

# Learning about Atrial Fibrillation using Social Media: A Qualitative Inquiry

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## Abstract

*Health information is one of the major topics searched on-line. Social media is increasingly used by patients for health education, empowerment and support. There is a lack of systematic data on what kind of information is being sought by patients via social medial channels. By analyzing information exchange in an on-line support group we can better understand what information is not provided reliably to patients in a clinical setting. The aim of this study was to analyze a content of messages exchanged between participants in an online support group for people with atrial fibrillation. Using Grounded Theory, we conducted a content analysis of 626 messages, which were grouped into seven categories. We described each category and provided examples of users' citations belonging to each category. In addition, proportion of initial posts and responses to them was analyzed depending on message category. Social media facilitated health education on major topics related to atrial fibrillation. Practical implications of qualitative analysis of messages posted on an online support group are discussed.*

## Keywords:

Atrial fibrillation, online support group, qualitative analysis, knowledge gaps, social support

## Introduction

Atrial fibrillation (AF) is the most common cardiac dysrhythmia which affects over 6 million patients in Europe and approximately 2.3 million in the United States. The number of patients with AF continues to grow rapidly due to an expanding elderly population. AF increases the risk of embolic stroke by about 4-5 times [1]. Furthermore, AF is responsible for one-third of all hospitalizations for cardiac dysrhythmia, and the number of hospital admissions for AF increased two- to three times from 1985 to 1999 [1].

Despite high hospital admission rates and high prevalence of the disease, even after emergency room and hospital admission, patients with recently detected AF have limited knowledge about AF symptoms, purpose of medication, stroke prevention, and side effects of warfarin [2]. Gaps in knowledge about the disease and its treatment, detection of symptoms and how and when to seek treatment were found in another study in patients visiting emergency room for AF symptoms and 3 months after discharge [3].

AF significantly affects patients' everyday quality of life [4]. It may sometimes limit their everyday and extracurricular activities, such as physical exercise, travel and others. Treatment for AF symptoms has been shown to improve the quality of life [4]. Among treatment options available are prescription of medication, electrical cardioversion, radiofrequency ablation, implantation of atrial pacemakers, surgery and others.

With wide Internet expansion, individuals affected by AF turn to Internet in search of informational and emotional support from other people who are also affected by the disease by joining disease-specific online support groups. Online support groups help individuals to cope with their disease-related issues by overcoming distance, access, or communication-related challenges [5]. Members can share their experiences anonymously and ask questions that they may be uncomfortable to ask in person when interacting with their peers or a medical professional. Moreover, patients get access to more diverse points of view and information as compared to what they can get through established close relationships [6,7]. Therefore, online group members may obtain diverse information about their condition, treatment and related issues from other members. Such information is based on members' own experience and information from other sources like Internet web sites, books, patients' doctors and others. Thus, active participation in an online support group may help educate patients about their condition by addressing their knowledge gaps.

In addition to sharing information, patients share their emotions and feelings related to their disease. Participation in online groups promotes trust, empathy and emotional integration into a "virtual community" [8]. Higher levels of social support are related to lower psychological distress and better mental health in the sense of coping resources [9]. Social support buffers effect of stressors, like chronic health conditions, negative life events and other long-term conditions. In this case, social support may help a patient to cope better with the disease. Perceived availability of social support serves as a protective factor against psychological distress, depression, and anxiety [10,11].

Qualitative research methods are widely used to gain in-depth understanding of human behavior and the reasons that govern such behavior. The content of messages posted in online support group web sites may be a valuable resource for understanding experiences of group members and the utility of online interactions for the group participants [12]. Content analysis of the messages posted online has been previously successfully applied to investigate moderated and non-moderated online

disease-specific support groups [13-14]. However, analysis based on Grounded Theory (GT) has not been applied systematically to the content of online support groups, particularly in individuals with AF [15].

The goal of the present study was to analyze information content of messages exchanged between participants in an online AF support group using qualitative methodology in order to identify and classify major topics which are being discussed by the group participants. Understanding the everyday concerns and worries in the lives of patients with AF can help health care professionals to better meet their patients' expectations, and address patient-centered values, preferences and needs.

## Methods

A grounded theory approach was followed in the analysis of online posts [16]. Research based on GT employs inductive thinking, aiming to understand a situation from 'inside' rather than stating a hypothesis first. Therefore, no categories were specified in advance of data collection. We analyzed archived messages posted on one of the AF support group web site. The content of 626 messages posted during the period of 1/1 to 1/31 2008 by 144 anonymous users was analyzed using the NVivo 8 software. Messages were analyzed in terms of similarities or differences, which was followed by finding common themes and developing categories. These categories then were used as a basis for the creation of a hypothesis.

## Results

All messages have been grouped into seven major categories (see Table 1 for details). The most discussed category of messages was related to *medications*. Within this category, group members discussed medications prescribed to alleviate AF symptoms, which medications helped and which did not, and medication side effects. The most frequently mentioned medications were amiodarone and coumodin, e.g. "It (amiodarone) got me very sick and I did not know it until I had to be hospitalized."

The *procedures* category included postings about effectiveness of such procedures as ablation, cardioversion, and half/full maze procedure, e.g. "My ablation healing seems to be progressing very well. My EKG is fine. I have been AF free except for three post ablation episodes (of decreasing duration) the first week. I understand that is part of the healing process."

The *experiences with AF* category contained messages describing personal experience with AF symptoms, asking how common the symptoms are and how other members cope with them, e.g. "Sometimes I will feel dizzy beforehand, but very often it will come out of the blue (...) My heart does palpitate very strongly several times a day, but this seems to happen independently of other symptoms."

The category named *quality of life* included messages about the impact of AF on quality of life. The members discussed limitations in physical exercise and travel: "AF was basically ruining my life. I could no longer travel, I could no longer feel free to do simple things like paint a wall, or work in the garden on a hot day." Also, members shared how the disease affects their everyday life activities such as shopping, work, leisure time.

The *diet* category reflected the properties of various foods and drinks, such as green vs. black tea, fruits and vegetables, and how they affect the disease and blood coagulation: "A month ago after reading that green tea can cause palpitations I stopped taking the tea - and my AF has been behaving itself!"

In *helpful links and articles* helpful web sites, links and other sources of information were posted, e.g. "See Medscape, guidelines for the management of AF. Dr. Calkins has some very useful comments on Amiodarone in his interview with editor."

In the last category, *devices*, two devices helping to monitor and regulate the heart rhythm were actively discussed - atrial pacemakers and holter monitors, e.g. "I had a holter a few years ago, but unfortunately wasn't able to catch any of the episodes on it."

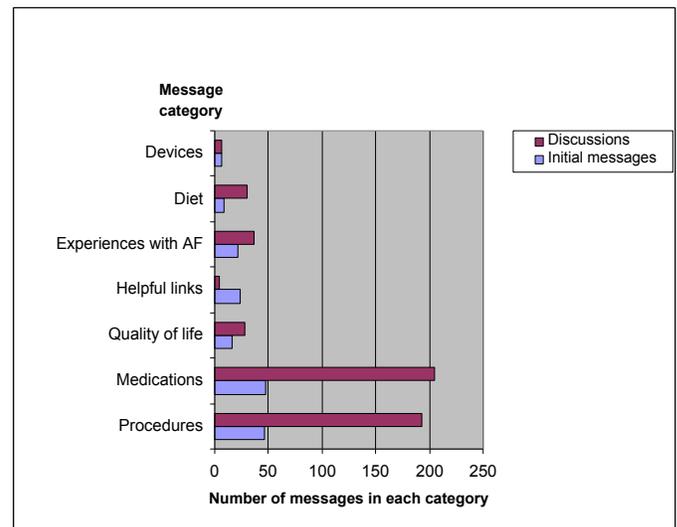


Figure 1- Number of initial messages and their discussions in each message category

As seen in Figure 1, messages posted in some categories initiated active discussion of a topic, whereas in other categories number of responses was relatively low. For instance, the two most discussed categories were medications and procedures. At the same time, posts related to helpful links and articles were not discussed as actively as other messages.

Table 1- Number of messages in each category and subcategory and their percentage values

Message category	Total number of messages in each category and subcategory and their percentage	
	Total number	%
Medications	252	
Antiarrhythmic drugs	79	31.35
Anticoagulants	59	23.41
Beta-blockers	27	10.71
Calcium channel blockers	9	3.57
Calcium and potassium	40	15.87
Side effects	33	13.01
Others	5	1.98
Procedures	239	
Ablation	151	63.18
Cardioversion	26	10.88
Maze	19	7.95
Location	19	7.95
Other	24	10.04
Life with AF	59	
Symptoms	17	28.80
Sleep	7	11.85
Dealing with AF	4	6.77
AF during pregnancy	3	5.05
Other	28	47.44
Quality of life	44	
Exercise	33	75.00
Travel	6	13.64
Influence of AF	2	4.55
Other	3	6.82
Diet	39	
Green tea	15	38.46
Red tea	3	7.69
Other	21	53.84
Helpful links	28	
Devices	18	
Holter	7	38.88
Pacemaker	4	22.22
AfibAlert	2	11.11
Other	5	27.77

## Discussion

We identified seven major categories of messages posted in the AF online support group: medications, procedures, life with AF, quality of life, diet, helpful links, and devices. With exception of helpful links and devices categories, in all other categories the proportion of messages offering support was much bigger than initial messages. This finding supports previous research describing major discussion topics in a disease-specific online support group [18].

We analyzed messages posted on the AF online support group during one month. Messages were content analyzed and grouped into seven major categories. We found that in five out of seven categories AF patients were more inclined to offer support than ask for it. This pattern was especially evident in topics related to AF medications and treatment procedures. At the same time, much less interest was expressed toward objective information related to atrial fibrillation available online, such as articles, web sites and useful links.

Messages posted in AF online support group provided insight into the disease-related topics that are the most important for AF patients and which were not addressed otherwise. The most common topics in group members' messages were related to AF medications and treatment procedures. This finding supports previous research demonstrating gaps in AF patients' knowledge about the disease and its treatment [2,3]. It also emphasizes patients' need in opinion from others who have similar condition, not just a medical professional. The number of responses to posts related to medications and treatment procedures was four times greater than the number of initial posts. Therefore, group members sought other members' opinion and advice in addition to their doctor's suggestions, e.g., "I have been advised to increase that (medication dosage) to 400 mg of paceron once a day, 200 in the AM and 200 at night. Anyone else take that large a dose with no side effect?", "I think I am ready to say goodbye to the meds, talk to my Doctor and go for rate control. Anyone have any thoughts or advice?"

Furthermore, AF patients paid much less attention to the discussion of validated sources of factual information related to atrial fibrillation available via online educational resources, such as articles, web sites and useful links, as compared to exchange of personal experiences and opinions. This demonstrates that the primary impetus for joining the online group for the AF patients was the desire to learn more about the disease from other people with the same disease, to understand how other people deal with this condition, and to validate their personal opinions by the group experience. Similar findings were reported in a case study of another online support group [8]. Our findings also correspond to results of a recent survey which demonstrated that patients preferred to discuss medical information online before talking with medical professionals [17].

Analysis of the content topics supported the notion that participation in the AF online group helped patients to cope with life challenges posed by their condition. Sharing emotions related to life with AF and getting understanding from others reduced psychological distress in patients, e.g. “Thanks for the additional information re: other rhythms. It has given me some stress relief from the concerns I had.” Moreover, in response to sharing personal experiences, the patients received information about a wide range of disease coping strategies that may be potentially effective in patient’s situation. The fact that the group participants were more inclined to provide support rather than request it from others underscored previously described phenomena according to which providing social support to others may result in health benefits comparable to—or even greater—than receiving support [19].

Previous studies demonstrated the efficacy of computer-assisted education in delivering knowledge and empowerment for disease prevention and management [20-21]. Social media can be used in conjunction with other tools available on the internet to improve continuous personalized patient education and support [22].

## Conclusion

Our study provides evidence that an online support group for AF patients can help them to address knowledge gaps about their condition based on others’ personal experience. In addition, by joining such groups, patients can find emotional and informational support and resources that can help them to deal with disease-related stress. Understanding information needs of people with AF can help medical professionals to provide better medical care and improve patient-provider communication.

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