalizations for theory. ID does not ask the researcher to bracket preconceived constructs but instead presumes there is some existing clinical pattern observation that is relevant (Thorne, Kirkham, & O’Flynn-Magee, 2004). ID also does not prescribe specific recommendations for study design. Instead Thorne (2008) describes it as a “logic model” in which decisions for data collection and analysis must remain consistent with the intent of the study. Interpretation is provided within the context of disciplinary knowledge for the purposes of

advancing that knowledge. While I proposed a theoretical framework for the initial data sorting, the intent was to move beyond the initial descriptive claims using a process of inductive reasoning that is further explained in the data analysis section.

Theoretical Framework: Experiential Health Information Processing Model

Most information seeking behaviour theories explain behaviour based on individual motivation or situational factors. The Experiential Health Information Processing model proposed by O'Grady et al. (2008) differs from other theories to include the collaborative aspect of Internet learning. The model is based on Kolb's four stage cyclical process of experiential learning, which is learning by doing or learning by experience (O'Grady et al., 2008, Appendix A). The first stage is "Concrete experience: an event," this is described as the diagnosis or decision-making points in the illness when the individual is confronted with a need for information. For example, many people receive an AF diagnosis in the emergency room after a series of unsettling symptoms. Generally, depending on the length of time in AF and symptoms experienced, patients are faced with treatment options, including medication, a procedure called cardioversion or simply doing nothing. The second stage in the model is "Observations and reflections: thinking about the event and its impact", in this stage an individual reads and reflects on online messages. During this stage individuals may conduct their own Internet research to confirm what they have been told by medical professionals and seek answers to questions. Stage three "Formation of abstract concepts and generalizations: what was learned," involves users posting messages about expectations for the future course of illness. In this stage I expected to see postings that responded to others questions with a relation of personal experience. Stage four, "Testing implications of concepts in new situations: active experimentation," is when the individual applies the knowledge gained to their situation and makes a decision. This stage is

unlikely to be captured online and would require further longitudinal study. The model was expected to provide a beginning organizing and sorting framework for analysis.

Next, I will explain and justify the naturalistic, observational, non-participant part of the study design. I had no interaction with the users of the board to maintain a naturalistic setting. This is important as Dickerson et al. (2000) documented a researcher effect on online interactions. When the nurse researchers posted online, message board participants posted medical questions directly to the researchers rather than continuing the patient-to-patient support seen previously. A theoretical assumption underlying the current study was that patients are experts with respect to their own experience, and when they collaborate online, patient-to-patient anecdotal evidence may become credible material from which patients may make decisions. This study aimed to identify what patients ask when they have the option of anonymity, what patients ask when it is the middle of the night and they are scared and so on. Thus, I felt that any active involvement of a researcher who has extensive experience working with the AF population could have changed the dynamic and potentially disrespected the tenets of what makes online collaboration satisfactory for patients. Although a purely observational approach poses some limitations for this research, it was deemed the most appropriate at this beginning stage of the inquiry.

Sampling Plan

Sample selection. In qualitative research, sample selection is motivated by the need to fulfill conceptual requirements and participants are sought for their ability to articulate and describe phenomena (Polit & Beck, 2012). To study the information exchanged between online participants, this research used a convenience sample derived from electronic messages in proxy to humans. As the intent of the study was to reveal knowledge that may be helpful to clinical practice, I initially proposed that some theoretical sampling would be necessary. Theoretical sampling involves seeking out specific cases to confirm, refute and fill out the categories to allow maximal patterns and themes to emerge in data collection and analysis (Thorne, 2008). For instance, I thought analyzing messages from a different time of year could enable comparison and contrast of a relevant concept as it pertained to seasonal variation. However, in actuality, the data set was rich with information and this was not necessary.

Website selection. I used the keywords “atrial fibrillation” and “forum”⁷ in Google to find a forum for analysis. The website: <http://www.afibbers.org/lafforum.html> was the first non-sponsored result. This website is both a paid subscription service to “The Afib Report” and a free bulletin board. In the ‘about the editor’ section of the website, the Webmaster indicates he is a professional engineer with a master’s degree in chemical engineering and has a “keen interest in alternative medicine and the biochemistry and effects of natural antioxidants” (Larson, 2012, para. 2). He reports that he started producing the Afib Report in 2001 as a means for disseminating his research. It is not apparent whether he is reporting on the results of his own research or that of others. According to the homepage, the bulletin board was started in September 2000 and contains messages from 100,000 contributors. The homepage description indicates the forum is for lone AF⁸ and is not intended to be medical advice. When assessed for activity level on August 6, 2013, 13 posts written by six different user names had been written in the last six days. Some posts had received as many as 250 views (how many users the views represent is unknown). The website is produced from Victoria, B.C., and while the board is described as having international participants, I had hoped the site would provide a more regional perspective than other larger American produced boards online. A regional perspective in this case is important given the differences in healthcare systems.

⁷ This search displayed approximately 3,130,000 results on July 6, 2013

⁸ Lone AF is AF without other medical co-morbidities

Sample size. The inclusion criteria was all messages posted by patients within a three month time period from the above mentioned message board. All messages were reviewed for content and relevance. I initially proposed to exclude messages that clearly reflected indirect experiences, such as postings from family or friends, thinking that these messages may differ in nature from that of the person with AF themselves. However, during data analysis I found eliminating posts from a spouse would have interrupted the natural story line of the messages and elected to keep them for contextual purposes. Three months of data allowed a sufficient degree of thematic redundancy within the sample to begin to detect patterns and interpret themes.

Data Collection and Analysis

Text based messages were downloaded from the publically accessible archives of one electronic message board into a Microsoft Word document. Brief descriptive statistics were performed to summarize such metrics as word count, number of discrete patients, and frequency of users postings.

ID emphasizes continuous engagement in strategies that shift “attention sequentially from individual cases to the whole data set, from groups of similarity within certain cases to various manifestations of difference within other cases” (Thorne, 2008, p.149). Alternate perspectives are sought by asking, “What am I seeing” and “Why am I seeing that?” (Thorne, 2008). In this manner I read through the data script in its entirety several times and guided my thinking by reflecting on the questions in my data collection guide (Appendix B).

In an attempt to avoid superficial conclusions I did not embark on an early coding scheme; instead as Thorne (2008) suggested, I used the computer’s highlight function to identify preliminary groupings of ideas. I documented my analytic thinking in a dated entry Microsoft Word document noting emerging patterns, themes, and questions for follow up. I also worked

with my supervisor to determine that no additional theoretical sampling was required. An iterative process of data collection, analysis, and synthesis continued until there was a “compelling basis” to support conclusions drawn from the findings (Thorne, 2008). I anticipated a description to emerge of how dialogue between patients creates a community of information exchange. The characteristics of the online participants and topics covered were expected to illuminate the function and purpose of the AF forum existence. The eventual identification of key themes both in the illness experience and in the process of using online support then answered the research question.

Ethical Considerations

A recent study lends evidence to suggest that online forum participants may want and desire researchers to use the information they have shared in order to ultimately benefit their illness community (Bond, Ahmed, Hind, Thomas & Hewitt-Taylor, 2013). However, the decision to use messages from an online message board as research data presented several ethical challenges; particularly in terms of privacy and consent issues. Bond et al. (2013) found that while participants in an online forum for diabetes were happy to have their information used in aggregate, they were split in terms of quotations. Some participants felt it was OK, others felt permission should be asked of them. Despite the fact that this type of data collection can no longer be considered novel, guidelines for researchers are somewhat lacking.

Exemption from review board. Article 2.2 of The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans states, “research that relies exclusively on publicly available information does not require REB review when: ... (b) the information is publicly accessible and there is no reasonable expectation of privacy” (CIHR, 2010, p. 17). The electronic message board this study examined is searchable on Google and has a publically viewable password for entrance. This password is required to prevent computerized spammers from posting on the message board and is openly displayed on the entrance page to the board. This is distinct from when users create a login and private password for entrance.

The public-private debate. The expectation for privacy on a publically accessible electronic message board is debatable. Many authors note that the distinction between public and private on the Internet is blurred (Eysenbach & Till, 2001; Hudson & Bruckman, 2004; Vayena, Mastroianni, & Kahn, 2013). Individuals may feel a sense of privacy when participating in a special interest group and not expect to be researched. Eysenbach and Till (2001) suggested three measures to estimate the perceived level of privacy within a group. The first is whether a form of registration is required. The second is to consider the size of the group, given that a group of 10 will feel more private than a group of 100. The third suggestion was to evaluate the aim of the group, its norms, and target audience. The authors suggested looking to a frequently asked questions document to see if there is an explication for whom the group is intended. The discussion board used for this study did not require registration to view posts, it contained over 22000 posts, and had no messages of intent for user categories. Based on this assessment, I considered the board in question to be in the public domain.

Waiving informed consent. It is important to consider the issue of waiving informed consent in the non-participant, observational study design. To assess participant vulnerability I reflected using ethical questions suggested from The Association of Internet Researchers (AoIR), 2012 document Ethical decision-making and Internet research document (Markham & Buchanan, 2012). I anticipated that the participants of the online message board were unlikely to consider themselves vulnerable. The participants in this study had chosen freely to post on the Internet in a publically accessible forum that does not require membership to view. Additionally, it is argued that participants of online chat rooms choose their level of anonymity and change their disclosure of self to suit the situation (Waskul & Douglass, 1997). The site is easily located from Google and data is easily searchable and retrievable. The website contains no statement of privacy. Lastly, I would argue as AF is an illness of advancing age, it is unlikely for minors to be posting within this forum.

Risk, Benefits, and Protection of Participants

Based on the public and non-sensitive nature of the electronic message board, subject risk was considered to be minimal and comparable to everyday life. There are unlikely to be any direct benefits to participating in the study. Knowledge generation for AF patient care is a general benefit. Coding each username will protect participants. The data will be kept for five years after which it will be destroyed. All identifying information will be removed from quotes and the electronic board name will not be published in the research results.

Rigor and Validity

I used several strategies to enhance the credibility and trustworthiness of this study. Thorne and Darbyshire (2005) detailed problematic patterns of inductive analysis and research writing within qualitative research. I referred to and was mindful of their list of cautions during

all phases of the study. In addition, I maintained a reflective journal to help clarify the role my own clinical experience, life experience, and personal biases add to my interpretation of the data. An audit trail was created to justify methodological and analytical decisions made. When analyzing and interpreting the data I ensured the meaning of postings was preserved within the context it was written. As this project is a master's thesis, I used my supervisor as an advisor and mentor throughout the process.

Strengths and Limitations

There are many benefits and limitations to conducting Internet-mediated research. Seale, Charteris-Black, MacFarlane and McPherson (2010) found online posts were more likely to be detailed about the bodily experience of the disease, tests and treatments, compared to in-person interview accounts. They also found Internet material had more day-to-day accounts of experience than in-person interviews. As Holmes (2009) described, there is great potential to reach a broad sample, including hard-to reach people who may not access healthcare or have mobility restrictions. Additionally, there is assumed to be geographic diversity in the posters online. Data already exists in textual format, saving time, money, and potential for transcription error. The Internet also avoids the social desirability response that may be seen with in-person interviews. Treatment of AF often involves the use of anti-arrhythmic pharmaceuticals and anticoagulants. Both classes of drugs have significant risk for injury if misused or taken in combination with other substances without medical review. Sampling from a website that attracts a population looking for natural or alternative treatments may reveal information not commonly disclosed in medical appointments that could improve patient safety.

There are also many limitations related to study design and sampling in this study. Several issues arise from the lack of demographic information available. International

differences in healthcare delivery and healthcare access may influence the views of posters online and this context may be lost without demographic information. Data from my literature review indicates online forum users are often white, female, and more educated than the general public. In light of the influence of socio-economics on health literacy and Internet access, it is important to be mindful that the sample represents a select, minority of AF patients. The website was also selected from English language Google search results and has no medical association affiliation. Thus, patients who choose to participate on this site may differ substantially from those who choose sites that are affiliated with medical organizations or are in different languages.

Internet posters can represent themselves falsely and there is no way of knowing if someone is a patient or family member. However, as Holmes (2009) points out, there is no guarantee people will represent themselves truly using telephone, mail or even in-person interviews either. As discussed in the sampling section, the views and perceptions of patients who read messages but do not participate and post online are not represented in this study. Text lacks the visual and auditory cues present in interviews and therefore, some nuances in conversation may be lost. Because the data is pre-existing, I am unable to go back and ask follow up questions or verify the themes found. I remain mindful of these potential limitations in order to reduce any potential impact they may have on my findings, and aim for transparency in my interpretive analysis within the written report of the findings.

Conclusion

The qualitative approach Interpretive Description and theoretical framework the Experiential Health Information Processing Model were proposed to guide this study based on their emphasis of the subjective and experiential nature of online learning. I reflected carefully

about ethical considerations and provided a defense for not requiring a review board.

Considerations were also given to the advantages and disadvantages of online data collection.

The following chapters present the research findings, discussion, and conclusion.

Chapter Four: Research Findings

In this chapter, I detail the findings extracted from the three-month data collection period (June 17, 2013 to September 18, 2013). As I will explain, the analytic process involved consideration of how the findings might best be displayed to be useful to nursing practice, while remaining respectful of the authors of the data set. Ultimately, I noted the majority of postings described strategies and discussed AF treatments, in order to gain a sense of control over an unpredictable illness. I therefore entitled the findings “Taking Command of AF.” This process is illustrated by four component themes articulated in order to bring nurses an understanding of the intricacies involved in using the online medium for the self-help process. I will review the process of analysis, including the general content observed and its fit within the original guiding model, before expanding on the ultimate findings structure, “Taking Command of AF.”

Descriptive Statistics

I performed brief statistics using Microsoft’s Word and Excel programs to gain an understanding of the data set. The data collection contained a total of 181 threads (310, 677 words) (Table C1, Appendix C). Seventy unique usernames initiated discussion threads and an additional 33 usernames replied only. Each thread contained an average of nine posts (median 8) and an average of 206 views (median 195). The majority of usernames who initiated posts did so only once or twice during the data collection period; however, the range was from one to eleven times (Table C2, Appendix C). The number of replies made by each username was not tracked. Forty-five percent ($n=32$) of those who initiated threads either directly disclosed or gave information that insinuated their geographic location (Table C2, Appendix C). About half of those who gave geographic information were American ($n=17$), although participants also came from Canada ($n=5$), Australia ($n=1$), the United Kingdom ($n=6$), New Zealand ($n=2$), and the

Philippines ($n=1$). Thirty percent ($n=21$) of thread initiators listed or referred to their own age in a post, with a range of age 29 to 77 years. Gender was noted when it was explicitly stated by the participant, or when a conversation described an in-person meeting and used gendered pronouns.

Results of Data Analysis

During the analysis, the content was sorted initially into groupings and patterns of ideas related to the frequency of topics discussed. Individuals posted messages at the beginning of their diagnosis, in the midst of AF recurrences, and when they considered their AF to be either cured or dormant. Participants described a common goal to create member driven data, intended to help propel AF science towards a cure. In order to do this, members actively participated in searching for a solution to their difficulties by identifying AF triggers, treating themselves with nutritional supplements, and sometimes by undergoing the ablation procedure. Participants articulated rational thought processes, but sometimes seemed to base their decisions on evidence of questionable scientific quality (for example, anecdotal experiences or a retailer's website information). The essential content of messages included questions related to an individual's own situation, as well as topics of interest to the lone AF community. Such topics included: specific nutrients and minerals that posters believed were crucial to preventing AF, supplements, medications (including management and side effects), stroke prevention, selecting electrophysiologists to perform ablation, and ablation techniques.

From a healthcare professional's point of view, misconceptions about scientific information stood out. The data could have been organized into categories and examined for medical accuracy. However, as proposed, I made a decision to look beyond a content analysis of frequent topics on the discussion board. Rather than examining the postings solely for medical accuracy, I desired to find a balance that would respect the worldview of the individuals who

created the data, while keeping the findings relevant for clinical practice. I felt this was important considering that the credibility of knowledge remains contingent on an appreciation for the paradigm of thought that an individual subscribes to. I therefore made the decision to focus the analysis on the patterns of information seeking and behavior I observed online, opting to retain in the report some of the patterns of misunderstandings that I recognized as potentially relevant to patient education. In particular, I did pay attention to medical accuracy when there was a clear potential for an adverse outcome. To give the reader an accurate representation of the communication mode, quotes from the message board were left intact in their original form. Therefore, capitalization, spelling, punctuation, and other grammatical errors remain in the quotes used to display the findings.

I next considered the Health Information Processing Model (HIPM, O'Grady et al., 2008), as it was the proposed analytic framework. Although it would have been possible to “fit” the various messages into the different steps of this model, I came to realize that this would not have effectively conveyed the AF specific information that would be most relevant to nursing practice. Thus, despite the apparent fit, I concluded that the important elements of the findings would be better illuminated if presented in a manner that departed from the original guiding HIPM in several key ways. Explanation of those departures will set the stage for an understanding of the approach I eventually chose to display the findings for this study.

First, the HIPM describes information-seeking stemming from a decision point or information need; it does not explicitly conceptualize information sharing for other purposes. Acknowledged expert patients often posted to share their knowledge rather than solicit knowledge from others. For example, an expert patient posted a summary of a recently published scientific study in his lay terms for the benefit of the group, rather than in direct response to an

inquiry. Because these expert patients greatly facilitated discussions, I concluded that this aspect of communication deserved further emphasis within the findings.

Secondly, postings about such elements as changing lifestyles to avoid triggers, deciding to take medication and/or supplements, and considering the ablation procedure, clearly had a large impact on daily lives as articulated in the postings. I therefore concluded that the intricacies of the information that led to those decisions needed to be given due attention in the reported findings. Additionally, anecdotal, scientific, and pseudoscientific information were used to support the logic individuals expressed in board discussions. Therefore, rather than simply making note of the information *per se*, I sought a mechanism to describe the complexities of the information an individual must consider before forming an interpretation or generalizing to their own experience.

Lastly, as I read the postings, I became aware of the implications of the depiction of HIPM as a linear process, as per O'Grady et al. (2008). In this linear process, a need for information occurs, the individual ponders, posts a question, deliberates, and acts. However, the dialogue I observed was better characterized by individuals who were actively experimenting and posting updates. Therefore, I felt that this active experimentation seemed much less of a final step and more of a cyclic process of engaging with information throughout decision making and remaking.

Thus, I sought to conceptualize the findings in a manner that would reflect the spirit of the board's purpose and highlight some of the important processes not articulated by the HIPM. Therefore, as I next describe, the final findings structure takes into account the HIPM model, but refines the themes to a more relevant conceptual structure to AF.

I observed an iterative process to take command of AF. Individuals appeared to enter the board with a generally common set of precipitating beliefs and experiences. They used the board to make sense of their AF events by sharing experiences with medications, supplements, trigger avoidance, and ablation. To inform their decision-making and fuel the trial and error process, individuals waded through volumes of information, often complex, and sometimes of debatable scientific quality. Using the learning gained from the board, individuals proceeded with strategies to treat their AF. Throughout the process, individuals came back to the board, to update on their progress and gain assistance from others. In order to illustrate how this occurred, I will next describe each aspect of taking command in further detail.

Taking Command of AF

As I worked with this material over time, I came to understand that the process of experiential learning, in an effort to take command of their AF, was a dominant and overarching theme across the various postings in this data set. To ‘take command’ implies an active participation that I believe is consistent with the board’s philosophy, as attitudes implying a personal responsibility for health underpinned the data set as a whole. Four themes within this conceptualization of the data set illustrate the core components of the experiential learning process as represented by these individuals within the online forum context. These are, sharing experiences and values, searching for sense, managing the complexities of information, and acting as a wise consumer.

Sharing experiences and values. In naming the first theme, “Sharing experiences and values” it was my intention to illuminate some of the reasons that may have contributed to patients going online, to this particular forum, to search for help with their AF. First, I will overview some of the common experiences and concerns related to AF that precipitated participation on the board. Then I will discuss the frequently expressed sentiments towards Western Medicine that seemed to contribute to the widely held opinion that patients are responsible for doing their own research, rather than relying on a physician’s advice. An understanding of these background contextual issues in the lives of these study participants gives context for the subsequent components to the process of taking command of AF as observed on the web board.

Experiencing uncomfortable and unpredictable symptoms. Although some members did describe themselves as asymptomatic, generally most of the participants on the board were highly symptomatic. The descriptions of AF varied. One participant wrote that AF felt like being “kicked in the stomach all night, no sleep, pure misery” (Joseph, thread: Need Some Good Advice, September 12, 2013 08:58AM). Another stated, “Most times my afib will shift from the typical two hamsters break dancing inside my chest to a short period of tachycardia and back again to the skippy dance.”⁹ (Mikedadt, thread: Stuck in tachy, August 15, 2013 04:49PM). Others described it as hard beats or a rumbling in the chest. Many posters did not describe their symptoms, but instead the impact on their life, especially when they were plagued with worry about when an AF episode would occur. Kamkin wrote, “for me the anxiety of waiting for another bout is probably worse than having it happen” (when to have ablation? and dr info,

⁹ All quotes are displayed as originally written, complete with spelling and grammar mistakes to showcase the nature of the online experience.

September 10, 2013 11:41AM). Others described avoiding physical activities and stressful situations for fear of provoking an attack.

Difficulties with control. An interesting analogy that came up frequently was to compare AF to “a beast”. Participants wrote about fighting, wrestling, controlling, and eliminating the beast. However, the forum members also lamented that the complex nature of the beast made it difficult to control and predict.

What was a little disturbing was that in 14 years, all of my episodes have been vagally mediated, (I have a hiatal hernia and GERD) I exercise regularly and not once have I 'flipped' while exercising. In the past couple of months I've been gradually getting my jogging distance up to 5 miles. And then this week my two episodes happened, firstly, when I was golfing, and second, when I was running. Is it possible that the beast can morph like this? (JeffBass, Can Vagally-Mediated Change?, July 29, 2013 08:26AM)

Even when participants did not use the beast analogy, messages frequently spoke to the difficulty of predicting and controlling AF. A typical example came from Kamkin:

Anyway after stopping the flec next afib was 18 days later and after 2 hrs took a pill and within an hour it went away. I had eaten big meal prior to this. Next afib 11 days later , after 2 hrs took a pill and within 2 hrs went away. I had also gulped down a meal. I know I should have taken the propafenone right away but I hoped it would stop on its own. My anxiety level skyrocketed and I called my primary care the next day and got an rx for xanax to take 2x/day. This was 27 days ago and I have not had any afib episodes and I have gone to taking the xanax as needed. ([Kamkin](#), MY story--😞 recent diagnosis of PAF; new to this forum (long post), September 09, 2013 09:36PM)

While I observed many descriptions of patterns of AF and difficulties with variable treatment responses, I rarely saw mention of the natural progression of AF, from paroxysmal to permanent, as an expected illness trajectory. Instead, as I will discuss further in the context of searching for sense, individuals focused intensely on lifestyle and dietary measures as a means of control. However, before I expand discussion of the participants search for sense, I will explain some of the common values that frequently permeated through the messages. An understanding of these shared values will then set the scene for searching for sense on this particular message board.

Mistrust in Western medicine and pharmaceuticals. A prevailing theme amongst the data collection postings was the suggestion that the individual has a personal responsibility to conduct their own health related research and not rely solely on their physician's advice. One forum member used the term "defensive medicine," reflecting a belief that patients need to protect themselves within healthcare.

Quite frequently, doctors don't know enough about the drugs they prescribe to recognize adverse effects. The technical aspects of medicine -- and overwhelming faith in pharmaceuticals -- outrun the ability of MDs to be current regarding the drugs they hand patients every day. It's up to the patient to practice defensive medicine. One site I like is [drugs.com] Look drugs up in FDA Prescribing Information in the Health Professionals menu. Use the Drug Interactions Checker to check the safety of your drug cocktail. Do not let your doctor ignore symptoms of adverse effects you identify in yourself. If he or she does, leave with a sharp comment and find another doctor. This is what distinguishes a good doctor from a schmo. (Iatrogenius, re: If you are on this drug dronedarone beware, September 14, 2013 12:27PM)

Beliefs about pharmaceuticals and the pharmaceutical industry came up frequently as reasons to conduct personal health research. For some members, the idea of taking medication interfered with their concepts of what it meant to be healthy. A typical comment came from NormanG who wrote generally, “I don't like any of these drugs, and intend to get off of them as soon as possible” (Reply in thread: Xarelto, August 10, 2013 07:53PM). Side effects were also a frequent concern. “He told me that all anti-arrhythmic medication is toxic over time and that the next medication I would take (if Multaq lost efficacy) would be even more toxic. That was the tipping point in my decision for an ablation” (EAGLE1, reply in thread: Ablation scheduled with Dr. Natlae August 26). Many participants worried that medications would be detrimental in the long term because of feared potential interactions with the body.

Contributing to these worries was the belief that physicians lacked information related to the importance of nutrition for health and disease prevention. Commonly, participants aligned a lack of support for supplements with a lack of knowledge about nutrition. Two frequent board contributors, Janice and Jesse, argued that the empirical method relied on by physicians for critiquing evidence was problematic and as a consequence of the methodology, support would never be shown for nutrition based supplements. Janice, put it this way:

Trials attempting to compare benefits of nutrients are extremely difficult to control when it comes to identical parallels or baselines... as every person in the trial is different in terms of nutritional status as there is no way to control or even determine how they assimilate nutrients from food that they do take in. Therefore, the overall observations can often be skewed unintentionally. (Janice, reply in post: Acid reflux drugs can raise the risk of heart disease, July 15, 2013 01:38PM)

Jesse, referring to physicians, wrote: “their thinking often seems to go something like ' ... if it isn't patented and hasn't gone through a handful of hugely expensive clinical trials then it can't be any good” (Jesse, reply in post: Acid reflux drugs can raise the risk of heart disease, July 14, 2013 01:23PM). In another thread, Jesse further expressed his belief that conventional medical practice will never accept supplements for dubious reasons.

Drug companies and many research institutes have a huge vested interest in trying to throw cold water, or some degree of doubt, on any non-patentable herbal agent that is showing promise in an area these companies are spending billions of dollars to develop competing drugs for. (Thread: Questions about keto-adapted diet, August 23, 2013 11:26AM)

These sentiments may reflect characteristics of the sample that contributed to participants participating on this particular online medium. Most of the individuals on the board expressed a high degree of wellness prior to their diagnosis that may have influenced their reluctance to include pharmaceuticals in their lifestyle. For example, at the end of a posted story of AF, a person might remark on their otherwise completely healthy lifestyle, younger age, and state of mind. Markn wrote:

Incidentally I can't believe that all three of us ie the two people mentioned above and me ended up with AFIB in our late 40's. We are all fit and healthy though not extreme in our sport pursuits, my only thought is we partied hard on weekends and holidays but then so do a lot of people. (Reply in thread: For Wayne re U.K. Ablation, September 11, 2013 08:35PM)

After describing her AF illness journey, Melissa wrote, “prior to getting my first afib episode I was slim, very fit, a jogger, swimmer, gym bunny (weights and laughably cardio pump) and

weekly aerobics class with a few forays into Zumba” (response in thread: Calling All U.K. Afibbers!, June 21, 2013 02:35PM). Because some participants felt they were too healthy to have AF, they may have been motivated to search beyond their physician’s advice to the alternative health related AF forum.

Clearly, it would be impossible to conclude that all the forum members held similar values towards pharmaceuticals or contributed on the board for the same reasons. However, the website that hosts the board has an alternative health perspective. The majority of participants who I observed interacting with the site clearly had a common set of beliefs about the importance of not solely trusting Western Medicine that facilitated acceptance of non-pharmacologic strategies for AF prevention and control. I will next explain further how individuals used the board to make sense of AF and its treatment.

Searching for sense. Individuals frequently engaged with the board to share experiences with AF episodes for the purposes of gaining insights and support from others. As opposed to simply seeking empathy, it was evident from the messages that participants used the board to support a trial and error process of treating and preventing AF. To illustrate how this became apparent within the data set I outline the ways in which participants used the board to make sense of symptoms and treatments. I also discuss the common root attributions of cause for AF, as mentioned by forum participants.

Making sense of symptoms and treatments. In the messages, I observed a high level of motivation to seek out information related to stopping AF. JamesM was a particularly motivated individual:

When I started trying to figure out an afib remission strategy nine years ago. I searched everywhere, from anecdotal reports to medical journals and studies for ideas of things to

try. My core program of taurine, potassium and magnesium was the result, but it took a lot of experimenting till I figured out what worked, for me. The resources here were a great boon. I read many of four or five years of posts, plus all the back issues of Moderator's "The Afib Report," Moderator's first book, the Conference Room archives and many other things. I was so motivated that before I figured out the supplement approach, I'd started devising a monitoring system, based on heart rate variability, to predict when afib was imminent. My plan was to then take a PIP med to ward off the episode. Designing a predictive algorithm is very challenging and I'm glad the supplement path worked as it is much easier and simpler. The predictive approach would have required wearing a monitor all the time. I'm happy I don't have to do that! (JamesM, reply in post: Extended-release potassium in the evenings?, August 27, 2013 10:13AM)

JamesM was clearly very driven to design a series of trial and error experiments in pursuit of control over his AF. His willingness to research solutions, alter his life, and make adjustments as he saw fit, was typical of the sample.

Commonly, novice participants on the board shared messages that described their pattern of AF as well as a list of supplements and prescribed pharmaceuticals leading to the question, "what else can I do?" For example, this post from Willow was quite typical of the sample in that she described both prescription medications and multiple supplements. She ultimately asked for help from the group to understand new symptoms and described her trials with adding potassium supplementation to attempt to stop and prevent her arrhythmia:

In the past, I've had from 2 to 12 hr episodes of afib where I have tachycardia and irregular heart beats. I've been able to end these by taking 50 mg Metoprolol, 200 mg of Flecainide, 500 mg d-ribose, 1000 mg taurine. I've been able to stay afib free for several

months at a time by watching my diet, taking 650 mg of magnesium a day, along with 1500 mg taurine, 100 mg Ubiquinol, 50 mg x 2 Flecainide, and 2000 mg fish oil, 5000 IU vitamin D, and 400 mg vitamin E.

But since June 8, I have had daily bouts of a different kind of afib that is new to me. I have no tachycardia, and my HR stays between 58 and 72 bpm, which is normal for me. I get irregular beats and they are not consistent. When I listen to my heart with my stethoscope for 3 minutes at a time, the first minute may have zero irregular beats, the next minute may have 15 irregular beats, and the next minute may have 6 irregular beats.

(Willow, Need Help Understanding How to Stop New Afib, June 20, 2013 08:26AM)

Willow made no mention in her post of how these new symptoms affected her life or how she determined that the new symptoms were indeed AF. She seemed most bothered by the irregularity rather than, for example, shortness of breath or reduced exercise tolerance. However, while to an observer this symptom may not warrant urgent action, Willow went on to describe her participation in various medication and supplement trials towards addressing it. When reading this next illustration, keep in mind that her serum potassium was reportedly 4.6 mmol/L (completely normal)¹⁰.

I tried taking my usual PIP method (but without the Metoprolol since I wasn't having tachycardia), and the afib would stop briefly then come back again in a couple hours.

¹⁰ Normal serum potassium ranges from 3.5 – 5.0 mmol/L (depending on the laboratory used, values may vary). Symptoms of too much serum potassium include: muscular weakness or flaccid paralysis, ileus, and ECG changes that can cause life-threatening arrhythmias (Hollander-Rodriguez & Calvert, 2006). Ingestion of herbal and nutritional supplements containing high potassium levels can lead to dangerous levels of serum potassium, especially in the presence of reduced renal function.

When this didn't work, I increased my daily Flecainide to 100 mg twice a day, but that didn't stop it either, so I went back down to 50 mg twice a day. Then I took 500 mg of potassium, and that stopped it completely for several hours, then it came back. So I am now taking 250 mg of potassium at each meal and two snacks (total of 1250 mg per day) and am watching my sodium levels carefully. My afib continues. I also stopped my 500 mg per day of calcium supplement four days ago, but that hasn't helped. (June 20, 2013 08:26AM)

Willow clearly shared accounts of her trials in the hope that someone could make sense of her experience. In these types of messages, the online community supported each other to crowd source the identification of both triggers and potential errors in medicating or supplementing to stop AF.

In a similar fashion, forum members navigating a complicated post-ablation recovery also used the board to make sense of symptoms that felt differently to that experienced pre-ablation. In general, patients are told to expect some arrhythmia post-ablation due to the inflammation from the procedure itself. However, it was difficult for the individuals experiencing new symptoms to decide whether those symptoms warranted concern or not. For example, ToddB wrote that he felt less energy and an unsettled heart feeling after the ablation.

I wonder if this is the flips and blips everyone who has an ablation is told to expect. If it is then I can report first hand that when it is happening to you it doesn't feel like just flips and blips. (thread: This is harder than it sounds!, June 29, 2013 11:30AM)

People who perceived they were experiencing arrhythmias, like premature atrial contractions (PACs) and premature ventricular contractions (PVCs) were particularly unsettled as they worried the premature beats would turn into another episode.

[I] have been in NSR since albeit a few runs of pacs/pvcs for a few hours every week or so which is very discomfoting. I too keep waiting for the beast to rear it's ugly head and the anticipation it might is nerve racking. (Mack, reply in thread: Success Story, There is Hope for A Fib, July 30, 2013 06:51PM)

Both of the participants in these exemplars went on to later describe their diagnosis with post procedure atrial flutter¹¹. By posting about their confusing symptoms and giving updates about their diagnosis and treatment, these members gave readers an accurate portrayal of a common procedure complication. This could possibly be quite helpful for those contemplating or actually undergoing the procedure to know what to expect. Interestingly, in threads about post procedure arrhythmias, members often opined that the individual might have brought on the event by their own actions. Board members suggested continuing the same trigger avoidance strategy from pre-procedure throughout the first few months post. I will discuss this in further detail next.

Environmental and dietary triggers. Another aspect of searching for sense seemed to involve the search for environmental and dietary triggers. Common triggers discussed on the board included stress, eating too late in the day, drinking alcohol, drinking coffee, eating gluten, too much dietary or supplemental calcium, strenuous exercise, and physical body position changes. For each trigger, individuals often suggested a biochemical rationale for its effect. For example, respondents in threads about physical position changes often suggested that irritation of the vagus nerve, from changes in sympathetic nervous system tone, was responsible. Another attributed the vagus nerve irritation to spinal misalignment and sought care from a chiropractor.

¹¹ Atrial flutter can occur for the first time post procedure either because it was unknown to exist previously (due to the presence of AF), or it can occur as a complication of the procedure itself.

The crowd sourcing of opinions about the causes of an individual's AF led some participants to greatly alter their lives. After experiencing post-ablation arrhythmia NormanG wrote, "my heart is so touchy that I would not dare let any wine, coffee or gluten enter my system" (Coumadin vs Xarelto). Avoiding triggers was particularly problematic when they were something as common as stress. ToddB described how this affected his life:

The one thing i could not get a handle on was stress Almost any stressful event would cause full blown af or an unsettled and uncomfortable heart for several days. I felt my universe was shrinking. There were so may things that caused great concern like foreign travel, work related and social events. I discovered my children and siblings were keeping things from me for fear provoking an af event. I sort of got tired of feeling guilty for eating a banana if I got af that night too. (ToddB, reply in post: Ablation scheduled with Dr. Natlae August 26)

From the dialogue it was apparent that some board members were inclined to link any situational factor occurring prior to the AF event as a trigger. It was hard for some members to accept counsel that events occurring at the same time were coincidental rather than triggers. For example,

2 weeks prior to this I had peridental surgery and had been taking lots of motrin (6-800 at least every 3-4 hrs) and rubbing lots of benzocaine on the area (the motrin was my idea, the benzocaine was periodontist). So I questioned whether this was an overdose so to speak. Pretty much consensus was no correlation, but in my mind there was/is. (Kamkin, September 9, 2013, post: MY story --⊗ recent diagnosis of PAF; new to this forum (long post))

Thus, from the dialogue it was clear that while trigger identification can be a tool to gain control over AF, it could also lead to undue stress for some people. The expected course of AF often involves random clusters of episodes that eventually get longer and progress to persistent and permanent. As such, when individuals blamed their own actions for episodes, they may have been unnecessarily attributing causation to what was actually a correlational event. Avoiding all possible triggers was only part of the strategy participants discussed.

Systemic imbalances. By far the largest component of discussions about causes and treatment for AF involved a belief that AF is caused by a systemic imbalance related to nutrition problems. Many authors participated in these discussions – from the experienced person with AF to the newly diagnosed, the long time message board participant to the first time message board poster. There was a general sentiment that AF must have a root cause related to some combination of nutritional deficits, Western lifestyles, and the aging process.

I think we all search for the elusive afib triggers and try to change and mitigate wherever possible. ... And one common theory is that we likely have compromised guts that are not facilitating proper nutrient and mineral absorption. Basically it comes down to the conclusion that something, or a number of things that we put in our mouths might just be causing the problem. Afib is really just the symptom, the canary in the coal mine telling us our bodies are very ill. (NormanG Post: Need some good advice)

In fact, the website was really geared towards facilitating persons who wanted to partake in trial and error strategies with nutritional supplementation to treat their AF. One of the most prolific posters on the board was Janice. She wrote and archived an AF prevention report (The Strategy – Metabolic Cardiology) on the website to disseminate the theory that nutrient deficits cause AF, and therefore supplements can prevent and treat it. In the report, four books, as well as

numerous websites written by physicians or naturopaths are referenced. The primary source is a book, *Metabolic Cardiology* by Dr. Stephen T. Sinatra. Three supplements are emphasized as crucial to preventing AF: magnesium, taurine, and potassium. In one of the threads Janice explained,

Determining the influencing factors is the challenge and one that is rarely if ever addressed in the world of cardiology or electrophysiology other than to ablate the areas of electrical conduction errors. Thinking should be in terms of 'systemic' rather than the linear approach to one single influencing factor because the body works as a whole or a symphony of finely tuned orchestrations throughout the 70 to 100 trillion cells in the body. Sleuthing out a cause requires systemic evaluations. Multiple systems can be involved at one time. (Janice, August 24, 2013, underlying reason for afib)

While it was evident from the observed discussions that many forum members participated in the supplement program, there were also frustrations expressed.

If we continue to choose only nutritional methods to fight this beast, then we'll all be sorely disappointed. Yes, the minerals and supplements are a given, and if there's anything redeeming from afib for most of us is that it's forced us to watch what we eat and drink. But between you and me and everyone else on this board, I'm sick and tired of chasing a hundred rabbits down a hundred different holes, which is all we are doing when we solely rely on lifestyle changes and nutrition. (mikedadt, Re: when to have ablation? and dr info, September 10, 2013 06:06PM)

For mikedadt, nutritional supplements were clearly considered second best to ablation but, interestingly he still considered 'minerals and supplements' to be a given. For others the primary

frustration expressed towards using supplementation to prevent AF, centered around the potential for AF to progress to persistent while putting off an ablation.

Janice blames her problems on Lyme disease, I have afib issues with a chronic prostate infection....but are those the reasons for the afib? I doubt it. Most people with Lyme disease or chronic prostate infections don't have afib. As time progresses, more researchers are admitting the easy answers aren't there for afib. For most, It isn't just a simple matter of diet, high blood pressure, or even stress. So treating the "reason" for afib first is not so easy when that reason is hard to fathom. Beware holding off of an ablation while attempting to cure the reason for afib...my experience and many others is that the disease still progresses resulting in less probability for long-term ablation success.

(Steven B, reply in thread: Treat the Reason for Afib First - an old article I just found, August 24, 2013 08:10AM)

Although there were members who chose to solely use supplementation as AF treatment, the majority described nutrient supplementation as an adjunct to AF treatment with ablation, rather than a substitute. Regardless of viewpoint, the board facilitated conversations about the practicalities involved in nutrient supplementation. Discussions included which products to buy, where to buy them, how much to take, how to take them, and how to titrate them based on symptoms and lab test results. For the reader undertaking the strategy, all of these practical considerations required them to synthesize and apply a vast amount of information.

Managing the complexities of information. Individuals used a variety of information to inform their knowledge of what causes AF and to make decisions. I therefore sought the inclusion of an additional conceptual theme to highlight the sifting of complex information that an individual must undergo to apply knowledge to their situation. I named this “Managing the complexities of information,” recognizing that it deserved its own conceptual discussion. In this theme I reflect on how some participants functioned as peer experts and supported other members. Additionally, I conduct a careful consideration of how varying levels of research evidence contributed to participant’s understandings (or misunderstandings) of complex information.

A main goal of the online forum seemed to be the support of individuals through their experiments treating and preventing AF, as well as to act as a repository for learning. The Webmaster facilitated this by maintaining the site and offering a paid subscription service to his “AF Report” service. However on the board, members themselves also offered support in this regard. Perhaps unsurprisingly, given the nature of group dynamics, a handful of members from the assortment of 70 unique usernames, dominated the postings. I decided to explore this pattern further and found these particular peers often acted as experts on the board.

Peers acting as subject matter experts. I use the term “expert” to describe authors identified by the board members as being especially helpful, knowledgeable, and experienced. Having some members who routinely checked the board and could be counted on for responses helped the board to function and provided a level of social support. The expert peers also helped others to sift through the large amounts of information more quickly. They did this by helping members navigate previous posts, and offering their own insights, personal stories, and information gathered from other media sources. I will further discuss my interpretation of how

three board members, Janice, Jesse, and Moderator, functioned in the role of peer experts and facilitated information exchange on the board.

While each of the three experts seemed to participate in a wide variety of conversations, they each had their own particular areas of expertise. Janice tended to write most frequently about electrolyte supplementation. She posted replies frequently, was knowledgeable about a large number of supplements, and compiled a written report of her reviews into nutrient supplements for AF. In replies, she often gave direct advice and cited proposed biochemical mechanisms for supplements using definitive language that suggested readers would miss important research information if they solely relied on a physician for advice. For example, Janice informed a participant that the member's long-term use of an antidepressant had likely caused fluoride toxicity. "Be aware that the fluoride toxicity (in your system) is undoubtedly still working behind the scenes and is undoubtedly, at least in part to your many hypersensitivities" (Janice, re: Your favorite potassium-rich recipes, June 25, 2013 11:16AM).

Jesse also replied frequently on the board and was a go-to resource in conversations about ablation. Several reasons contributed to Jesse's trusted status on the board. He frequently cited abstracts from peer-reviewed journals and gave detailed explanations of AF procedures- including statistical chances of success, as well as potential complications. He also used detailed bodily sensation descriptions of his own procedure experiences and described an almost collegial relationship with an electrophysiologist. In contrast to Jesse and Janice, Moderator, the Webmaster, wrote less frequently. Moderator often referred others to his subscription series, to archived posts, or commented on more technical aspects of supplementing.

The data collection contained many messages of gratitude for advice and comments received from peer experts. From these messages, it seemed evident to me that many participants

placed great trust in their peers' expertise. A typical gratitude comment came from Ceciltop to Jesse when he said, "It and all your posts should be required reading for those contemplating an ablation" (reply in thread: Ablation Los Angeles, CA, September 12, 2013 07:22PM). Janice's participation was compared to a nurse more than once. "Pay attention to any responses from Janice. She is our resident nurse & Vitamin K2 expert" (jim tate, Re: Need Help Understanding How to Stop New Afib, June 22, 2013 01:01PM). In fact, Janice was not a nurse; her listed credentials indicated that she was a retired dental hygienist. This was interesting because it seemed the trust in Janice was built up from the reciprocal relationship of posting and replying over time, rather than nursing credentials. Other comments towards Janice indicated that the trust in her as an author was more important to the participant than the actual information content. For instance, participant Francis wrote, "Can't remember why I started to take it, but Janice recommends it in The Strategy and I trust her advice" (thread: Electrolyte solution recipes? Add to Waller water?, June 17, 2013 10:56AM). Because the peer experts played a frequent role in facilitating information exchange on the board, I felt it was critical to examine their role when pseudoscientific reasoning or misinformation was perpetuated.

Perpetuation of misinformation. An interesting example came from a discussion about the relevance of imbibing alkaline water and foods. Some messages used sources from Pubmed and the American Dietetic Association to explain that the body has a tightly regulated pH system that operates irrespective of the foods eaten. However, Janice proposed a counter view from a written book. The book, dramatically titled "Alkalize or Die," was authored by Dr. Theodore Baroody. On investigation I found that Dr. Baroody has many degrees: a Bachelor of Science in psychology, Masters degree in educational counseling, a "DC" degree from Life Chiropractic of Marietta, a naturopathic doctor degree, and a PhD in Nutrition from American Holistic College.

However, Dr. Baroody is not a medical doctor, which could be misleading for some readers who simply read the author line on the book cover. Essentially, readers of the thread were presented with conflicting information and had to decide which information was the most trustworthy. The information endorsed by Janice, or the information a member posted from the Dietitians association.

Regardless of the topic, it was clear to me from the messages, that peer experts had a doubly important role in delivering information. First, peer experts appeared to have credibility related to their longstanding experience on the board. Second, all of the peer experts used outside sources in addition to their own experiences to lend credibility to their comments. How readers integrated conflicting information or even simply un-debated information from peer experts was not clear. This represents a limitation of using data from an asynchronous message board and not being able to ask follow-up questions.

However, who presented information and the source used were only part of the misinformation perpetuation problem. When I further interpreted AF related content in the dialogue for patterns of misinformation, I understood it was a multifaceted problem. Other aspects included the nuances of the medical information itself and the ability of participants to synthesize that information. For some participants, basic AF information was quite complex.

I have an "irregular heartbeat" all the time. I have had it since Jan/Feb 2010. Isn't that atrial fibrillation? I read about people having an "afib episode" for 2 or 3 hours and going to the hospital. I have never gone to the hospital -- I would be there all the time. I never "self convert." My heart rate is high 70's before I get out of bed in the morning, but during the day can be from 77-high 90's. I occasionally get short of breath going up the stairs too fast, but just stop for a few seconds and it goes away. Also I "feel" my heart

pounding harder at times, which I think are "ectopics?" (PACs or PVCs). At what point would I think I should go to the hospital? Or, is what I have not even atrial fibrillation?

(Lori, Definitions, September 18, 2013 07:56AM)

Board experts or other peers tended to answer straightforward AF information questions with their own personal experiences and often offered great counsel. On the other hand, it seemed evident to me from observing conversations about stroke risk that there were also some common challenges for readers. While the ablation procedure has never been shown to reduce stroke risk, this nuance was not always understood by board members. For example, Steven B wrote in response to a comment that ablation does not lower stroke risk. "Huh? I suppose if the stroke risk you refer to had nothing to do with AF that would be the case...but if the ablation was successful (no more AF), the stroke risk from AF would be eliminated" (Re: Stroke risk in lone atrial fibrillation, August 30, 2013 07:19AM).

Some members felt that healthcare providers unnecessarily overemphasized stroke risk. Speaking to stroke risk, Steven B clearly regarded anecdotal experiences highly, he wrote:

How many people die from strokes specifically where clotting is the culprit? Not very many, when compared to heart attacks, cancer, organ failure and accidental deaths (often caused by health care professionals) - . So even if one had twice the risk of a clot-caused stroke, it doesn't seem likely that a stroke will be what kills you. I don't know anyone who died from a massive stroke - but I've had a bunch of friends and relatives die from various kinds of cancers. (Reply in thread: higher risk of developing large blood clots, August 26, 2013 11:53AM)

A fact not appreciated by Steven B was the catastrophic nature of an ischemic stroke regardless of its incidence. After several other members chimed in with their anecdotal evidence of a lack

of stroke in AF, one member countered that despite having a low CHADS score he had experienced a stroke. In a separate thread, Louise98734 expressed frustration with the reliance on anecdotal evidence, “Moderator, the reason you don't hear of strokes on this list is that when members have them, they are likely too disabled to get back on the list (they'll just drop off and you'll never hear from them again)” (re: Stroke risk in lone atrial fibrillation, August 29, 2013 08:45PM).

In the dialogue about stroke risk, discussions also involved credible scientific sources. However, the analysis and context of that information was easily misinterpreted by readers. Because this information has great potential to affect patient safety I chose to examine this aspect of the data collection in further detail. For instance, a conversation occurred on the board about a published commentary in the Journal of the American Medical Association about the “Discerning the Incidence of Symptomatic and Asymptomatic Episodes of Atrial Fibrillation Before and After Catheter Ablation (DISCERN AF)” trial. The trial demonstrated higher rates of asymptomatic AF post ablation compared to pre-ablation (Verma et al., 2013). The invited commentator suggested the trial confirmed the need to continue to provide anti-coagulation to patients after ablation, even if symptom free (Kazi & Hlatky, 2013). Discussions in the thread indicated that participants did not always have the necessary scientific reading skills to interpret the comments within the context of the related study. For instance, Iatrogenius commented: “I found this letter to be very disturbing as well. I wonder what asymptomatic afib is? It seems to me if the symptoms are so slight, perhaps they do not cause the blood pooling leading to clots.” (re: Asymptomatic Afib, June 21, 2013 06:02PM). In this case it may be that Iatrogenius’s knowledge level was not sufficient to understand the article. In other instances, confusion was created when a member took scientific information out of context. For example, StuartL L

quoted from an UpToDate® article, “This line ruined my day: Its under: Prevention approach by CHADS2 score[.] Patient preference is an important issue, since the absolute reduction in stroke risk is likely to be small, but stroke remains a feared outcome” (August 27, 2013 01:08PM). In context, the authors from UpToDate® stated that the absolute risk reduction provided by anticoagulation for a CHADS score of one is likely to be small, because the stroke rate for a score of one is only about 2%. Without context, the statement makes it appear as though there is little benefit to anticoagulation, except to help alleviate the fear of stroke. However, in actuality, a stepwise reduction in absolute stroke rates occurs with each compounding risk factor.

The mixed issues of using poor quality references, misunderstanding scientific information, and taking information out of context also often occurred in conversations about supplements. Board members were frequently resourceful and eager to find supplements that would improve their health. These posts often contained links to scientific reports, supplement retailers, popular media articles, and weblogs, in addition to personal testimonials. The information was often presented without hierarchy to the source consulted. A typical example comes from a novice member on the board, ltdrier, who posted her research into dietary silicon for the benefit of others (June 25, 2013 07:32AM). She wrote her motivation to research this topic began after she started taking diatomaceous earth as a treatment for “mild digestive issues.” She noted that she was younger looking, healthier, and more energetic after the supplement. She posted extracts from five Internet links for the benefit of other members consideration. The links revealed one research abstract, two academic review papers, a link to the European Food Safety Authority, and a link to a supplement manufacturer site. While the conclusions from the academic paper authors indicated that more research was required before recommendations

could be made, the forum member used selected quotes from the articles to support her positive feelings towards supplementation.

In working with the data collection over time, I came to understand that participants on the board had an additional information network to that of their family and friends in the outside world. This study cannot answer the question as to how participants' integrated advice received from their online peers; however, clear challenges were evident. Dialogue on the board often contained hyperlinks to written information from elsewhere on the Internet. The reading level of the information varied and in my view often required a high level of scientific literacy. There was rarely a discussion of the credibility of that material. However, the information also clearly met a need for the participants who wanted to hear both stories of personal experience and scientific information. Despite the complexities of the information shared on the board, participants seemingly made decisions to participate in actions towards improving their health based on experiential learning gained from reading the message board.

Acting as a wise consumer. In each component of taking command, participants engaged with the board intent on acting wisely to improve their health. My objective in examining this process separately is to illuminate some of the actions taken by board members as a consequence of learning gained on the board. To illustrate I include dialogue about contemplating the ablation procedure and selecting healthcare providers. Lastly, I consider some of the specific actions participants took to act on advice obtained on the site, including testing electrolytes using home point of care devices, and monitoring heart rhythms through mobile apps.

Contemplating ablation and selecting “the best” provider. Ablation was one of the most commonly discussed topics on the board. It is an elective procedure and as such, the decision-

making process can be influenced by patient preferences and vulnerable to outside influences. The online discussion format presents a potential complement to decision-making through the experiential learning obtained from others experiences. In this fashion, the act of seeking out and reading others experiences and opinions, is part of acting as a wise consumer. I therefore concluded it was necessary to consider the various influences on the ablation decision-making process evident within the messages.

Board participants commonly expressed similar information needs related to the procedure. A typical example came from Jan:

Who did the operation? How did you get referred to them? What method was used? Did you go private or N.H.S.? What was your post-op consultation like & and was there more than one? What medications were you on before the op and for how long? Give detailed information on the op. What meds after the op and for how long? What consultations did you have afterwards? Etc.! Etc.! (Jan, Calling All U.K. Afibbers!, June 18, 2013 07:22AM)

Participants also frequently requested to know if a poster had success after their ablation. The perception of success, as described by the board members, often depended more on their opinion of the electrophysiologist (EP), rather than the absence of arrhythmia symptoms. For example, if the EP was an acknowledged expert (as defined by a list Moderator compiled through an online survey), the board members were more likely to attribute post procedure arrhythmia as a matter of disease complexity. In that light, an additional procedure was seen as a positive step towards the ultimate achievement of sinus rhythm. However, if the EP was not part of the elite group, board members were more likely to attribute post procedure arrhythmia as a failure attributable

to operator ineptitude or inexperience. In these cases, board members often recommended that the individual switch providers rather than undergoing multiple procedures with the original EP.

When a board member had a good procedure experience, they commonly encouraged others to undergo the procedure and wrote that they wished they had done it sooner. “My ablation experience was far easier than I expected. To be off any of my medications is a thrill, and the PAC's I've had are nothing compared to my previous episodes of fibrillation. Wish I'd had it done sooner” (Ceciltop, post: Ablation Los Angeles, CA, September 08, 2013 04:11PM). The use of language to describe sinus rhythm was always very positive- one participant likened it to heaven. More frequently members described improved energy. However, a forum member who experienced post ablation arrhythmia wanted the messages to reflect a more balanced view:

Often for me I notice someone reporting that they are submitting to an ablation and the next time they report is on their yearly anniversary. It is always the best thing they ever did and how many miles they run every week. [This is] just a different slice of the process hopefully with the same outcome. (ToddB, reply in post: This is harder than it sounds!, June 29, 2013 08:12PM)

In line with current medical opinion, board members also acknowledged that ablations done earlier in the AF illness course had more chance of success. This was the primary argument given against partaking in the supplement strategy as the risk of progressing to persistent AF increases over time. Other factors influencing ablation success discussed by board members included dietary triggers, specific ablation techniques, and co-morbid conditions. To illustrate how conversations frequently came back to the experience of the EP, I give an example from Jesse. He responded to a request for information about when to get an ablation.

Let the tech take a backseat to the man with the catheter and regardless of which catheter they choose. You will be on safer ground. While some improvements in Cryo gear are being made, until now it has mainly proved attractive to less skilled EPs who are looking for a tool that seems to promise an easier way for them to make more consistent PVI lesions, which is often a difficult skill to master with RF catheters. (Jesse, Re: when to have ablation? and dr info, September 12, 2013 01:43PM)

The very strong emphasis on the competence of the EP as the primary determinant of success encouraged a supportive attitude towards medical tourism. NormanG, one of the few posters who reported being Canadian, travelled to France to undergo the ablation procedure (at a cost of \$15000 for the first procedure, \$6000 for the second, and \$4000/day of extra hospital stay). He reported his decision was based on not having a guaranteed choice of procedure operator in his home province. NormanG's main concern was that the electrophysiologist would have performed less than 1000 procedures, and would therefore, be a beginner in his eyes. NormanG reported satisfaction with the personnel he encountered but withheld a full recommendation of the French Hospital due to disliking the foods and the condition of the hospital grounds.

When BrianB asked how follow-up care works with out-of-town procedures, Jesse (the board expert on ablations) touted:

... I wouldn't worry about that at all, now that you can see Dr N¹² either the west coast, Austin or NYC, there really isn't any 'too far' distances within the US to travel from and it is certainly not as expensive or nearly as far as going to France from Calgary for example, which is still a highly recommended step if you really want the best possible

¹² Dr. N refers to Dr. Natale an EP located in the United States who was frequently revered on the board.

care you can reasonably arrange for yourself and you are from Canada and don't have US health insurance. (Jesse, reply in thread: Follow Ups Long Distance, July 01, 2013

11:13AM)

While I expected to find discussions on the board about ablation, I did not anticipate the very strong emphasis on selecting an EP provider. Jesse is a highly respected board member. He is also an American. When I reflected on this, I wondered how Canadian readers would perceive and be influenced by these comments. Canadian EP programs do not advertise or make their money in the same way that American programs do. The question remains whether a higher proportion of Canadians in the sample would have led to the same focus on selecting providers.

Selecting alternative healthcare practitioners. While participants described care from a variety of alternative health providers, the messages did not contain the same emphasis on provider selection as seen with EPs. Members of the board expressed frustration that their physicians would not comment on unproven therapies and would not engage in discussions about alternative health products. They wanted physicians to discuss the safety of trying a method regardless of the known efficacy. At the same time, there was discussion that it was wisest to seek out the “best” health care practitioner in each field and not expect anyone person to know or understand everything. In these cases, members sought alternative healthcare providers, as they did not expect their Western medicine physicians to have the right knowledge.

Participants described care from a variety of health care practitioners including: general practice physicians, cardiologists, nutritionists¹³, naturopaths, chiropractors, one naturopathic

¹³ In Canada and the United States, nutritionist is a non-accredited title. In both countries only dietitians have completed a bachelor's degree, are responsible to a regulatory body, and have a protected registered title.

cardiologist, and integrative medicine physicians¹⁴. Generally, participants described consulting alternative care providers to provide complementary therapy for AF treatment, usually through a regimen of supplements. Or in the case of chiropractors, physical adjustments to the spine, often to help with gastric symptoms believed to be triggering AF. A few times, quotes described some potentially dangerous advice from non-medical health care providers. For instance, in this post, Willow described her nutritionist's advice to suddenly stop a prescribed anti-depressant.

... my nutritionist said that my body has built up antibodies to Mirtazapine and sees it as an allergen now. He says it is completely shutting off my intracellular energy light and my cells cannot properly communicate with each other because of it, which is causing the afib. He wants me to stop the Mirtazapine immediately, or to at least get off it in 2 weeks. But I am very sensitive to medication withdrawals and know I must go slowly. I'm afraid my afib may get much worse if I withdraw too fast. (Willow, post: Need Help

Understanding How to Stop New Afib, June 20, 2013 08:26AM)

Regardless of whom the individual consulted with, participants frequently looked to each other for advice.

Acting on advice. Board participants took a variety of actions to treat their AF. The most passive process was gathering information. Participants frequently researched about medications and supplements through requests for anecdotal reports. For example, a participant wrote that his physician considered him to be tolerating an antiarrhythmic well despite the side effect of “balloon head” that he complained about. This poster solicited from the board, “still looking for

¹⁴ Integrative medicine most commonly refers to the combination of conventional medicine with alternative health therapies. Some medical schools contain an Integrative Medicine component. This is controversial as dissidents argue there is potential for the acceptance of pseudo-science to medical school curriculum. Locally, a degree in Integrative health can be obtained from Pacific Rim College which is not affiliated with a medical school.

experiences with TIKOSYN; please keep them coming. I have come across some that could not tolerate TIKOSYN at all due to the side effects.” (Ronald L, post 80). Clearly, the forum member wanted to see if other people experienced this bothersome symptom, rather than accepting his physician’s view that he was tolerating the medication. When a writer spoke highly of a medication or supplement, others would often comment on it and ask about their experiences with side effects and efficacy.

Readers who decided to act on Janice’s strategy of nutrient supplementation to prevent AF frequently used the board to guide their actions. It was common for members to give direct advice. For example

Once you are established on a bowel tolerance dose of Mg glycinate and are consuming 4 to 5 grams of potassium each day, wait and see if you are still getting afib episodes. If not, keep things just the way they are. If you are still getting afib on any frequent basis, try adding taurine in 1 gram doses, up to about 4 grams a day. This may increase your bowel tolerance for magnesium, usually a good thing. Reduce your intake of processed foods to as near zero as you are able, thereby reducing your intake of salt and msg.

(CindyM, Re: Too much magnesium – correcting, July 12, 2013 01:37AM)

How to reach “bowel tolerance” of magnesium was a common discussion. To reach tolerance, members discussed a variety of methods of supplementing including rubbing oil on the skin, bathing in magnesium salts, ingesting tablets, and drinking electrolyte solutions.

Essentially, members advised continued increases in magnesium supplementation until the side effect of diarrhea was reached.

Participants also suggested ordering an online testing kit for magnesium levels. They recommended the “Exatest,” which requires patients to scrape sublingual cells onto a slide that is

sent off for analysis of intracellular magnesium levels (www.exatest.com). Conventionally, serum is used to test magnesium levels because of ease of testing and cost (Ismail, Ismail, & Ismail, 2013). Serum magnesium testing can be potentially flawed because magnesium is contained almost 99 percent in the cells (Ismail et al., 2013). Nevertheless, Ismail et al. (2013) suggest cellular magnesium testing is both impracticable and inaccurate. They recommend a loading magnesium test as a more accurate (though also impractical) test. However, on the board, some members felt the conventional use of serum magnesium testing was another indicator of physician's misunderstanding of nutrition. Jesse stated,

This disconnect between understanding IC [intracellular] Mag and other IC electrolyte readings, and how to test for IC readings, versus their view through the lens of only serum ions, is highly misleading for most MDs and is a big part of the reason, in addition to all of the above, for why they almost universally underestimate the value that proper diet can lend to many Afibbers not only in helping many time in quieting the heart a good deal, but also in improving many other areas of health. (Jesse, reply in post: Acid reflux drugs can raise the risk of heart disease, July 14, 2013 05:30PM)

Some individuals also described drinking electrolyte solutions to “tame” premature beats. These solutions varied from the commercially prepared Pedialyte drink to variations on a recipe Moderator hosts on the site. Participants used the online forum format to ask each other questions about how to mix the solutions and where to buy additives.

These discussions revealed important safety implications when users needed to purchase pharmaceutical grade magnesium online. Several discussions occurred about what type of magnesium to order and how to mix the correct concentrations. Not easy information for a layperson. Moderator, a chemical engineer wrote,

If you are using magnesium hydroxide $Mg(OH)_2$ (molecular weight 58) then you would need to add 3.6 grams to 1 liter of carbonated water in order to end up with a concentrate containing 1500 mg of elemental magnesium. The bulk density of powdered $Mg(OH)_2$ varies between about 0.4 g/mL and 1.0 g/mL, so 3.6 grams could be anywhere between 9 mL (2 teaspoons) and 3.6 mL (about $\frac{3}{4}$ teaspoon) depending on the fineness of the magnesium hydroxide powder. (Re: Magnesium Hydroxide Q for UK folks please, July 24, 2013 02:36PM)

In addition to electrolyte testing, other actions taken to manage AF at home included diagnostic testing such as electrocardiograms and point of care electrolyte testing. Members wrote about using the iPhone and other devices to monitor their heart rhythm and using a device called the “Cardymeter” for checking potassium throughout the day. It seemed that a variety of incentives motivated using these devices, such as convenience, instant gratification of immediate results, and a sense of control. As Steven B reported, “my little EKG machine really came in handy, as I was able to FAX the EP copies of my afib print-out bypassing the carry-monitor that would have delayed my situation even more” (re: The beast returns... , July 07, 2013 02:34PM).

When I reflected on this part of the data set, I wondered how likely patients are to disclose similar actions to that described on the board in clinic or hospital visits. Many patients I have met have described using heart rate monitors, blood pressure monitors, or taking their radial pulse regularly. So descriptions of these devices and techniques were not surprising to me. However, the extent of electrolyte manipulation and titration by AF symptoms, bowel tolerance, and portable testing kits was a surprise. The descriptions of actions taken by board members illuminate several unmet patient care needs, including a desire for a concrete strategy to manage episodes, a desire to discuss non-pharmacologic therapies for AF, and a need for open

discussions with healthcare providers. Ultimately, for participants on the board, specific actions were part of an overall process of interacting with the board to gain information from others experiences, suggestions, and advice, with the intention of acting wisely to gain the best control of AF possible for their health.

Conclusion

In this chapter, I identified how participants of an online message board used the forum as a tool for learning strategies to manage their AF. I presented an organizing framework consisting of four components (sharing experiences and values, searching for sense, managing the complexities of information and acting as a wise consumer) to facilitate discussion of the findings. The four components are intended to illustrate a process wherein participants shared their experiences in order to make sense of them and gathered information to guide their actions towards participating in their health. Threads and replies posted asynchronously over time indicated the cyclical nature of this process. Some peers acted as lay experts, they facilitated discussions, and gave credibility to information linked to outside of the website. Challenges inherent in this process related to the vast amount of information shared, the credibility of the information cited, and the health literacy of the reader.

This study demonstrates to nurses how a patient may enter and participate with the online environment in their search to treat AF. But, perhaps more importantly, it highlights that AF patients may have unmet needs including the desire for a concrete non-pharmacologic plan to prevent AF. It seemed that many participants desired to act on information based on the shared experiences of other message board members. Additionally, hyperlinks to outside material often presented pseudoscientific reasoning to support natural healing methods and supplements. Thus, there are important safety considerations stemming from the findings, including the manipulation

of electrolytes by participants, the ordering and preparation of chemical compounds to make electrolyte solutions, and unknown interactions with antiarrhythmic pharmaceuticals.

Chapter Five: Discussion

The purpose of this study was to better understand the online health information searching behavior (HISB) of AF patients, by identifying the nature of content and dialogue on an AF forum. Congruent with other online forum analyses, the participants in this study used the board to share experiences, and seek informational and social support (Attard & Coulson, 2012; Coulson, 2005; Coulson et al., 2007; Dickerson et al., 2000; Evans, Donelle, & Hume-Loveland, 2012; Radin, 2006). I found that the participants used the board to make sense of unpredictable symptoms by interacting and learning from the experiences of other patients. As a group they were highly motivated to find non-pharmacologic strategies to prevent AF. In a cyclical fashion, participants posted their trials with avoiding triggers, changing lifestyle factors such as diet, self-titrating medications and supplements, and undergoing the ablation procedure. Influences on the information shared included who presented the information, the actual information source quality, and the individual's ability to synthesize the information. Some but not all of these elements have been described in the research literature.

Contemporary research examining quality of life in AF has focused primarily on the impairment in quality of life experienced by some patients, the determinants of that distress (personality and illness coping factors), and the impact of that distress on outcomes, with the purpose of furthering knowledge towards identifying patients at high risk for distress (Kang & Bahler, 2004; Kang et al., 2004; Ong, Cribbie et al., 2006; Ong, Irvine et al., 2006; Suzuki & Kasanuki, 2004; Thrall, Lip, Carroll, & Lane, 2007). With the same intention, a few studies have also looked at the influence of illness perceptions and beliefs on AF (Lane, Langman, Lip, & Nouwen, 2009; McCabe, Barnason et al., 2011; McCabe & Barnason, 2012; Steed et al., 1999). Many other studies have used measures of quality of life impairment to evaluate the ablation

procedure (Cha et al., 2008; Pontoppidan, Nielsen, Poulsen, & Hansen, 2009; Reynolds, Walczak, White, Cohen, & Wilber, 2010; Wokhlu et al., 2010). In keeping with the findings from the qualitative studies, participants in this study expressed feelings of emotional distress and shared their beliefs that emotional stress contributed to their AF symptoms. However, the intent of the current study was to extend knowledge beyond documenting the use of Internet sources to express distress associated with AF. I was concerned primarily with illuminating the process of HISB on the message board as it related specifically to the AF illness experience. By observing the descriptions of living with AF on the message board, the opportunity existed to gain insights from an entirely patient oriented perspective. This enabled the extension of existing knowledge to include a preliminary understanding of how some people with AF may use the Internet to acquire self-management strategies to reduce their distress.

Thus, this study adds to the AF literature in two important and novel ways. It adds an introductory interpretation to the literature about how some people with AF make sense of it, using information and tips from other persons with AF encountered online; and it sheds light on a previously unexamined population, AF patients who use complementary and alternative medicine (CAM)¹⁵. In order to better understand the findings and further knowledge, I will next review some of the key interpretations from this study in comparison to the existing AF and chronic disease literature.

¹⁵ A frequently used definition of CAM comes from The National Centre for Complementary and Alternative Medicine, who suggest that complementary medicine refers to an “array of health care approaches with a history of use or origins outside of mainstream medicine” (2014, “Complementary, Alternative or Integrative,” para. 1). Complementary medicine is further divided into two subcategories, natural products (such as herbs and vitamins), and mind body practices (for example, spinal manipulation or meditation).

The Need for Control: Insights from Existing Studies

The overarching finding in this study was that participants used the board to gain a better sense of control or “take command” of their AF. Components of this process, such as the desire to understand the cause of AF and the desire to find meaning in symptoms by looking to lifestyle factors, have been clearly documented by two other qualitative research studies (Ekblad, Rönning, Fridlund, & Malm, 2013; McCabe, Schumacher, et al., 2011). McCabe, Schumacher, et al. (2011) described the lived experience of AF from a sample of 15 participants with recurrent symptomatic AF. The authors organized the findings into seven themes to reflect the participants’ experience of AF over time. These included “(1) finding the meaning of symptoms, (2) feeling uninformed and unsupported, (3) turning points, (4) trying to steer clear of AF, (5) managing unpredictable and function limiting symptoms, (6) emotional distress, and (7) accommodation tempered with a hope for cure” (McCabe, Schumacher, et al., 2011, p.338). McCabe, Schumacher, et al. found that participants used a variety of strategies to manage their AF symptoms, such as slowing down, changing work and activity habits, and getting more sleep. Participants also described an anticipatory fear of AF episodes and a desire for a permanent “fix” or cure, similar to that in this study.

Ekblad et al. (2013) interviewed 25 AF patients. They found results in line with McCabe, Schumacher, et al. (2011). Discomfort and limitations in daily life led participants to participate in self-care strategies aimed at preventing or controlling AF. These strategies included: feeling constantly on guard for an episode and planning to avoid perceived triggers, relaxation techniques, accepting their condition, and calling a healthcare provider for support. The findings from these two qualitative studies provide evidence that the online data collection used in this study achieved a similar relevant AF patient perspective to that of in-person interviews.

Insights into Unmet Needs in the AF Population

In contrast to the findings from prior studies, participants in this study frequently described self-titration of antiarrhythmic medication and supplements using information and support from other message board members. I will next contextualize this finding within the context of unmet needs in the AF population and follow with a discussion of the actual information sharing process.

AF is a chronic condition, as it currently has no cure and commonly progresses to a permanent state. The illness course of symptomatic paroxysmal AF involves clusters of episodes followed by periods of remission. Research from the field of psychology suggests this pattern may be particularly vulnerable to misattributions of causation (Matute, Yarritu, & Vadillo, 2011). This was seen in the findings as some message board members linked any situational or nutritional factor occurring prior to the AF event as a trigger. Peers online contributed their opinions of potential triggers and highlighted nutrients and minerals that they believed to be crucial in preventing AF.

Looking to the larger body of AF research, there is some evidence that these types of actions by patients may not always be discussed in clinic visits. When Siouta, Brostrom, and Hedberg (2013) videotaped 23 different AF related clinic visits involving either physicians or nurses, they found that both professions dominated the conversations with topics such as pathophysiology, treatments, and diagnostic procedures. In either type of visit, the patients were most likely to initiate conversation about activity and how AF impacts their daily life. However, the healthcare workers always guided the conversation back to the medically driven agenda. The authors suggest that this practice may inhibit the exposure of a patient's line of reasoning, thereby preventing patients from learning how to integrate medical knowledge of AF within the

context of their own lives. Additionally, as Siouta et al. (2013) identified, there is always a risk during consultation with healthcare providers that the patient may feel obligated to ask only questions that fit within the traditional medical paradigm. By contrast, individuals participating online may be more likely to disclose personal information and in a more present or future based context, in comparison to in-person interviews (Seale et al., 2010).

International reports from Canada, the United Kingdom, and the Netherlands suggest that patients benefit from nurse-led AF care through reduced readmission rates to hospital (Gillis et al., 2008; Hendriks et al., 2012; Ismail & Coulton, 2015). Although each country's approach to nurse-led AF care differs, it seems that improving adherence to AF practice guidelines based care is a major focus of the nurse role (Gillis et al., 2008; Hendriks et al., 2012; Ismail & Coulton, 2015). An evaluation of the UK-based "arrhythmia care-coordinator" specialty nurse role found that while the program reduced health care costs and readmissions, it did not significantly impact high baseline anxiety levels in the studied AF population. This is suggestive that despite the admirable efficiency and cost savings, some patients may not get all of their needs met in medical care models.

Researching online as an obligation. The participants in our study valued themselves as participants in their own care. As one participant stated, it is important to practice 'defensive medicine', to not rely solely on a physician, and to accept responsibility for looking up and researching factors related to their condition. A perceived close relationship between both physicians and researchers and the pharmaceutical industry was a dominant factor driving participants to research on their own. This is consistent with current public opinions towards the pharmaceutical industry. Kessel (2014) argues that the pharmaceutical industry's public reputation is declining due to a multitude of factors, including the changing perceptions of

stakeholders such as patients and physicians, as a result of actual suspect practices committed by corporations. Examples include: putting shareholders interests over patients, dubious marketing practices, as well as, unfair pricing and access issues (Kessel, 2014). Additionally, the public's awareness of pharmaceutical industry scandals and regulatory oversights are enhanced with today's technologies that distribute news and information over the Internet quickly such as Twitter, Facebook and blogs (Kessel, 2014).

It may also be that some AF patients are particularly cognizant of the pharmaceutical industry because of the development of four novel anticoagulant drugs in the last four years¹⁶. The integration of these drugs into clinical practice has had some controversies, including high cost, a lack of effective compliance monitoring mechanism, a lack of antidote, a lack of guidance for use in chronic kidney disease, and a tendency for off-label uses (Mohanty et al., 2014). The Canadian, American, and European AF guidelines also differ slightly in their recommendations for prescribing anticoagulants (Verma et al., 2014). The primary concern expressed by participants in the data collection messages related to the bleeding risks from the new drugs. However, some participants also expressed uneasiness with the financial motivations of pharmaceutical companies who may promote the drugs without due attention to the side effects.

The perception of alignment with industry impacts trust. Comments from some members indicated a general awareness and wariness of gift giving between pharmaceutical companies and prescribers. For example StuartL wrote, "perhaps all drugs cost could be lowered if kickbacks not given" (Re: Xarelto, August 11, 2013 06:32PM). Looking to the literature, a systematic review of ten studies found wide variation in awareness of gift giving practices by the pharmaceutical industry to physicians, ranging from less than 25 percent to 83 percent depending

¹⁶ The four new anticoagulants are: dabigatran, rivaroxaban, apixaban, and edoxaban.

on the type of gift (Arkinson, Wiercioch, & Holbrook, 2010). There was also a large variation in whether patients considered gift giving appropriate. Grande, Shea, and Armstrong (2012) conducted a random digit dial telephone survey and noted that the majority of their sample believed industry to physician gift-giving occurred. They found that patients who believed physicians accepted gifts were significantly more likely to distrust them. These results are supported by the work of Green, Masters, James, Simmons, and Lehman (2012) who found that as the value of the gift increased (above 100 dollars), the proportion of patients reporting mistrust in their physicians increased.

The majority of data examining the public's awareness and acceptance of physician-industry relationships have been obtained through US studies (Arkinson et al., 2010). This is important because the two countries differ in their approaches to healthcare delivery. Additionally, direct-to-consumer advertising (DTCA) is legal in the United States. However, despite the fact that DTCA is not permitted in Canada, a recent review of Health Canada's response to complaints about DTCA indicates there are serious weaknesses in the government agency's regulatory responses (Lexchin & Mintzes, 2014). Additionally, Shnier, Lexchin, Mintzes, Jutel and Holloway (2013) found that the majority of Canadian medical schools either had no policy related to conflicts of interest with industry, or had permissive policies. Given that Canadians are exposed to the same media coverage of pharmaceutical scandals as Americans and there are clear weaknesses in Canadian regulations of the pharmaceutical industry, it seems reasonable to infer that similar mistrust towards industry may exist for the Canadian public.

Consistent with the overall expressed feeling towards the pharmaceutical industry in this study's sample, Ohlow, Brunelli, and Lauer (2013) found Internet users with cardiovascular diseases ranked information from the pharmaceutical industry as the least credible. In that study

the pharmaceutical industry scored lower than Internet communities and magazines in terms of accuracy and reliability, however, the ranking was only marginally worse than neutral.

Interestingly, the participants in this study often used information from supplement manufacturers or retailers, suggesting their feelings towards the natural health product industry were different than the pharmaceutical industry.

Insights on CAM Use by AF Patients

One of the major findings of this study was that people were using the message board to implement CAM strategies such as diet change, herbal therapies, and nutritional supplements, as well as visiting CAM practitioners such as chiropractors to aid their AF. Although there are many studies of online communities in the research literature, a paucity of data exists to describe online discussions of CAM use. Chen (2012) used cluster analysis to crawl through discussion forums and noted that fibromyalgia sufferers were talking about both supplements and vitamins. However, the clusters of words did not give enough detail to draw interpretations or influence practice. From a sample consisting of posts on an online depression forum Barney, Griffiths, and Banfield (2011) noted that side effects of medications led some participants to consider alternative treatments. However, Barney et al. did not expand on the alternatives considered. In that study, only five percent of the participants expressed mistrust in healthcare professionals. Neither study set out to expressly study alternative health usage.

Prevalence and determinants of CAM use. To my knowledge, no existing studies have reported specifically on the prevalence of CAM therapies in the AF population. In survey studies of outpatient cardiology clinic patients, between 12 and 81 percent of patients reported CAM use (Gücük İpek et al., 2013; Krasuski, Michaelis, & Eckart, 2006; Prasad et al., 2013; Yeh, Davis, & Phillips, 2006). Unfortunately, prevalence rates are confounded by variations in the definition

of CAM. Additionally, there is little Canadian data examining CAM use in cardiac patients. Esmail (2007) reported seven percent of their Canadian sample of 2000 participants disclosed heart conditions. Sixty percent of those patients reported using an alternative therapy in the last 12 months (Esmail, 2007).

There are many factors associated with choosing to participate in CAM therapies. The most extensive research in this area exists in cancer populations. In a systematic review of 52 cancer related studies Verhoef, Balneaves, Boon and Vroegindewey (2005) found that, “while reasons for CAM use varied widely, a perceived beneficial response was stated most often (38.4%), followed by wanting control (17.3%), a strong belief in CAM (17.3%), CAM as a last resort (9.6%), and finding hope (9.6%)” (Verhoef et al., 2005, p.275). Consistently reported socio-demographic determinants of CAM include: younger age, female sex, higher education, higher income level, and presence of chronic disease (Esmail, 2007; Pierard, 2012; Verhoef et al., 2005; Williams, Kitchen, & Eby, 2011). Using a community survey of people in Ontario, Williams et al. (2011) further examined health related factors with respect to CAM use, and found that having a chronic condition, rating their condition fair/poor, and answering ‘yes’ to having unmet needs, all significantly correlated with seeking alternative care. There is also evidence that persons with chronic disease select CAM therapies not as a rejection of traditional medicine but instead as a critical component to increase their sense of wellbeing (Thorne, Paterson, Russell, & Schultz, 2002). Thorne et al. (2002) found that CAM therapies enabled their participants to take an active responsibility for their health and provided a sense of control by attending to emotional and spiritual needs not comprised in conventional therapies (Thorne et al., 2002).

An important aspect to consider for British Columbians with AF, is whether long wait lists to see an EP provider and to undergo the ablation procedure could contribute to increased CAM use. In a non-cardiac context, Pierard (2012) found long wait lists to see a specialist did not have a statistically significant impact on CAM use. However, the self-report of unmet care needs was associated with an individual being eight times more likely to use an alternative therapy.

In this study, some message board members wrote that they wanted to be able to discuss the safety of a supplement for their AF, regardless of its known efficacy. These participants expressed disappointment towards care providers who were dismissive of CAM therapies. However, other members simply accepted that physicians would never accept CAM as a matter of course and didn't bring it up. In these messages, participants expressed a rejection of the biomedical paradigm when it came to evaluating nutrition and CAM therapies. They believed it was inappropriate to evaluate a supplement in a clinical trial because of baseline differences in nutritional status for study subjects and the need for individual titration. This argument is refuted by some scientists, who maintain that titration of a therapy should not preclude its investigation in a trial format (Pigliucci & Boudry, 2013). Pigliucci and Boudry (2013) argue that when there is not an available treatment group to compare to, due to confounding factors, it is true that a clinical trial is not a fair measure – for example in the case of psychotherapy. However, they maintain that study design decisions always involve tradeoffs about what to measure and an effect should not disappear because it is examined independently (Pigliucci & Boudry, 2013). Regardless of what side of the argument an individual remains on, the important point is that AF patients need to feel comfortable disclosing their use of alternative medications due to the risk of adverse drug events.

Disclosure of CAM use. The literature demonstrates that healthcare providers and patients frequently do not discuss the use of CAM during patient visits (Robinson & McGrail, 2004). One systematic review reported non-disclosure rates of CAM to physicians ranged from 12 to 72 percent (Robinson & McGrail, 2004). A slightly more recent Canadian study reported that 53 percent of participants did not discuss alternative treatments with their doctor (Esmail, 2007). The top three reasons participants selected for not discussing CAM with their physician included: thought it was not important, the doctor never asked, and thought it wasn't the doctor's business (Esmail, 2007, p.28).

Safety implications. An AF patient who does not or is not able to disclose CAM use during their visit may risk receiving suboptimal care due to the risks of adverse drug events. In a recent review of herbal therapies, Brenyo (2014) found that, despite the plethora of natural health products advertised online, information was available on PubMed for only six herbal products known to have antiarrhythmic properties (barberry, chinchona, hawthorn, khella, motherwort, wenxin keli). Khella is the precursor to the modern antiarrhythmic amiodarone and chinchona relates to the modern drug quinidine. The safety profiles for these products were estimated based their modern day counterparts. The other herbs had limited safety information based on small studies, often in animal models. All of the herbs had significant potential interactions with common cardiac medications.

The majority of CAM research evidence in cardiology has been directed towards cardiovascular disease rather than AF (Vogel et al., 2005). However, traditional cardiovascular disease risk factors such as hypertension and obesity are known to impact pressures in the heart leading to structural disease that is related to AF (Mattioli, 2011). There is also some thought to suggest that lone AF (AF in the absence of structural heart disease) may also be modulated by an

unhealthy lifestyle (Mattioli, 2011). Therefore, heart healthy diets such as the Mediterranean diet or dietary approaches to stop hypertension (DASH) are advocated for prevention of AF in the absence of direct AF studies (Mattioli, 2011). There are also a few quantitative studies that examine CAM therapies in AF such as acupuncture, magnesium, poly-unsaturated fatty acids, yoga, and vitamin C (Kim, Choi, Lee, & Ernst, 2011; Lakkireddy et al., 2013; Liu et al., 2011; Reinhart, Baker, & Ley-Wah Siv, 2011). Thus, a review of the literature suggests that there is indeed research evaluating non-pharmacologic strategies for treating AF, and the evidence from this study suggests that some patients may be very interested to discuss it.

In the data collection supplementation with magnesium came up frequently. Numerous AF studies have examined the role of magnesium in AF with the bulk of the literature coming from the post cardiac surgery AF population. Data from the Framingham offspring study demonstrated a non-linear, threshold based association between incidence of AF and serum magnesium (Khan et al., 2013). The lowest quintiles of magnesium were associated with a 50 percent increase in AF incidence, but the association was not apparent amongst the upper quintiles (Khan et al., 2013). A second community based cohort study similarly demonstrated an inverse relationship of AF risk and serum magnesium concentrations (Misialek et al., 2013). However, interestingly, Misialek et al. (2013) did not find an association between dietary intake of magnesium and AF. In this study, participants suggested taking magnesium to the maximum level tolerated without diarrhea. It seemed that participants used each other, online information sources, and CAM practitioners to guide their use of supplements rather than physicians. Given that magnesium supplementation is well within the realm of current biomedical practice, a lack of discourse with physicians may mean missed opportunities for improved safety and electrolyte testing within the conventional system.

Insights on the Information Sharing Process Online

Another major aspect of the findings of this study had to do with the nature of information sharing observed on the message board. Board members used information and tips from other persons with AF that they encountered online to self-manage their own illness. The message board provided a place for information exchange about manipulating medications, supplements, and lifestyle factors such as diet and stress. As well, participants used the board extensively to research ablation providers and discuss procedure experiences. Board members gave information and tips from their own personal experiences, as well as from a variety of outside information sources. I will next discuss three major influences on the information sharing process: the desire for multiple sources, the credibility of the person sharing the information, and the credibility of the actual information.

The desire for multiple sources of information. In analysis of the information sharing process on the board I found that participants valued all types of information when trying to make sense of their situation. This finding is in line with previous research conducted within an offline context. Thorne et al. (2002) found that participants with chronic diseases tended to make decisions based on multiple opinions, even if the original advice came from a conventional practitioner. In this study, posts often contained requests for personal experiences with medications, supplements, and ablation providers. Messages also contained hyperlinks to a variety of information sources, from retailer websites to academic journals.

Some evidence suggests that when people are looking online for health information, they are most focused on the search process as a source of reliability, rather than a specific site's trustworthiness (Adams, de Bont, & Berg, 2006). Some of the elements that people describe as important to legitimizing their search include: finding the same information repeatedly on

different sites (Adams et al., 2006; Nettleton, Burrows, & O'Malley, 2005), finding local sources of information, and sites that are associated with a real institution or body (Nettleton et al., 2005). Most people are aware of the issues related to trustworthiness of online information, but, will describe themselves or their search strategy as more sensible than others (Nettleton et al., 2005). Several researchers have noted that people not only compare multiple websites but also compare data to offline sources in order to reduce misinformation through triangulation of sources (Adams et al., 2006; Adams, 2010; Nettleton et al., 2005).

Peer experts: Facilitating information exchange. In the current study, information and tips often came from particular users whom I called peer experts¹⁷. Evans et al. (2012) studied an online post-partum depression forum and used the term 'peer experts' to describe participants who dispensed advice based on their own experiences. In that study, the women tended to not reference traditional mediums for pharmaceutical side effect information, but instead relied on others personal experiences (Evans et al., 2012). In this study however, the peer experts used combinations of anecdotal and scientific evidence.

There is a healthcare trend to use expert patients as facilitators in self-management programs such as the United Kingdom based Expert Patients Programme (EPP), or the United States based Chronic Disease Self-management program. Wilson, Kendall, and Brooks (2007) interviewed expert patients in the context of obtaining a deeper understanding of the EPP. They found expert patients tended to be systematic, proactive, and organized. The expert patients came to physician visits prepared to have informed discussions, held back their emotions, and used

¹⁷ I selected the term "peer expert" to describe authors who routinely participated on the board and who were identified by other board members as being especially helpful, knowledgeable, and experienced.

clear and succinct language to communicate (Wilson et al., 2007). Interestingly, the authors noted that these traits were similar to those described by physicians for an ideal patient.

In the current study, the participants who I informally identified as peer experts seemed to garner trust from other members in a variety of ways. In addition to sharing their own experiences and knowledge, they could often point to someone else who might have had a similar question or experience. They also tended to either quote or hyperlink to outside sources such as books or medical journal articles. Like the expert patients in formal self-management programs, they demonstrated organized and proactive characteristics, gathering and synthesizing information prior to answering questions. However, an important question remains as to how patients process information from multiple sources, especially when a valued peer endorses it.

Influence of source credibility. The findings from this study indicated that the author of a post had the potential to add additional credibility to information shared from an outside source. This was particularly noteworthy when the trustworthiness of the outside source was debatable, such as a person who uses the term doctor in a misleading way or a physician who holds views that are inconsistent with current consensus guidelines. In the field of psychology, persuasion research has examined the influence of source credibility on an individual's perceptions of content reliability. Early research suggested that the opinions of an audience change based on the perceived trustworthiness of the communicator (Hovland & Weiss, 1951).

Contemporary application of persuasion research is seen online by marketing and business firms that harness the word-of-mouth power in social networks such as Facebook to recommend products (Singh, Mani, & Pentland, 2014). Research demonstrates that family and close friends are very influential in their power to persuade. Celebrities, thought leaders, and

early adopters are also known to influence behaviours through persuasion (Singh et al., 2014); so, it seems reasonable that a peer made online could also act as a similar agent.

A real life example of the power of social networks to change public opinion comes from reduced childhood vaccination rates. Despite agreement that the initial science supporting the linkage between autism and vaccines was falsified, erroneous information continues to circulate (White, 2014). Using social network theory, White (2014) summarized three factors that contributed to the change in public perception of vaccines. First, the media provided extensive coverage of lay people (especially celebrities) expressing their concerns rather than academic experts (White, 2014). Second, journalists covered the issue as though it was a debate with two sides. In actuality, they compared credible evidence to opinions based in extreme ideology (White, 2014). Third, online social networks composed of well educated, upper-middle class women who desired to push parenting norms, contributed to confusion and peer pressure for parents (White, 2014). So it is clear that online social networks have great power to influence perceptions of health matters. But, it is less clear how commonly this occurs and in which situations.

A last example of the public's desire to hear health information in a social or entertaining way comes from the popularity of televised medical shows. One study looked at advice given on syndicated medical advice talk shows (Dr. Oz and The Doctors) and found that approximately half the recommendations made on the show had either no evidence to support them or current evidence contradicted the advice (Korownyk et al., 2014). They also found that the magnitude of benefit, potential for harms, and cost were discussed less than 20 percent of the time. While participants in this study did not refer to these television shows, they did frequently reference medical blogs, however, little information is available as to how individuals processed this

information. Ultimately, it is clear that whether information is endorsed by a family member, online peer, television personality, or blog writer, more research is needed to determine how people evaluate the basis of the commentator's expertise and how the person integrates that information to that received from their own physician.

Conclusion

In this chapter I situated the findings in the context of the greater AF literature, confirming that the online study design was indeed able to achieve a similar relevant patient perspective to that of in-person interviews. The overarching finding from this study was that participants used the message board to gain a sense of control over their unpredictable symptoms. A strong preference and desire for non-pharmacologic strategies led participants to self-manage their illness using alternative health modalities. These findings suggest that patients with AF may share similarities in their desire for information as other chronic illnesses. However, illness specific features such as a paroxysmal course make individuals particularly vulnerable to illusions of causality when alternative treatments are applied. The board facilitated information sharing but also presented challenges in the form of conflicting or simply complex information from a variety of outside sources. I will discuss the implications of these findings, as well as the strengths and limitations of the study design in the next chapter.

Chapter Six: Conclusion

The findings of this study support the literature related to describing the AF patient experience. Prior work demonstrated that AF patients experience high levels of psychological distress and that information and support may reduce uncertainty related to the illness experience (Kang, 2011). On the basis that Internet use is rising, this study sought to improve understandings of the type and nature of information patients encounter on an online message board for AF. The purpose was to gain an AF patient's perspective of information and support needs with the hope that by identifying these needs, as well as potential safety risks, this study will contribute to clinical practice.

Summary of the Study

Using the qualitative approach, interpretive description, I studied three months worth of messages from an online message board webhosted in Canada. The board I studied emphasized alternative health. It primarily existed for persons with lone AF to exchange information in the hopes of furthering knowledge towards preventing AF. In the course of data analysis I came to conceptualize the findings as a cyclical process of "taking command of AF." Four aspects to this overarching theme of wanting control contributed to the description of the content and dialogue on the message board.

Table 1

Summary of Main Findings

Component Title	Description
Sharing experiences and values	Participants described uncomfortable, unpredictable symptoms. Many expressed a fear of long-term effects of medications and mistrust in the pharmaceutical industry.

Component Title	Description
Searching for sense	As a group, participants were highly motivated to find non-pharmacologic strategies to prevent and treat AF. Participants often described adjusting their medications and/or supplements in response to their perceptions of arrhythmia.
Managing the complexities of information	High value on anecdotal experiences. Hyperlinks to a variety of outside sources ranging from medical journals to supplement retailers. Advice gathered from CAM practitioners and ‘fringe physicians’ ¹⁸ .
Acting as a wise consumer	Purchased point of care electrolyte and mineral testing devices and rhythm monitoring apps. Emphasis on finding the “best” ablation provider.

The findings from this study in concert with the larger AF literature suggest that AF patients may have unmet needs. Participants wanted to gain control over their AF but they tended to want a non-pharmacologic method to do so. They opted to use supplements and ablation as primary strategies, in addition to avoiding perceived triggers. The message board facilitated participants to seek out these strategies and connect with like-minded individuals.

¹⁸ The term “fringe physician” refers to a physician who holds views outside current consensus guidelines.

For the AF patients under study, it appears that several factors contributed to the desire for non-pharmacologic strategies and for using the Internet to research them. First, the nature of erratic, paroxysmal episodes and remissions is associated with a tendency for the mind to accept correlational events as causation (Matute et al., 2011). Accordingly, I found that some participants linked any situational factor that occurred prior to an AF event as a trigger. This led the participant to make changes to their lifestyle, diet, medications, or supplement regime. Second, AF patients may face difficulties when trying to explain the impact of symptoms on their lives to healthcare providers (Siouta et al., 2013). The Internet alternatively provides a place where patients may feel more able to discuss and disclose information that may not fit within the traditional biomedical paradigm. Third, health beliefs about pharmaceuticals and cynicism towards physician-industry and researcher-industry relationships all seemed to contribute to the participants going online to look for non-pharmacologic strategies.

The overall pattern of health information seeking noted in this study was in keeping with the larger literature. Participants tended to value all types of advice and sourced information equally from physicians to suppliers of supplements. A notable finding in this study was the manifestation of peer experts online as contributors to credibility for outside sourced information. This is not a completely novel finding; expert patients are included in offline self-management programs and other Internet forum studies have described patients taking on a mentor-like role (Evans et al., 2012). However, research has not focused on the role that a peer met online may play in adding credibility to information, particularly when the peer advocates for information inconsistent with current medical advice.

Limitations

The findings are necessarily limited by the individual and relativistic context that the interpretive description methodology provides (Thorne, 2008). However, the intent of the study was not to produce generalizable knowledge in the fashion that a quantitative study aims to. Instead, the findings should be viewed as contextually dependent, embedded within the time frame and nature of the users who happened to be participating on the message board at that specific time (Thorne, 2008). However, rather than being irrelevant, this study adds to our clinical experience by allowing a deeper insight and understanding of factors that may lead AF patients to use the Internet to improve their wellbeing related to AF. In that several of the potential implications for future research follow logically from specific limitations of this study, I will address them in that context below.

Implications

Further research. Several questions remain that may be best investigated using other angles of inquiry. For instance, given the potential for adverse drug interactions while on antiarrhythmic and anticoagulant drugs, how commonly are AF patients using CAM? A better understanding of this prevalence through a quantitative design may assist in the decision of whether to assign further resources to patient education in this area, or accept that participants in this study may have been unconventional and in the minority.

A significant limitation to the use of study design in the current study included the lack of demographic information for participants. The message board users focused intently on the ablation provider as a determinant of procedure success. Several members wrote about traveling to obtain a procedure with a highly desirable ‘elite’ EP. However, it is unknown how relevant the ‘physician shopping’ so to speak was reflective of a Canadian context. Regardless, some of the

information that the patients in this study wanted in regards to ablation, including the statistical chances of success, amount of procedural volumes an operator achieved, expected post procedure course, and chance for discontinuation of medication, are all relevant to the Canadian population. In our current environment in British Columbia, the focus for electrophysiology procedures is not on trying to attract patients, but instead to manage the waitlist and volumes of people wanting to access it. So, it may be that British Columbians in consultation for the procedure may have quite a different pre-procedure experience compared to Americans. Thus, a study examining psychological distress and education needs in a Canadian context may contribute useful insights to our knowledge.

Lastly, the phenomenon of peers acting as experts who give advice online raises other curiosities for further investigation. The results of one study suggest that nurses do not always feel comfortable working with an informed patient (Wilson, Kendall, & Brooks, 2006). Wilson et al. (2006) found that the majority of their nurse sample perceived expert patients as a threat to their own knowledge and time, whereas physicians and physiotherapists did not. This is important. Increasing Internet use and the high prevalence of online forums suggest that the public wants to be informed and that many people value learning from anecdotal experiences. Research is needed to investigate how nurses can best support patients who utilize forums, especially when that patient presents ideas challenging to the status quo.

Clinical practice. The views expressed by participants in this study support prior research demonstrating that some AF patients need support to express how AF impacts their life and to integrate AF knowledge within that context (McCabe, 2011; Siouta et al., 2013). This study highlights three pragmatic clinical practice points for nurses working with AF clients.

First, to address a pattern observed in this study and likely pertinent to the wider population, during patient education, stressing the natural course of AF may assist patients to better understand which triggers and treatments are merely correlational versus causative. An adjunctive strategy, that Matute et al. (2011) suggest may help to break up an illusion of causality, is to ask patients to think about whether a treatment was the actual cause of a benefit, rather than asking them whether they believe treatment was effective or not. Nurses can also make use of the available literature surrounding healthy heart lifestyles to suggest strategies to AF patients that may have the most impact.

The second practice point is that there is a known risk for adverse safety events when patients combine and self-titrate cardiac medications and supplements. However, the findings from this and other studies suggest that patients may have difficulty communicating their desire to use CAM therapies, or not understand the importance of its communication. Nurses can take a leadership role in educating patients about the importance of disclosure and removing barriers to that communication. This necessarily involves respecting a patient's wishes to hold views that are inconsistent with the dominant biomedical paradigm. Nurses and physicians may feel unprepared to discuss CAM (Buchan, Shakeel, Trinidad, Buchan, & Ah-See, 2012; Schofield, Diggins, Charleson, Marigliani, & Jefford, 2010). However, the take-home message is not for healthcare practitioners to know everything about CAM modalities, but instead to simply be receptive to discussing it.

The third practice point stems from the finding that actual or perceived associations between physicians, researchers, and the pharmaceutical industry may erode patient confidence in healthcare professionals. It is therefore crucial for nurses to remain cognizant of their role with industry. It may be useful to consider strategies to bolster trust between healthcare providers and

patients in situations wherein patients express doubts about their medications secondary to mistrust in industry relationships.

Conclusions

The findings from this study extend pre-existing knowledge of the AF patient experience. Prior research has demonstrated that uncomfortable symptoms and psychological distress contribute to patients using self-management strategies such as resting or trigger avoidance to prevent episodes. In line with prior work, the overarching finding in this study was that participants wanted to increase their control over AF symptoms. However, this study adds to the literature by illustrating a level of supplement and medication manipulation previously undocumented in the AF related literature.

Patients used the online message board to facilitate their learning about methods to manage AF, such as using supplements, manipulating electrolytes and medications, and researching the ablation procedure. It was clear that the online message board offered a peer-to-peer experience desired by patients that met their needs for anecdotal and experiential information.

A focused examination on the HISB observed online demonstrated that for the most part participants felt they had the capacity to interpret and integrate information from different sources. Members of the message board viewed certain participants as lay experts, who clearly had gained trust over time through the process of posting and replying. I suggest that further research occur to better understand how patients integrate information from these peers when it conflicts with conventional medical advice. Practical points for nursing clinical practice include asking patients about CAM use and maintaining a respectful, non-biased attitude towards CAM therapies in the discussion. Further research is suggested to examine the prevalence of

CAM use in the AF population and to support nurses encountering patients who present with information gained online.

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Appendix A

The Experiential Health Information Processing Model

Kolb model for experiential learning	Steps in patient experience
1. Concrete experience: an event	The diagnosis of an illness, presentation of treatment options or other decisions related to care creates a need for information.
2. Observations and reflections: thinking about the event and its impact	By entering an online community an individual observes by reading the messages and reflects about their own experience in relation to the information shared.
3. Formation of abstract concepts and generalizations: what was learned	Inquiry through posted messages is made regarding a patient's next steps or treatment decisions related to their care from other community members.
4. Testing implications of concepts in new situations: active experimentation	By using knowledge acquired from the group the patient proceeds to a treatment decision

(O'Grady et al., 2008, p. 5)

Appendix B

Data Collection Guide

Research question:

What is the nature of content and dialogue exchanged between patients in online forums about AF?

Guiding questions:

How do posts that get many responses differ from those that get few responses?

What characteristics differentiate frequent posters from non-frequent?

How is personal disclosure used? Do members share personally identifiable information?

Do some questions or topics tend to be written in a higher or lower writing level?

Do members ever acknowledge lurking on the board prior to posting? If so what type of topics or questions caused the member to participate?

Do messages fit well within the stages in the Experiential Health Information Processing model?

Are any stages of the illness trajectory more represented than others?

How are brand names of pharmaceuticals discussed?

Do members correct misinformation?

Appendix C

Descriptive Statistics

Table C1

Threads by Title, Author, Number of Views and Number of Posts

Thread Title	Author	Views	Posts
Definitions	by Lori	64	2
Taurine - reminders of importance	by Janice	47	1
My new normal, meds, continuous afib, drugs, invasive procedures, etc.	by dehalia	135	6
Lipoprotein (a) risk	by NormanG	106	8
The afibbers.com database	by Moderator	143	2
rarely mention of anticoagulants	by Kamkin	148	6
Hives are back. Lovenox? Wafarin?	by Karen	111	10
Phytates and magnesium absorption	by Moderator	100	4
Follow-up to recent reports from DECAAF trials as reported by 'Dr. John'	by Jesse	186	5
If you are on this drug dronedarone beware	by laura	191	7
Xarelto and aspirin	by Kamkin	118	3
Motherwort	by bobzz21	119	2
Useful site	by StuartL	152	1
Need Some Good Advice	by Joseph	301	21
For Wayne re U.K. Ablation	by Jan	130	9
50% odds of success is not good enough for me.....	by George C	378	24
when to have ablation? and dr info	by Kamkin	263	29
MY story-- recent diagnosis of PAF; new to this forum (long post)	by Kamkin	208	10
Ever been in afib during minor surgery?	by Karen	162	17
ANS nature of AF	by WayneR	147	1
Stress & magnesium tolerance	by JamesM	145	6
What are the most important supplements to take after an ablation?	by tobbler	115	2
Ablation Los Angeles, CA	by ceciltop	136	5
Dr. N procedure #4 - The Watchman	by Mary O	157	4
I struck out ----- only have 5	by StuartL	156	3
AFIB and Low Blood Pressure	by Jan	137	7
Afibber has talent!	by Janice	160	1
If clot discovered prior to CV or Ablation	by StuartL	126	9
Preparing for a cardioversion	by George C	114	5

Thread Title	Author	Views	Posts
Groundbreaking ablation study	by Louise98734	261	9
Home from N ablaton	by tobbler	152	5
Potassium and diarrhea?	by Karen	78	8
Alkaline and Acidic Food Charts and Philosophy	by Willow	98	7
My first 24-hour fib	by Karen	115	7
Sparkling Water	by In502	110	3
Barb is in her room and still kicking!	by Jesse	211	14
Milk of Magnesia available in UK again	by Francis	67	2
Dr. N Ablation this Thursday!	by tobbler	182	20
Yoga	by Lori	110	3
Low Carb Diet helping acid reflux	by JamesM	94	5
4700 mg potassium a day? Really?	by Iatrogenius	175	8
What is causing afib upon arising at night?	by LanBallet	192	8
Mineral-electrolyte supplement from goat milk, 1g potassium in 2 tbsps!	by Iatrogenius	133	14
I hate hiccups.	by linda s	109	7
Is There a Need to Take Metoprolol with Flecainide for PACs/PVCs?	by Willow	137	8
Trouble getting Keto-adapted	by Richard21	89	6
September 2013 issue of International Health News	by Moderator	79	1
3 P's of Afib	by George C	192	6
Is there a one size fits all answer to a/fib-I dont think so	by laura	152	4
Stroke risk in lone atrial fibrillation	by Moderator	398	22
Article FYI - DHA & EPA increase post op (bypass graft) risk of AF	by npcfc	59	1
St. Jude Medical acquires Endosense	by George C	95	1
My Ablation with Dr. N	by GaryS	255	11
How many ablations performed by a doc you are considering?	by George C	195	7
Radiofrequency (RF) vs. cryoablation	by George C	122	1
Help - What to expect before and during the ablation	by tobbler	254	17
higher risk of developing large blood clots	by StuartL	363	15
Extended-release potassium in the evenings?	by Iatrogenius	195	14
Magnesium Absorption	by Lori	256	13
Is having a cardioversion just a temporary fix?	by George C	305	17
underlying reason for Afib	by craigo	418	28
Eliquis	by laura	222	4

Thread Title	Author	Views	Posts
Treat the Reason for Afib First - an old article I just found	by Karen	370	10
Keto-Adaptation	by Richard21	230	20
Pradaxa side effects listed and unlisted	by StuartL	160	2
Latest on Waller/Magnesium Water?	by In502	261	12
Today is 1 Year Ablation Anniversary - REPORT CARD	by Domino	272	12
Ablation - too much radiation?	by tobblers	436	28
Has Anyone Used Trimethylglycine?	by Willow	191	13
Measuring Potassium	by Lori	207	5
Questions about keto-adapted diet	by Richard21	249	17
Calcium, Afib and Osteoporosis	by Moderator	279	8
Timing of mammogram and ablation...does it matter?	by tobblers	179	8
High Potassium levels can cause afib	by LiamC	303	20
CoQ10,Taurine with Pradaxa and Xarelto	by StuartL	205	5
Neprinol - has anyone experience with this new version of enzymes?	by NormanG	195	8
Stuck in tachy	by mikedadt	228	5
Thanks	by bobmark	284	10
magnesium tolerance need help please	by kstomos	202	11
big Pradaxa leap	by StuartL	201	3
Ablation Update	by bob52	323	14
PACs/PVCs Starting Up at 3 Months Post Ablation	by Stuart	229	8
supplements to take prior and after ablation	by tobblers	203	8
Lipid Replacement Therapy and NT Factor--Starting Point?	by In502	127	5
Introduction and Thanks	by bob52	269	14
Xarelto (Pages: 1 2)	by StuartL	447	35
First night after Lariat procedure (Pages: 1 2)	by Jesse	628	41
Magnesium IV Didn't Stop PACs--Need Advice	by Willow	253	14
Checkups? Adult Aspirin? after ablation??	by chcagofox	144	5
Review of AF catheter ablation for females	by scientist	202	12
Angels for Jesse	by Janice	260	18
skipped Beats and Toprol	by CharlieDale	147	1
Has a single ablation worked for anyone?	by Karen	342	10
8 years since ablation	by chcagofox	261	8
for Norman G	by anna	183	3
Slight change of plans with upcoming Lariat	by Jesse	288	17
Moderator, how do I make a link become active?	by Willow	100	3

Thread Title	Author	Views	Posts
Has anyone tried d-limonene for indigestion?	by Willow	136	11
August/September 2013 issue of The AFIB Report	by Moderator	150	1
P.A.F. and Glaucoma	by alfred	133	6
Rythmol	by Karen	198	10
Success Story, There is Hope for A Fib	by Bobby	421	25
TIKOSYN SIDE EFFECTS?	by Ronald L	137	9
Can Vagally-Mediated Change?	by JeffBass	141	9
Hybrid Maze Procedure	by KevinG	91	2
Is Ginger My Cure	by craigo	334	15
report on increase in AF	by Marilyn	284	8
Ablation Report from Dr. N	by Kenneth	319	6
Info on my ablation	by ltdrier	238	3
AFIB and Tums	by scott	196	3
Acid Reflux Causes Arrhythmias	by Willow	210	9
Xarelto and Liver Enzymes	by Kenneth	213	8
Carvedilol (Coreg) for rate control	by snowbum	146	3
Appointment with Dr S.	by Richard21	131	4
Magnesium IV Causing Paradoxical Reaction??	by Willow	195	15
episodes last for 15 hours	by susan mac	261	5
Scheduled for Dr. N on 8/23	by GaryS	197	8
Post procedure pleurisy	by csteven	124	2
Why am I experiencing cold hands and feet	by NormanG	294	14
Is this bad timing to get an ablation?	by tobler	283	13
"Work on the back wall" in ablation	by Iatrogenius	197	7
Magnesium Hydroxide Q for UK folks please	by npcfc	229	21
Silent stokes when in AF. What next?	by StuartL	298	7
Lariat Procedure - Part II: Benefits and Risks to consider	by Jesse	227	15
Lariat Procedure - Part I: Left Atrial Appendage Ligation	by Jesse	111	1
magnesium injections vs IVs	by Willow	100	5
Turning over in bed a trigger...go figure	by Karen	160	3
Ut Oh - A Bump In My Road	by Domino	201	11
Acid reflux drugs can raise the risk of heart disease	by Victoria N.	217	11
9 Days Post Ablation Question	by Kenneth	314	14
Ablation scheduled with Dr. N August 26	by Rick Canes	297	13
Arginine - a precautionary reminder	by Janice	191	1
Post second Bordeaux ablation	by NormanG	260	13
One year afib free	by De Da	294	7
Switch from Pradaxa to Xarelto --- timing	by StuartL	165	7

Thread Title	Author	Views	Posts
Too much magnesium - correcting	by Karen	275	15
Afib cause - Lax Lower Esophageal Sphincter	by Jan	165	4
Depression & Afib	by Karen	227	6
7/3 Ablation in Austin	by Kenneth	241	7
17 years Proxysynml AF and now permanent - Conclusions	by sbambini	391	7
Using the Laqua twin Cardy meter for K+?	by Adamsmith	103	2
One year anniversary successful 4th ablation!	by Anonymous User	367	24
Ablation 6/24 in Austin	by csteven	244	10
IC Ca Q for James N and Janice Please	by npcfc	195	9
has anyone heard of this MRI during ablation	by laura	143	1
July/August 2013 issue of International Health News	by Moderator	143	1
Follow Ups Long Distance	by BrianB	163	6
Iatrogenus ?	by Melissa	235	10
Ablation setbacks - how soon for a touch up	by NormanG	363	18
Ablation on 7/3 in Austin, Supplement Question	by Kenneth	248	9
This is harder than it sounds! (Pages: 1 2)	by ToddB	559	34
Direct Contact Information For Dr. N's San Francisco Location Please	by BrianB	96	3
AliveCor heart monitor	by Paul	147	6
How do you know it is flutter?	by Guy McWhine	222	8
Afib returned 10yrs after ablation??? Help	by Adamsmith	351	23
The bleeding risk of aspirin the same as warfarin?	by Louise98734	178	5
Is Dr Sonny Jackman really the creator of catheter ablation, not Dr. Natale?	by Louise98734	206	10
Botox	by Mel	136	7
Failed lariat procedure	by Mary O	208	14
Interesting material on silica	by ltdrier	175	8
Supplements at risk - again - Awareness Alert	by Janice	211	2
Long term AAD use and ablation outcome - Q for Moderator & others please	by npcfc	276	16
Your favorite potassium-rich recipes	by Iatrogenus	167	6
Dr. N's Three Clinics - Waiting Time	by BrianB	284	19
Ablation with Dr. H set for Thurs., 6/27/13	by Iatrogenus	197	16
The beast returns...	by Steven B	425	30
Can AFlutter run at around 80-100BPM??	by npcfc	169	6
Need Help Understanding How to Stop New Afib	by Willow	257	14
Asymptomatic Afib	by Lisa Ngf	239	9
Reminder: Taurine is part of the Essential Trio	by Janice	276	10

Thread Title	Author	Views	Posts
Sotalol pills ???	by Larry Z	143	4
Differences in Potassium Powder	by Lori	149	10
Calling All U.K. Afibbers!	by Jan	128	3
Dr John on co-enzyme Q10	by Francis	256	8
Coumadin vs Xeralto ?	by Simone	251	17
Possible hiccup on insurance coverage for Dr. N..	by tobbler	186	6
How or should I take potassium when on a diuretic?	by tobbler	101	4
Flutter after ablation and Titrating off propafenone - ideas please.	by Angie	137	9
Electrolyte solution recipes? Add to Waller water?	by Iatrogenius	162	16
4weeks post uk ablation	by Melissa	135	9
Ear felt beats/ potassium	by Karen	129	3
Tikosyn	by Paul	98	3

Note. Usernames have been changed.

Table C2

Number of threads initiated by username, and age and location if disclosed

Username who Initiated Thread	Number of Threads Started	Age	Geographical location
Adamsmith	2	29	
anna	1		Australia
Anonymous User	1		Atlanta
bobzz2	1		Canada
scott	1		
GaryS	2	50's	
cstephen	2		?USA
mikedadt	1		
George C	7		
Bobby	1		South Carolina
Mary O	2		?US
craigo	2		New Zealand
JeffBass	1		?UK
ToddB	1		
Louise98734	3		
chcagofox	2	74	
Larry Z	1		
Simone	1		
Victoria N.	1	late 70's	Michigan
Guy McWhine	1		
JamesM	2		
Francis	2	75	UK
Moderator	7		Victoria
Melissa	2		UK
kstomos	1		
Iatrogenius	7	62	US
Janice	6	77	
Laura	4		New Zealand
Richard21	4		
BrianB	3		Florida
Kamkin	4		Florida
Kenneth	5	55	?USA
LanBallet	1	57	
KevinG	1	65	
susan mac	1		
linda s	1		
Lisa Ng	1		

Username who Initiated Thread	Number of Threads Started	Age	Geographical location
ltdrier	2		Texas
In502	3		
Lori	5	64	
Angie	1		Ontario
Marilyn	1		
Rick Canes	1	55	
Ronald L	1		
npcf	5		
Karen	11		
Mel	1		
dehalia	1		
WayneR	1	?late 40's	UK
De Da	1		
Domino	2		Charlotte NC
Paul	2		
Joseph	1	58	
scientist	1		
bob52	2		USA
bobmark	1	50	Calgary
NormanG	5		Alberta
Jan	4	?late 40's	UK
ceciltop	1	72	LA
Jesse	6	?66	Hawaii/Arizona
alfred	1		UK
Stuart	1		?USA
StuartL	10		
CharlieDale	1		?PA
sbambini	1	65	Philippines
tobbler	10		
Steven B	1	65	
LiamC	1		?USA
Willow	10		
snowbum	1	60	

Note. Usernames have been changed. An additional 32 unique usernames replied to threads but did not start their own threads.