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## Supraventricular Tachycardia and the Struggle to be Believed

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### Abstract

**Background**—Little research exists examining patient experiences of life with supraventricular tachycardia (SVT). Realistic expectations of symptoms, patient management strategies, and treatment options are important components of patient education and treatment decisions.

**Aim**—This descriptive qualitative study explored patients' experiences living with SVT.

**Methods**—Grounded theory methodology was used with semi-structured interviews of 25 SVT patients undergoing radiofrequency ablation treatment.

**Results**—The main core category that emerged from the data was the “struggle to be believed”. The struggle or work of living with SVT entails: (1) living with the uncertainty of the occurrence and duration of an episode, (2) “covering up” to manage symptoms and appear normal, (3) searching for causative factors to prevent further episodes, and (4) experimenting with management techniques to shorten or end episodes.

**Conclusion**—Clinical diagnosis and referral for ablation treatment were more difficult for women suggesting existence of a gender bias. As with many other chronic conditions, the illness trajectory work is formidable. Patients in this study with SVT, however, reported facing the additional difficulty of being believed. Disruption in self-esteem and personal relationships are the effects of not being believed. Providers could avoid minimizing women's symptoms by listening seriously and offering realistic expectations; including insight into patient experiences and the trajectory of the dysrhythmia; and efficacy of drug and ablation treatments.

### Keywords

Supraventricular tachycardia; qualitative research; diagnosis; uncertainty; gender bias

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## Introduction

Supraventricular tachycardia (SVT) includes a variety of types of reentrant fast heart rhythms originating in any part of the heart's conduction system above the ventricles. The major types of SVT include: atrioventricular nodal reentrant tachycardia, atrioventricular reciprocating tachycardia, atrial tachycardia, inappropriate sinus tachycardia, and atrial flutter.

Physiologically atrial fibrillation is also a type of SVT, but typically discussed outside of other SVT rhythms because of the complex differences between it and other SVT rhythms.

Atrioventricular nodal tachycardia is the most common type of SVT, representing 50% to 90% of all SVT cases.<sup>1,2</sup> This type of SVT, along with inappropriate sinus tachycardia, has a higher prevalence in women. Atrioventricular reciprocating tachycardia is the second most prevalent type of SVT, accounting for approximately 33% of all SVT.<sup>1</sup> Atrioventricular reciprocating tachycardia and atrial flutter are seen more frequently in men. Other details of the mechanisms and clinical manifestations of SVT rhythms have been described elsewhere.<sup>1-3</sup>

Although the types of SVT may differ in physiological mechanisms, the outcome of each is a rapid heart beat that has a paroxysmal onset and termination. Supraventricular tachycardia episodes initially occur in late teens to early thirties, with a natural history of increasing episodic frequency over time. Duration of SVT episodes vary widely from seconds to hours. Episodes are typically associated with symptoms of palpitations, dizziness, presyncope, nausea, anxiety, atypical chest pain, diaphoresis, and frank syncope.<sup>1-11</sup> While clearly not as life-threatening as sudden cardiac death or other ventricular arrhythmias, many features of SVT make it particularly difficult and frustrating for patients to deal with. The unpredictability of the episodes and inability to control the disabling symptoms can render the patient incapacitated. Researchers have noted that up to 27% of SVT patients stopped driving because of symptoms of near syncope or syncope.<sup>4,5</sup> Patients with SVT have averaged four hospital admissions or emergency department visits per year in the 2 years prior to radiofrequency ablation treatment.<sup>10</sup> Investigators have also reported non-lethal cardiac arrest in 2% of SVT subjects, with 16% requiring an electrical cardioversion to restore normal rhythm.<sup>9</sup>

Chronic antiarrhythmic drug therapy is the first line treatment for SVT. However, these medications have a low long-term efficacy requiring frequent changes of drugs and/or dosages that can add to patients' frustration. Since the late 1980's however, catheter ablation therapies have dramatically changed the treatment options for these patients, offering a permanent cure without the need for long term drug therapy or surgery.<sup>10,12-14</sup> Access to ablation procedures, performed by cardiac electrophysiology specialists, is acquired through a referral from a cardiologist or primary care provider.

Despite the highly specified symptomatic and EKG diagnostic criteria, diagnosis and referral for ablation treatment is not always straightforward. Researchers have noted that the symptoms commonly reported by patients with SVT mimic other conditions and are often mistaken for anxiety attacks or panic disorders, especially in women.<sup>11</sup> Other researchers have noted gender related differences in referral patterns for radiofrequency ablation procedures.<sup>15</sup> Due to the sporadic nature of the episodes, it may be difficult and time consuming to capture the SVT on an EKG or ambulatory cardiac monitoring. If patients are misdiagnosed, they are not referred in a timely manner for curative ablation therapy. If the SVT is not diagnosed correctly, patients' lives may be affected tremendously by these not only intrusive, but potentially life-threatening symptoms. Symptoms of SVT may seem well understood clinically, but how the symptoms and SVT episodes affect patients' lives has not been explored. To our knowledge, this is the first study to examine those patient experiences.

## Methods

### Design

The data presented here were part of a larger study measuring symptom distress and quality of life in patients with regular, narrow complex tachycardias referred to as SVT. Inclusion criteria for both studies were as follows: (1) adults  $\geq 18$  years old who speak, read, and understand English; (2) confirmed SVT diagnosis through electrophysiological testing of: atrioventricular nodal reentrant tachycardia, atrioventricular reciprocating tachycardia, atrial tachycardia, inappropriate sinus tachycardia, or atrial flutter; (3) adults who have undergone successful ablation treatment of the SVT as reported on electrophysiology laboratory records; and (4) physically, mentally able, and willing to participate.

### Data Collection

Our study included 25 patients who were interviewed about their experiences of managing and living with SVT. Twenty-nine subjects were approached for participation, but four declined to be interviewed. The sample was selected from patients on the electrophysiology service at a large university-affiliated medical center after approval by the university's human subject research committee. Participants were approached at the time of hospitalization following a radiofrequency catheter ablation procedure, after recovery from sedation, and asked for their consent to be interviewed. Participants were provided verbal and written details of the study and consent was obtained. Following the Glaser and Strauss<sup>16</sup> maximum variation sampling technique, purposive sampling was used to obtain as broad a range as possible of patient experiences. Male and female participants were selected to include diversity in age and race, varied length of time living with SVT, and a representative reflection of five types of SVT.

Interviews, ranging in length from 30 to 90 minutes, were open-ended and conducted in patient hospital rooms within 24 hours following the ablation treatment, or arrangements were made for telephone or face-to-face interviews within one week of the ablation procedure. All interviews were conducted and transcribed by one researcher (KW). Eighteen of the interviews were tape recorded, but seven patients refused to be taped. The interviewer took notes during the interviews for these seven patients. A guide was used for the semi-structured interviews, but in keeping with grounded theory methodology, the guide was refined and revised as concepts and categories became apparent. Initial themes for the interview guide were drawn from clinical experience and spontaneous comments from patients that occurred during clinic visits or conversations outside of the interviews. The interview guide was initially reviewed by medical and nursing experts in the field and other patients with SVT to enhance validity. Sample open-ended questions included, "Tell me about your first episode of SVT" or "What has living with SVT been like for you?" Participants were also asked about the frequency/duration of their SVT episodes, descriptors of precipitating factors, and any symptom management strategies they may have adopted.

### Data Analysis

Quantitative data collected from the medical record included: demographics, number of emergency room visits for treatment of SVT, number of antiarrhythmic medications used, and left ventricular ejection fraction via echocardiography. Measures of central tendency were used to analyze the demographics and clinical variables.

Qualitative data collection and analysis were carried out concurrently according to the process of grounded theory methodology.<sup>16,17</sup> Interview transcripts and notes were examined line by line to identify meanings and openly coded into conceptual categories using constant comparison of participants' comments. Properties of each category were outlined and compared to tease out the similarities and differences. Through axial coding, attempts were

made to interrelate categories by comparison of condition, action/interactional strategies and consequences. Through selective coding, a core category was identified, and a beginning theory about the experience of living with SVT was refined from relating other categories to the core category. Saturation, referred to by Dey as “theoretical sufficiency”,<sup>18</sup> was established when further interviews confirmed existing data and yielded no new concepts. Feedback on data coding and analytical memos was obtained from four nurse scientist colleagues to assure ongoing confirmation and trustworthiness in the analysis.

Field notes were invaluable for capturing the emotional responses of participants, strengthening interview data. The field notes contained interviewer observations of the participants during initial contact, during the face-to-face interviews, and during subsequent clinic visits after the interview. These non-verbal observations added to the understanding of the meaning of life with SVT that was not always captured in the verbal interview data alone. Field notes were reviewed periodically in the search for additional dimensions of the categories that had emerged from the interviews.

A question raised by one reviewer of this paper regarding “truthfulness” and “auditability” of the analysis deserves attention. Regarding truthfulness, grounded theory has roots in the sociological perspective called symbolic interactionism, which avers that society, reality, and self are constructed through interaction. This perspective is concerned with the way people create, shape, resist, and negotiate the meanings of what happens to them, thereby forming diverse definitions of the situations they face, which in turn, affect their actions. A basic tenet of both symbolic interaction and grounded theory is that things perceived as real are real in their consequences. Thus, the focus is on “truth” as *interpreted* by respondents.

The question of auditability is essentially a question of validity. Every mode of discovery develops its own standards, canons, and procedures for achieving verifiable results. Therefore, qualitative research has its own conduct for attaining validity, conduct which is different from that used in quantitative research. Grounded theory is an inductive method designed to build theory by following disciplined procedures of coding, theoretical memo writing, comparison among data, theoretical sampling, theoretical sorting, and identification of a core category. It is certainly conceivable that another qualitative researcher could come into the same setting and develop another theory or one that would enlarge upon the one presented in this paper.<sup>19</sup> Both theories could have equal validity. In the end, a theory should be judged on whether it is useful, fitting, and generative of further inquiry through which its generalizability can be discovered.<sup>16</sup>

## Theoretically Sensitizing Concept

Strauss and colleagues’<sup>20,21</sup> identification of the complex types of illness trajectory work performed in acute hospital settings broke new ground by portraying not only health professionals but also patients and their families as “workers” and the home as an equally important work setting. This concept has been augmented by other discussions of the concept of illness trajectory in examining how patients work at managing different chronically ill states.<sup>22,23</sup> Illness trajectory has been defined as: “not only the physical unfolding of a disease, but ... the total organization of work done over the course of the illness—together with the impact that the consequences of the illness and its work exert on the lives of the people involved: patients, family, and health professionals”(p. 37).<sup>22</sup> Illness trajectory proved to be a theoretically sensitizing concept when collecting and analyzing data from these participants living with SVT.<sup>16,24</sup> Sociologist Herbert Blumer introduced the notion of “sensitizing concepts” to denote interests that give the researcher ideas to pursue and that sensitize the researcher to ask particular kinds of questions.<sup>25</sup> As Charmaz explains, “Grounded theorists use sensitizing concepts as tentative tools for developing their ideas about the processes that

they define in their data. If particular sensitizing concepts prove to be irrelevant, then we dispense with them” (p. 17).<sup>26</sup> In the research discussed in this paper, the illness trajectory concept proved to be highly relevant as a means of understanding the illness trajectory work of living with SVT and the conflicting viewpoints that affect the struggle to validate symptoms and obtain a correct diagnosis---in short, to “be believed”.

## Findings

The sample included 15 females and 10 males, ranging in age from 18 to 81 years. The age distribution of the 25 participants is presented in Table 1. The majority of the participants were Caucasian, married, and employed full time; however, there was a range of ethnicities, marital and employment states in the sample. In all cases, the tachycardia mechanism was ascertained from invasive electrophysiologic studies at the time of the ablation procedure. The participants had a variety of types of SVT (Table 2). Cardiac function, measured by ejection fraction, was normal for all subjects (Table 2); however one subject had a trace of mitral valve prolapse noted on echocardiogram.

The estimated frequency of SVT episodes ranged from 2–4 times a year to greater than 3 times a day (mean four times per week). Frequency of SVT episodes in this study, similar to others,<sup>9,27</sup> was extremely variable with a median of 4 times per month and a median duration of 30 minutes (range was one minute to greater than twelve hours). Neither frequency nor duration of episodes differed significantly between types of SVT, although the participants with inappropriate sinus tachycardia and atrial flutter tended to have episodes consistently lasting longer than 2 hours. All subjects reported an increased frequency, duration, and/or severity of SVT episodes as years passed since their first episode. Participants reported visiting the emergency department from 0–4 times (mean of  $1.3 \pm 1.1$ ) within the last year for urgent treatment of the SVT.

The core category to emerge from the data was “struggling to be believed”. Participants struggle in an attempt to validate their symptoms and obtain a correct diagnosis. The major factors associated with this struggle surround the unpredictability and paroxysmal nature of onset and relief of symptoms, including duration, frequency, and etiology of episodes. The sporadic nature of episodes required the SVT to be “caught” or documented on an EKG for correct diagnosis and belief of the patient’s symptoms. The substantive theory evolved from this study indicated that the illness trajectory work of living with SVT while attempting to surmount the believability problem included the following categories: (1) living with the uncertainty of the occurrence and duration of an episode, (2) covering up to manage symptoms and appear normal, (3) searching for causative factors to prevent further episodes, and (4) experimenting with management techniques to shorten or stop episodes. Although as with many other chronic illnesses where the illness trajectory work is formidable, patients in this study reported the additional stress of dealing with the difficulty of obtaining a diagnosis and the related difficulty of being believed. Patients are continually engaging in these processes, with varying emphasis, making modifications as they progress through the trajectory of the illness. For example, successful manipulation of causative factors and management techniques will be reflected by less time spent in covering up and decreased uncertainty. Most important, “success” at any point in the trajectory is only temporary as the episodes will randomly recur, adding further to the uncertainty. Other examples of the way these processes are intertwined, each affecting one another, are described below.

### Living with Uncertainty

Patients with SVT often have to manage uncertainty by balancing limited options. The paroxysmal, random nature of the SVT episodes continually kept these participants “on edge” and unsure of when the next event would occur. Many reported feeling an incredible emotional

burden that they carried constantly as they worried that the frightening physical symptoms may happen anywhere at any time. Uncertainty was also expressed and related to the fear that this could be a potentially serious “heart problem” and their mortality would be adversely affected.

“Having this thing totally wrecked my life. I felt so scared and helpless because I never knew when I’d have another episode, how bad that episode would be, if this new drug would work ... because many of them didn’t.... or if it never stopped racing.... would I die?”

Managing the illness became the focus of their lives as they juggled activities of everyday life around the SVT episodes. To decrease the uncertainty, patients spent much energy in efforts seeking causative factors they could eliminate or manipulate; making dietary or lifestyles changes to lessen the frequency of episodes; and developing strategies to shorten the duration of episodes. To avoid potential episodes of SVT, many patients stopped participating in recreational sports on the possibility that exercise was a precipitating factor, or to escape embarrassment in front of others.

Patients frequently noted having to completely stop working, driving, or performing leisure activities because of the severity of symptoms and/or the unpredictability of the SVT episodes. One female participant shared her concerns:

“I have to drive for work, but I’m always scared it might happen while I’m driving. Now I always drive in the right hand lane, so if it happens, I can pull over to the shoulder quickly.”

These actions did nothing to interrupt the cycle of recurrence and often increased the uncertainty, furthering the sense of struggle, as well as emotional and financial toll on families.

“The episodes followed no pattern. I never knew when they would occur and that was what was so scary. I was so afraid of having an accident if it occurred when I was driving, that I just stopped driving all together. This really put a burden on my husband, because he now had to drive me everywhere. It was pretty tough on my husband.”

Fatigue further exacerbated the feelings of uncertainty. Patients consistently described the post-episode fatigue as corresponding to the length of the SVT episode. An episode of SVT lasting seconds to minutes caused extreme fatigue, but the fatigue was short-lived. Longer episodes of SVT were associated with more severe fatigue lasting 1–4 days. This type of fatigue was repeatedly described as “disabling”, “overwhelming”, or “formidable”. Patients became anxious once the episode began, not only dealing with the uncertainty of the acute episode, but also the uncertainty of nervously anticipating the need to curtail activities thereafter due to the impending fatigue. Patients would have to take time off of work, cancel planned activities, and/or stay in bed for the majority of the next 1–3 days. Anticipating and living with the fatigue further increased patients’ stress level, which many patients thought would precipitate additional episodes, exacerbating the cycle of uncertainty.

“The fatigue was overwhelming. I was afraid of taking too much time off work because I might lose my job or people would think I was really ill. So I started drinking at least 3 cups of coffee before I went to work the day after an episode to get myself out the door. But then I realized that the coffee was actually starting up more episodes of that fast rhythm. It was all so exhausting.”

Both types of fatigue were noted to be associated with an inability to concentrate or focus on tasks, as mentioned by this 28 year old attorney:

“After each episode I was really worn out for a few days. I had a hard time when I was in law school because I wouldn’t be able to concentrate or have much energy for

a good day or two after an episode. I felt a lot of pressure to stay ahead in my studies, in case I had another episode and had to take days off.”

**“Covering up” to Appear Normal**—Patients dealt with the unpredictability of SVT in differing ways. One category which emerged from the data was “covering up” to appear normal. Patients would develop strategies to assist them in *normalizing* life, or making their lives appear normal to others. Wiener<sup>28</sup> describes the process of normalizing in a group of patients with rheumatoid arthritis, as “suppressing the physiological imperative and proceeding with the activity imperative as if normal” (p. 99). The behavioral phenomenon of covering up or “concealment” has also been noted in other arrhythmia and chronically ill patient groups.<sup>29–32</sup> A female participant recalls how she would cover up in elementary school:

“As a child I would usually pretend that I had a stomach ache if I felt my fast heartbeat starting. Then I’d have an excuse to run quickly to the bathroom to lie on the floor and try to slow it down. It was too embarrassing to do that in front of my classmates.”

One woman noticed her friends were including her less frequently in social activities. She describes her attempts to “cover up”:

“My friends would become nervous when they saw my neck pulsating fast. Some of them told me they were afraid they might have to do CPR when they were out with me. I figured out that if I wore a turtleneck or scarf, they wouldn’t ever notice, and I could kind of hide the fact that I was having one of those episodes.”

A 28 year old man said that he had never shared anything about the SVT events with his new wife. He didn’t want her to worry; so to “cover up” an episode while they were driving, he would pull over to the shoulder of the road with the excuse that something seemed wrong with the tire. He would get out and squat down by the tire; this action usually stopped his SVT. “That’s how I covered it up.” He was concerned about how long he could continue using this excuse before his wife caught on.

Several patients mentioned that they had to “cover up” the fact that they had SVT at work in order to keep their job. Patients did not want to be seen as abnormal, too ill to function, or taking too many sick days, as these concerns worsened the uncertainty.

**Searching for Causative Factors**—The majority of patients felt there was no one consistent precipitating factor related to the SVT episodes and causative factors changed over time. Patients’ frustration was clear in trying to identify causative factors, through trial and error with little or no advice from health care providers, to prevent further episodes and decrease the need to “cover up”. Some patients noticed episodes started only after ingestion of caffeinated beverages, alcohol, or chocolate. All patients, whether experiencing these triggers or not, reported making numerous dietary and lifestyle changes on the chance that this would prevent future episodes. Anxiety during social or business dinners was common when patients would have to “cover up” with excuses why avoiding alcohol, chocolate, or caffeine was necessary. Others noted that strenuous physical exercise (i.e., jogging, climbing stairs, or vigorous exercise) triggered episodes of SVT, or felt that emotional stress was the major precipitating factor. Patients spoke of the frustration and energy expended trying to eliminate all stress from their daily life, as many of their physicians recommended. Some patients additionally reported that a rapid change in body position (i.e., quickly going from sitting to standing), ingestion of certain foods (i.e., spicy foods or very cold beverages), lying on their left side, lack of sleep, being overheated, or the act of bending over forward would precipitate a SVT episode. All patients spoke of the ongoing struggle to eliminate causative factors or activities one-by-one from their life, in order to eliminate episodes. Frustration and further uncertainty followed when attempts to eliminate causative triggers proved futile for preventing additional SVT episodes.

**Experimenting with Management Techniques**—The participants also spoke of employing a variety of management strategies (i.e., Valsalva maneuvers, lying down supine or prone, squatting, coughing repeatedly, standing on their head) when an episode occurred.

“I always felt I could stop the fast rhythm if I could stand on my head as soon as it started. When this happened in Penney’s one day, I just panicked because I couldn’t do a head stand without causing a scene. I quickly grabbed a pair of pants that weren’t even my size as an excuse to go into the dressing room and do a head stand. It worked, but it also made me anxious about going shopping again.”

Six patients reported trying carotid sinus massage or ocular pressure at home after they had seen this performed in the emergency department, but they had never received any instructions on how to correctly carry out these maneuvers. Other patients additionally noted that drinking ice water, placing a cold, wet towel on their face, or inducing vomiting would usually terminate their SVT episodes. All patients noted that although some of these maneuvers worked frequently, no one strategy worked every time increasing the uncertainty of living with SVT. When the usual management strategies stopped working, patients had to try additional maneuvers or experiment with new management techniques compounding the feelings of uncertainty and anxiety.

**The Work of Obtaining a Diagnosis**—After the difficulty being diagnosed emerged from the data as a theme, patients were asked directly about their experiences. On top of struggling through the illness trajectory work of living with SVT, many participants reported that they had to “work” at obtaining the correct diagnosis of SVT. Primary care physicians were often unaware of what the patients’ presenting symptoms indicated, and therefore did not refer them to a specialist in cardiology or electrophysiology. Or, if providers did diagnose the patient correctly, management consisted of starting and stopping multiple drug regimens over a period of years. Many patients reported being told that they “had failed” this drug or another, and ended up feeling like it was something that they personally could have caused, instead of an ineffective drug. Referral for an ablation was often not suggested, or offered years later with the disclaimer that “there is this invasive type of procedure, but I don’t think it is the right thing for you yet.” Patients consistently reported relief followed by frustration when finally diagnostic testing such as a Holter monitor or EKG was performed and then the tests were read as normal. Patients perceived that their physicians required documentation of the rhythm in order to make a diagnosis; otherwise there was hesitancy to label the condition as SVT. This became a frustrating process as patients tried numerous measures with a variety of EKG recording equipment to “catch” an episode of the SVT for documentation. All patients felt they were diagnosed or referred for ablation only after EKG, Holter, or event monitor evidence was obtained. Although in the case of four patients, the EKG evidence was misinterpreted. In these cases, the final diagnosis at the time of ablation differed from the original diagnoses because of the ability to more accurately diagnose arrhythmias with intracardiac electrophysiological testing.

Typically, patients tried several primary care physicians before they found one who would “believe them” and refer them to an electrophysiologist for an ablation. In one instance, a woman reported going to six physicians before one believed her. After numerous visits to three additional cardiologists, she was finally referred for ablation treatment. Not being believed perpetuated the self doubt and low self-esteem. The category of working to obtain a correct diagnosis was noted to have dimensions ranging from: being disbelieved to being believed.

**Contrast between Disbelief and Being Believed**—Being disbelieved was interpreted by patients as being seen as untrustworthy, mentally unstable, invisible, or a hypochondriac. Disbelief also discounted or minimized the significance of the patients’ symptoms and illness. One female participant describes her experience:



“I just felt like none of the doctors believed me. I think they thought I was making it up because they can’t see it or get it on an EKG. They gave me Valium or Xanax and sent me home.”

Another woman echoed similar experiences of feeling discounted and having her symptoms trivialized:

“He told me that I was just too stressed out, and that I should stop working and concentrate on being a good wife and mother. Then he gave me a prescription for Ativan to help me relax. I did everything he said and still had that fast heartbeat.”

Many of the patients expressed disappointment and frustration when an episode of SVT abruptly ended before it was documented on an EKG. Variations on the following quote were common:

“Of course, by the time that I got to the emergency room, the fast rhythm had stopped. On one hand that was a relief; but on the other, that meant I had to continue trying to get the fast rhythm recorded on paper. The doctors would look at me like I was crazy and wasting their time when I told them I was having a fast heart rhythm but it had just stopped.”

Patients spoke of being falsely diagnosed as having panic or anxiety attacks. Some patients believed this to be the correct diagnosis, but were confused when anti-anxiety drugs did nothing to prevent further episodes. One female participant expressed relief and hopefulness when her doctor finally referred her to a specialist. She next described her feelings of shock and betrayal when she learned that the “specialist” was a psychiatrist, not a cardiologist.

Although described by men and women, being disbelieved was more often seen with female patients (11 women/2 men). Being believed however, was more often seen among male patients (4 women/8 men) and had a much shorter trajectory from first physician visit to correct diagnosis. Patients were not always referred for ablation immediately after seeing an electrophysiologist, but patients whose symptoms were believed were referred for ablation more quickly than those patients who were not believed. Men in this study were also more likely than their female cohorts to initially be prescribed anti-arrhythmic agents instead of anti-anxiety drugs (8 men/4 women received anti-arrhythmics; 2 men/11 women did not). They spoke less of frustration and self doubt than the patients who were not believed. Examples from patients who were believed include:

“My only symptoms were heart palpitations and dizziness. The first doctor diagnosed me with panic disorder. I was confused by this diagnosis, so I asked for a second opinion. The second doctor knew immediately it was my heart rhythm and sent me to a special cardiologist.” “I told my doctor about these things and he asked a lot of questions. He told me what he thought it was, but also said that it is difficult to catch these episodes when they are so sporadic and short-lived.”

The second quote above was from a 42 year old man who was treated empirically with anti-arrhythmic drugs by his physician, even though the diagnosis of SVT was not yet “proven” by an EKG recording.

**Consequences of Not Being Believed**—The patients who felt discounted were frustrated because no one believed their symptoms or experiences. They often felt overwhelmed at having to manage the SVT by themselves. Not being believed was associated with receipt of anti-anxiety drugs rather than anti-arrhythmic drugs. The self doubt caused by being discounted lowered the participants’ self esteem. One woman expressed a common feeling shared by other participants:

“They did all sorts of tests ... but found nothing. I think they thought I was making it up. I thought about it a lot. Was I really crazy? Was this all in my head? Was I just thinking I had a fast heart rhythm?”

Some patients noted other friends and family members beginning to doubt them as well.

“I think my friends, especially my husband, may have thought that this was all in my head. My husband told me later that he had wondered if I was losing my mind, since the doctors could never find anything wrong.”

Relationships changed as patients avoided dating or social situations for fear that an embarrassing or frightening episode may happen in public. Spouses/partners became frustrated over time with the effects of the SVT on their relationships. Many participants reported that spouses or family members had to take on more responsibilities, as patients' lives became seriously affected by the symptoms of SVT episodes. Other patients felt so incapacitated by the fatigue or emotional despair that they withdrew from family and friends. Still others became more dependent due to the increased uncertainty and fear of being alone, which required adjustments in family roles and routines.

Jobs were also lost or work activities limited due to the symptoms associated with SVT episodes. One patient, a community-based respiratory therapist, had to quit her job, because carrying the heavy equipment to patients' homes would initiate an episode of the SVT. Another woman reported losing her job because her employer felt her multiple physician visits to obtain a correct diagnosis were increasing health care costs for their company.

Relationships with health care providers also changed if patients felt disbelieved. Many patients reported a previously positive, trusting relationship with their providers. These relationships soured quickly however, if the patients felt they were not believed or had their symptoms discounted. The patients began a pattern of uncertainty and self doubt as they were told it was “in their head”. After multiple episodes that did not respond to anti-anxiety agents, or repeated visits where their symptoms were disbelieved, patients' frustration and anger at their provider increased. Patients expressed other feelings of betrayal, having great mistrust, anxiety, and depression over interactions with health care providers. This began the vicious cycle of searching for other providers, decreased self-esteem, and negative relationships with future health care providers as time went on.

**Consequences of Being Believed**—There was great validation and relief after obtaining a correct diagnosis. The relief was not only verbalized, but physically obvious by participants' non-verbal behavior of smiles, waving of arms, and other animated actions. Patients reported that in many cases, just the fact that someone believed them and understood the problem, much less offered curative treatment, was a relief and a type of treatment in itself. The poignancy of their condition is captured in the euphoria one woman described when she finally found a doctor who believed that she was not some “crazy, anxious, hysterical woman who was making all of this heart rhythm business up.” Often just finding out that there were other patients with similar experiences brought obvious relief and reassurance. Many patients verbalized feelings of shock and surprise to find they were not the only person who had SVT and had experienced these symptoms. Another female participant said:

“Overnight I felt such relief after the ablation. I was beginning to believe that I was truly crazy and these attacks were all in my head. The doctors finally believed me and thought I wasn't crazy, but had a real medical problem.”

## Discussion

Patients' personal perspectives of life with SVT offer health professionals valuable insight into the patient experience. These data demonstrate that the experience of living with SVT is one of continuous uncertainty with periods of overwhelming fatigue; searching for elusive causative factors to prevent further episodes; experimenting with a variety of management strategies to control the paroxysmal episodes; and struggling to be believed in order to obtain a correct diagnosis. The theoretically sensitizing concept of illness trajectory work illustrated a similar phenomenon in patients with other chronic illnesses that increased our perception of the dimensions of work patients undertake while struggling to live with SVT. The struggle to be believed strongly impinges upon the ability of these patients to receive timely curative medical treatment, carry out activities of daily life, and have positive social relationships. If not believed, life becomes further complicated by self doubt and isolation, the stigma of being labeled a hypochondriac by friends and family, spending more time covering up, and searching futilely for ways to prevent or manage the episodes. If patients are believed, the struggle is shortened and becomes less uncertain, less time is spent covering up, and curative treatment is accessed sooner.

Other researchers have used qualitative methods to explore the experiences and uncertainty in chronically ill patients' lives, strategies for managing the loss of control, as well as other consequences of the illness.<sup>28-38</sup> Investigators have also noted similar feelings of uncertainty in studies with cardiac patients: pacemaker recipients,<sup>32,33</sup> sudden death survivors,<sup>31, 34-36,39-40</sup> atrial fibrillation patients,<sup>37,41</sup> those with angina,<sup>42</sup> and patients awaiting heart surgery.<sup>38</sup> Others have reported similar experiences of being minimized with mistaken diagnoses,<sup>11,32,37,43</sup> a lack of management options,<sup>37</sup> limitation of activities of daily living,<sup>32-34,37,42</sup> continuous pursuit for curative treatment,<sup>37</sup> and a need to maintain normalcy shielding family or friends through concealment of their symptoms.<sup>28,31, 33,37</sup> As with previous study findings, the authors recommend that providers avoid minimizing women's symptoms by listening seriously and offering realistic expectations.

Contrary to our assumption that patient experiences would differ based on the type of SVT diagnosis, the patient experience of struggling to be believed and living with uncertainty was found to be similar across types of SVT. The patient experience did however, differ based on gender, with more men being believed, noting a less difficult time obtaining a correct diagnosis and shorter trajectory prior to curative ablation treatment than the majority of women in this study. This finding is supported by Dages and colleagues who reported significant gender differences in treatment and access to radiofrequency ablation for SVT patients.<sup>15</sup> Women were maintained on anti-anxiety drugs for longer periods of time before being referred for ablation treatment after a significantly longer duration of symptoms than male patients with SVT.<sup>15</sup> The reason for this delay is unclear because success, complication, and recurrence rates for radiofrequency ablation show no difference between men and women with SVT.<sup>14, 15</sup> Data were not gathered in the current study ascertaining how each gender of patient described or presented their symptoms to providers, as this could also affect diagnosis. Women with SVT have however, been reported to be incorrectly diagnosed with panic or anxiety disorders more often than men.<sup>11</sup> Gender bias in the approach to treatment of other female cardiac patients has also been reported.<sup>44-47</sup>

Kralik and colleagues have also reported similar findings in their exploration of women's experiences with the process of being diagnosed.<sup>43</sup> Although these researchers included women with non-cardiac, chronic illnesses such as multiple sclerosis, breast cancer, or leukemia, the experience of being diagnosed was similar to many of the participants in this study. Many women spoke of similar frustration when practitioners questioned the reality of their symptoms. Women who were eventually diagnosed after chronic symptoms also felt

instantly validated by providers and perceived by others as having a real illness. Like the SVT patients in this study, hearing the name of the illness was a tangible detail that patients could refer to and use to pursue potentially curative treatment.<sup>43</sup>

Participants offered promising and helpful details for health care providers to embrace in caring for SVT patients. Our data support previous findings that SVT episodes become more frequent and severe over time,<sup>48</sup> underscoring the need for realistic patient education counseling including the natural course and illness trajectory work associated with the dysrhythmia and efficacy of drug and ablation treatments. Patient feelings of uncertainty may be lessened by realistic, objective information on patient experiences, specifics of management strategies used by others, and an awareness that no one management strategy will work consistently. Clinical outcomes of patients with SVT could be improved if practitioners provided realistic information to patients as well as listening closely to patient symptom descriptions; curative therapy could be offered in a more timely manner with less need to cover up while spending time and energy seeking a diagnosis and treatment.

This study was conducted at a tertiary referral center which often handles more difficult, refractory cases. The SVT patients in our sample may be more symptomatic and display a very different frequency of SVT symptoms/episodes than at other types of institutions. Subjects in this study, who dealt with SVT episodes for a mean of 20 years, may have had more severe symptoms than patients earlier in their illness trajectory. The differences in the dynamics of interviews based on timing and place (from within 24 hours in the hospital after ablation to one week later in another location or by phone) could have had strong consequences on the participants' responses. The authors however, feel that this was not the case in this study due to the consistent responses between patients regardless of their location or timing. One researcher (KW) had spoken with each of the patients at several points in their treatment process (prior to the procedure in the clinic, in the hospital, and in clinic one month after the procedure) and found their stories to be consistent in details and emotional responses throughout the interactions.

Further research could enlarge upon these findings to address how, or if, the ways in which symptoms are initially described by patients differ by gender or by age; a specific focus on uncertainty and fatigue as described by these patients; how patient experiences change following ablation treatment, as well as what the recovery process entails based on factors such as patients' culture, marital status, and gender; and whether socioeconomic status affects the ability to seek a correct diagnosis or the symptom experience of life with SVT. Pursuing issues of gender bias and delay in referral for ablation treatment is also crucial. Equally important is how this beginning theory might apply to other types of patients dealing with chronic or episodic illnesses when medical disbelief is encountered.

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**Table 1**

## Sample Demographics

	n=25
Age (range 18–81 years)	40 years ( $\pm$ 15)
Gender	15 (60%) female 10 (40%) male
Ethnicity-	20 (80%)
Caucasian	4 (16%)
Asian	1 (4%)
African American	
Employment-	11 (44%)
Full time	5 (20%)
Unemployed	4 (16%)
Housewives	3 (12%)
Retired	1 (4%)
Disabled	1 (4%)
Full-time Student	
Marital Status-	13 (52%)
Married	6 (24%)
Divorced	3 (12%)
Single	2 (8%)
Living together	1 (4%)
Separated	

Continuous variables are expressed as: Mean ( $\pm$  SD); Categorical variables are expressed as: n (frequency).

**Table 2****Clinical Characteristics (n=25)**

Types of SVT	AVNRT (n=9) AVRT (n=8) ATACH (n=3) IST (n=2) AFLUTTER (n=3)
Left Ventricular Ejection Fraction	65% ( $\pm$ 1%)
Number of Anti-arrhythmic drugs tried prior to ablation (range 0–6)	1.6 ( $\pm$ 1.5) drugs (median 2.0)

Variables expressed as Mean ( $\pm$  sd).

SVT: Supraventricular tachycardia; AVNRT: atrioventricular nodal reentrant tachycardia; AVRT: atrioventricular reciprocating tachycardia; ATACH: atrial tachycardia; IST: inappropriate sinus tachycardia; AFLUTTER: atrial flutter.