Recurrent Supraventricular Tachycardia Through the Eyes of the Patient: Describing Experiences and Developing Caring

Ann-Katrin Nordblom

UNIVERSITY
OF BORÅS

"…I don't think that you should have to wait and have it like this, you should be able to get help earlier when there is. There is a difference when there is no treatment, when you don't know what to do, when there is no help, but here there is actually help?"

Quotes from a person with experiences of seeking help in healthcare for decades.

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Academy for Caring Science, Work life & Social Welfare
University in Borås
501 90 Borås

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Preface

In my clinical practise as a nurse, I tried repeated to reach a woman in her 70s by phone for a follow-up one year after treatment with catheter ablation for supraventricular tachycardia. This woman had lived her life simultaneously struggling with the impact the tachycardia episodes, which had affected her since her teenage years. She recalled how, during lectures, she had to interrupt and collapse behind the desk until the palpitation stopped, after which she could continue lecturing. In those days, no sustainable treatment was available for this type of arrhythmia.

Finally, she answered the phone, a little out of breath, and said, “How can I help you?” I explained that this was a follow-up call and asked if she had experienced any episodes of arrhythmia since the catheter ablation. She laughed lightly and relieved, “You are in luck. I am just home, washing my clothes, repacking the suitcase, and now I’m leaving again. I haven’t had any heart palpitation since the ablation; they are all gone.” At first, she didn’t believe that the ablation had been successful, and the palpitations were gone. However, over time, she becomes more confident in her regained health. The dream she had always had, but never thought possible, was now a reality. With newfound confidence, she began planning trips to exotic destinations around the world. Living her dream, she added. “If you don´t need anything else, I’ll get back to packing.”

Through this story, I look to highlight the profound impact living with recurring episodes of tachycardia, the importance of proper treatment, with the significance of being able to realize life-projects and turn previously unfilled dreams into reality.

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ABSTRACT

Aim: The overall aim of this thesis is to describe how it is to live, with and being cared for, recurrent supraventricular tachycardia, with emphasis on the patient perspective and how to develop care given.

Approach and Method: The thesis, which has a theoretical foundation in Caring Science, takes an overall inductive approach based on the patient perspective. The lifeworld theory has been used to describe and understand the patient perspective, although several scientific methods have been used, in order to answer the specific research question. Study I was quantitative with a retrospective descriptive design, and II, III, and IV was qualitative with descriptive designs. Study I describe patients’ unplanned visit (2719) at healthcare facilities with symptoms of tachycardia, analysed with descriptive and comparative statistics. Study II describes catheter ablation as experienced when being treated awake for supraventricular tachycardia (SVT). Study III describes patients’ participation in their own health and care process. Both Studies II and III were based on reflective lifeworld approach and interviews (12 and 17, respectively study), using a phenomenological method. Study IV was based on a structured two-phase experience-based co-design (EBCD) methodology, involving participatory workshops with patients (4) and collaborative process development with healthcare providers (7) from specialist care, to reflect on experiences of care to capture and prioritize areas for improvements. A reflexive thematic analysis was used to analyse data.

Main findings: There is a significant difference in total visits in healthcare centres and/or emergency departments by patients of different sexes. Further, the referral rate is low, especially from healthcare centres to specialist care (cardiologists). Patients undergoing catheter ablation while awake experiences a range of emotions, including reliance on others’ expertise, being actively passive, and striving for a restored health and well-being. The process of undergoing catheter ablation serves as a confirmation of having a physically curable condition, transforming the future from being filled with obstacles due to the tachycardia into an everyday of possibilities. Patient participation involves trust to healthcare that is hampered by lack of continuity. This discontinuity leaves patients with the experience that their lives are on hold in an “existential waiting room” where they trust and hope for treatment for an unpredictable condition that significantly impacts daily life. Participation manifests as a sense of trust in being taken seriously as a whole person, bringing hope for help with their unreliable heart. Reflexive mapping highlighted areas where services were not corresponding with patients’ need and three themes derived: Confidence-building support, Tailored information, and Substantial communication.

Conclusions: This thesis’s findings highlight the patients’ need of support and involvements in all levels of healthcare, emphasizing the importance of addressing sex- and age-related differences to ensure equitable care. Repeated interactions with various healthcare providers results in a fragmented

and unstructured care, making it difficult for patients, especially those without documented tachycardia/SVT, to be taken seriously. Greater patient participation can be achieved through a joint effort to determine the diagnosis, grounded in a mutual trust in the patient's competence and narrative. A confirmed diagnosis validates patient's symptoms and guides treatment. Early assessment of recurrent arrhythmias and clear, supportive communication are essential for patients undergoing catheter ablations treatment. From the patient perspective, a lack of actively engaged professionals highlights the need for improved interprofessional collaboration, incorporating a holistic perspective in care. The EBCD approach was successfully used to identify areas for improvement in the care for patients with SVT.

Keywords: arrhythmia, caring science, catheter ablation, health, lived experience, patient perspective, phenomenology, reflective lifeworld research, supraventricular tachycardia, participation, experience-based co-design, reflexive thematic analysis

Original papers

This thesis is based on the following original papers referred to in the text by their Roman numerals.

I. Nordblom A.-K., Norberg Boysen G., Berglund, M., Kjellsdotter, A. (2022). Health care centre and emergency department utilization by patients with episodes of tachycardia. *BMC Cardiovascular Disorders*, 22:124. https://doi.org/10.1186/s12872-022-02568-y

II. Nordblom A.-K., Kjellsdotter A., Norberg Boysen G., Berglund M. (2023). Foreign movement in one's own body: Patients' experiences of being awake while treated with catheter ablation-a phenomenological study. *International Journal of Qualitative Studies on Health and Well-being*, 18:1, 2238972. https://doi.org/10.1080/17482631.2023.2238972

III. Nordblom A.-K., Kjellsdotter A., Norberg Boysen G., Berglund M. (202x). Being taken seriously: a phenomenological study of participation in care for patients with supraventricular tachycardia. Submitted, revision 2, October 2025.

IV. Nordblom A.-K., Berglund M., Kjellsdotter A. (202x). Improving care for patients with supraventricular tachycardia through experience-based co-design: A reflexive thematic analysis. Manuscript October 2025.

ABBREVIATIONS

AVNRT	Atrioventricular nodal re-entry tachycardia
AVRT	Atrioventricular re-entry tachycardia
EBCD	Experience-based co-design
ECG	Electrocardiogram
EP-lab	Electrophysiological laboratory (operating room)
HCP/s	Health care professional/s or providers
ICN	International Council of Nurses
RLR	Reflective Lifeworld Research
SVT	Supraventricular tachycardia

Content

Introduction

This thesis is situated within the discipline of caring sciences and is grounded in lifeworld perspective, with a particular emphasis on the patient's lived experience. Caring sciences is a research field whose intention is to gain knowledge about human existence, and it is a professional neutral and interdisciplinary science, alongside medical issues in healthcare (Arman, Ekebergh & Dahlberg 2022; Wiklund Gustin & Bergbom 2020). For most people, cardiac symptoms such as palpitations and high pulse rate are worrisome, especially before they understand what is happening in their own body and how to deal with it. Not all patients with palpitations and a high pulse rate have arrhythmia; they might have palpitations for other reason, such as stress - a physiological response to something. However, this thesis focuses on adult's experiences of palpitation and high pulse rate originating from supraventricular tachycardia [SVT]. SVT is defined as recurrent episodes of regular tachycardia that occur unpredictable, with pulse rates over 130 beats per minute and abrupt onset and termination (on-off) characteristics (Brugada et al. 2019).

Today, in the Swedish context, the care process for patients with recurrent SVT (excluding atrial fibrillation and atrial flutter) seems to be incoherent and unstructured (Carnlöf et al. 2017; Friberg, Krantz, Määttä & Järbrink 2016; Rosengren et al. 2018). This claim is based on patients' narratives concerning unmet needs, such as managing their health issues and finding proper, sustainable help. The claim has been confirmed by colleagues at various levels at the healthcare system across Sweden, with a resigned frustration concerning the limited possibilities to help these patients. The inspiration for this thesis is my experience as a registered nurse, collaborating with patients who have various kinds of arrhythmias, in the ward and in the electrophysiological laboratory [EP-lab]. Although the symptoms, signs, and impact of SVT are well recognized by healthcare providers [HCPs], there is limited knowledge from the patient perspective.

As part of my master´s studies in cardiological nursing, I conducted a study involving individuals living with SVT (Nordblom, Broström & Fridlund 2017). One key finding highlighted patients' struggles to access proper care. These reflections formed the basis for research questions exploring how patients navigate the healthcare system before, during, and after SVT treatment. By offering insights grounded in caring science and a lifeworld perspective, this thesis aims to enhance understanding and support for individuals with recurrent SVT. Throughout this thesis, I refer to myself as 'the PhD candidate', except in instances where further clarification is required.

Background

When palpitation becomes a recurring issue that disrupts daily life and causes disturbing symptoms, people often seek support from the healthcare system. It is the responsibility of HCPs to support the patients, assess the condition, begin investigations, and when necessary, propose and plan proper treatment measures. When HCPs lacks the resources to adequately support the patient, they must seek further help, typically through collaborating with specialist care for both acute and non-acute medically symptoms (SOU 2020:19).

SVT is a cardiac condition that can have a profound impact on an individual's daily life and overall well-being. From a caring science perspective, biological health and lived experience are not regarded as separate phenomena but as interwoven dimensions of the human condition (Dahlberg & Segesten 2010). However, a prevailing concern is that the biomedical paradigm dominates contemporary healthcare. This dominance risks reinforcing a dichotomy between objective clinical findings and the subjective experiences of patients.

Since this thesis is grounded in lifeworld theory, which supports the integration of both objective and subjective perspectives in care, these ideas will further be explored in the section on theoretical perspectives and concepts. The background section outlines the problem area and overall context of SVT as a complex condition. This section presents patient perspectives, including lived experiences of SVT and encounters with healthcare, medical perspectives, including the prevalence of SVT, history of treatment, and treatment options.

Patient perspective

When people become patients – that is, they seek care for health reason – they want to be seen in both their agency and vulnerability (Dahlberg & Segesten 2010; Dahlberg, Todres & Galvin 2009). The term 'patient' traditionally refers to someone who is suffering, with healthcare's role being to alleviate that suffering (Eriksson 2018) and support the restoration of health and well-being (Dahlberg & Segesten 2010; Arman et al. 2022). In this thesis, the use of terms as 'person' and 'patient' is not intended to diminish individuality but to highlight the complexity of everyday living. Individuals may simultaneously be partners, children, siblings, friends, or colleagues, striving to keep their social roles despite symptoms, treatment and care. The studies in this thesis were conducted in various contexts, including home, outpatient care, and hospital settings, where terminology shifts based on the situation. 'Person' refers to someone living with the condition prior to engaging with healthcare, while 'patient' denotes someone who has sought or received professional care.

In general, most persons who experience symptoms never become patients; experience of symptoms and other bodily sensations are just a fundamental element of everyday life, occurring in both sick and healthy people (Malterud, Guassora, Graungaard & Reventlow 2015). In a caring context, symptoms are understood as a subjective phenomenon of an experience that refers to a change in bodily order and reflects the existence of something that was not there before (Malterud et al. 2015). How the experience of having the palpitation affects the situation in which a person finds themselves is more than simply experiencing a symptom; it varies between people and depends on the specific circumstances. From a patient perspective, confidence in healthcare is high, and when the situation escalates with increased recurrent tachycardia and symptomatic disorders, people turn to healthcare with a hope and will to regain health (Malterud et al. 2015). In the context of caring science, having a patient perspective requires a basis in the person's life situation in order to approach reality as it is experienced by the patient. How patients experience their life situation is outlined in the narrative – what the patient chooses to talk about in the description. It involves the HCP attempting to see, understand, and to some extent describe and explain health, illness, and suffering as the patient experiences it (Arman et al. 2022).

Lived experiences of recurrent tachycardia/SVT

Previous research has shown that people living with recurrent tachycardia/SVT describe an inhibited existence due to uncertainty since they do not know how long a persistent episode lasts (Nordblom et al. 2017; Wood, Wiener & Kayser-Jones 2007). Some symptoms have long-term negative effects, forcing them to make changes in their plans due to the impact of these symptoms. This may last for hours after the SVT has ended, with a clear impact on daily activities (Walfridsson, Strömberg, Janzon & Walfridsson 2009; Wood et al. 2007; Yetkin 2018). The risk for new episodes causes people to limit activities for a sense of security and becomes an obstacle to the performance of ordinary activities of daily living, such as sleep, work, recreational pursuits, enjoyment of life, and social encounters (Withers et al. 2015; Wood et al. 2007). These limitations, brought about with the intention of avoiding tachycardia, is a known problem, with consequences for well-being and quality of life (Meissner et al. 2009; Walfridsson & Walfridsson 2005; Yilidrim et al. 2012). From an existential perspective, there can be a lack of trust

in one´s own body and the ability to manage pressure in daily life (Yilidrim et al. 2012). Uncertainty is related to the fear of a potentially serious heart problem and the lifespan being negatively affected (Wood et al. 2007). Previous research suggests that symptoms of recurrent tachycardia/SVT can significantly disrupt daily life for some individuals, while others report only minor impacts.

Self-care

Individuals with SVT manage their condition through self-care, which can be effective. However, if the condition progresses, self-care may lose its efficacy, leading to an increased number of episodes and more persistent symptoms. According to World Health Organisation [WHO] (2022), self-care is defined as "the ability of individuals, families, and communities to promote health, prevent disease, maintain health, and cope with illness and disability, with or without the support of a healthcare worker." In the context of chronic illness, patients often become their own primary caregivers, managing their condition continuously or in response to symptoms (Riggare 2025). From the perspective of caring science, the concept self-care has evolved to encompass physical and mental health, self-care management, active participation in care, emotional well-being, and co-creation of healthcare interventions (Audulv, Sampaio & Sousa 2025). This broader approach includes diverse strategies aimed at enhancing patient well-being and empowering individuals to manage chronic condition more effectively. Self-care is crucial for optimal health. For patients with SVT, self-care involves having an adequate level of knowledge about the illness, understanding various treatments, monitoring symptoms and signs, finding reliable sources of information, knowing when to act and navigating the healthcare system (Brugada et al. 2019). Although HCPs across all levels are expected to convey knowledge about self-care management, however, this is not consistently practiced.

Challenges in encounters with healthcare

Patients' encounters with healthcare are often characterized as traditional biomedical meetings between HCPs and patients, with a physician typically assuming a leading role (Bullington 2007). The dialogue primarily focuses on symptom descriptions, with follow-up questions intended to find a biomedical explanation. Although physicians may inquire about the patient's perspective, it is not always fully integrated into the consultation (Bullington 2007). For patients, the symptoms are perceived as something foreign in the body that only HCPs can manage (Johannisson 2013). The complexity of recurrent tachycardia was highlighted in an early paper where Campbell and Elliot, (1939)[1], who stated that "often the attack is not seen, and there is only the history" (p.123). This situation still occurs in modern time due to the unpredictability of episodes (Brugada et al. 2019).

Recurrent tachycardia/SVT might affect patients in numerous ways, so it is crucial to understand and have a comprehensive insight into the patient's own experiences (Lane et al. 2015). Psychological distress such as anxiety and uncertainty are common due to the impact of living with this condition, especially when patients perceive disbelief from the HCP due to the absence of tachycardia during healthcare visits (Withers et al. 2015; Wood et al. 2007). The difficulty of having the tachycardia 'captured' as a sign on an electrocardiogram [ECG] leads to added stress based on the sporadic nature of the episodes. For the patient, having tachycardia documented on an ECG offers the possibility of a diagnosis, which makes it easier to be believed (Wood et al. 2007). Being told that the palpitations are associated with a minor risk is reassuring. On the other hand, patient with recurrent tachycardia experienced their health problems were downplayed and not recognized as the significant concern it was (Nordblom et al. 2017; Withers et al. 2015).

Patient participation

The health- and care process is a dynamic process in which encounters between the patient and the HCP are central and measures are decided based on the patient's need for care (Eriksson 2018). The right to be involved and take part in one's own care and receive information about the condition and treatment is promoted in international guidelines (WHO 2013) and strengthened through laws and regulations in Sweden (SFS 2017:30).

Patients' experiences of participation contribute to a reduced vulnerability and improve their sense of control in the situation (Eldh 2006). Patients' participation meals the possibility of taking (back) responsibility for and influencing their own health situations (Johansson & Ekebergh 2006; Nordgren 2008). Participation means more than just receiving information; it requires a focus on having knowledge and on encounters with HCPs, rather than just partaking in decision-making (Eldh, Ekman & Ehnfors 2010). If information is one-sided and insensitivity delivered, research has shown that it can have the opposite effect and decrease participation (Johansson & Ekebergh 2006; Nordgren 2008). Not participating or being involved in their own care is described by patients as experiences of exclusion, powerlessness, and suffering (Berglund, Westin, Svanström & Johansson Sundler 2012). In the context of emergency care, patient has been shown to perceive HCPs' communication as disconnected and inadequate, which results in dissatisfaction with their care, a struggle to become involved, and not having a clear

[1] This paper contains references from the year of 1867, a historical review for the interested reader.

space for participation in their own care (Frank, Asp & Dahlberg 2009; Mackie, Mitchell & Marshall 2019).

Caring for patients with SVT

Following section are problematized from a Swedish context. The severity of symptoms, such as heart rate frequency and episode duration, and the person's coping with recurrent tachycardia influence the patient's first contact with healthcare. The first contact often occurs via a telephone call to the Swedish Healthcare Direct 1177 [SHD1177] or emergency number 112 (Högstedt 2022). During these dialogues, a first assessment is conducted to direct the patient to appropriate level of care: primary care, home assessment by ambulance personnel with possible self-care advice, or the emergency department when necessary (Högstedt 2022; SOU 2020:19).

In Sweden, healthcare management for patients with arrhythmias varies. Patients with atrial fibrillation often receive structured, nurse-led outpatient care through specialized atrial fibrillation-clinics (Holmlund 2024; Wijtvliet et al. 2020). Patients requiring device-based support, such as pacemakers or implantable defibrillators, are typically managed in hospital-based outpatient clinic led by nurses or biomedical analysts. While structured atrial fibrillation care is being piloted in primary care in an innovation project (personal communication Flimmerskolan), to the PhD candidate's knowledge, no equivalent structured care exists in for patients with recurrent tachycardias such as SVT in either primary or specialist care.

Previous research has shown a lack of knowledge due to patients' experiences of recurrent tachycardias/SVT in a healthcare context, which limits HCPs' ability to provide appropriate care. A literature search of caring for patients with recurrent SVT (excluding atrial fibrillation and atrial flutter) found only a few relevant studies (Withers et al 2015; Wood et al. 2007). Nordblom, Broström, and Fridlund (2017) emphasized the need for research that generates knowledge grounded in the patients' specific needs and concerns. This knowledge could improve the provision of optimal information to the patient as a basis for a reflective dialogue. The risk of a sudden episode of tachycardia and subsequent experiences of symptoms creates uncertainty and limits patients' existence. To support patients in managing uncertainty, it is crucial that they receive forthcoming and practical advice about how to manage and who to contact if episodes persist (Nordblom et al. 2017; Wither et al. 2015; Wood et al. 2007).

Patients in primary care experienced that the level of information and support varied considerably. While some patients reported that their primary care physician were unable to manage their arrhythmia and did not take their symptoms seriously (Withers et al. 2015), others experienced adequate response and felt that they received proper help. While good care is available, patients have reported shortcomings in their encounters with HCPs, particularly before a diagnosis is confirmed. Patients often do not feel as though they are believed during pre-diagnosis due to the lack of obvious symptoms and signs in recording the tachycardia to get a definitive diagnosis. Furthermore, information of tachycardia as harmless is positive but needs to be accompanied by explanations of what the condition entails, what the treatment options are, how to plan for next step if the condition progresses. Otherwise, the information risk being insufficient (Nordblom et al. 2017; Wood et al. 2007).

Following diagnosis, patients felt that they received insufficient information about arrhythmias, which increased their worry (Wither et al. 2015). They suggested that written information would be helpful, including details of support groups, with the intention to strengthening their own self-care abilities. Patients also reported that, where available, arrhythmia nurse specialist were a helpful contact point for information (Withers et al. 2015). Patients referred to the specialist care reported that they received useful information, which made them more confident and reduced their anxiety about what to expect in relation to their condition and caring (Nordblom et al. 2017; Withers et al. 2015).

Medical perspective

In this section, SVT is described as a disease. Disease and illness are separate but related concepts, where illness is the subjective experience, and disease relates to what can be seen or observed (Riggare 2025). People with episodes of tachycardia may experience moments as an individual experiences of being ill. Disease is related to what can be observed and includes a name for the biological dysfunction, categorized as a diagnosis (Svenaeus 2013, 2018; Toombs 2001).

In this thesis, 'acute' refers to an emergency in which a patient with persistent tachycardia/SVT, or at risk of critical circulatory impact, requires prioritized help and short-term treatment from healthcare to stabilize circulation. 'Non-acute' refers to a long-term approach to managing recurrent episodes of SVT, a condition that causes disturbing symptoms that affect the patient's daily life.

Prevalence of SVT

Symptoms of palpitations or tachycardia may indicate a heart arrhythmia as SVT. There are several kinds of SVT, each with a different aetiology and specific profile, including self-care management and treatment options. SVT affects about 0.17-0.20% of the population in the Western world, and its prevalence varies with age, sex, and the presence of other diseases (Go et al. 2018; Orejarena et al. 1998). Physiological SVT originates from part of the cardiac conduction system above the ventricles and the bundle of His. SVT is a generic term for cardiac arrhythmias on an atrial level, such as ectopic atrial tachycardia, atrial flutter, atrial fibrillation, atrioventricular nodal re-entry tachycardia [AVNRT] and atrioventricular re-entry tachycardia [AVRT].

In this thesis, a delimitation was made to the arrhythmias AVNRT and AVRT. These two arrhythmias are similar in terms of the symptoms experienced and are characterized by an abrupt onset and termination (on-off), with recurrent, regular tachycardia episodes that occur unpredictable. The episodes vary in duration, frequency, and intensity at the rate of 130-250 beats per minute and very seldom asymptomatic (Brugada et al. 2019; Lane et al. 2015). AVNRT and AVRT occur in variants together or alone, which are the most common (Brugada et al. 2019). As far as we known, they are remnants from the foetal development, and through re-entry mechanism or extra pathways forms the precondition for impulses that generate palpitations (Brembilla-Perrot et al. 2017; Rivaud, Blok, Jongbloed & Boukens 2021). The age at which the first symptoms occur provides indications of the aetiology. AVRT is a frequent cause of palpitations in younger people (<40 years), and AVNRT can be seen in any age (Boehmer et al. 2021). There are differences between sexes: females have AVNRT twice as often as males (70% vs. 30%), while the opposite is true for AVRT (45% vs. 55%) (Brugada et al. 2019; Musa et al. 2019).

AVNRT and AVRT are currently considered benign, except in rare situations, but this consideration is nuanced. Persistent SVT for days or longer can put strain on the heart and lead to secondary heart failure, tachycardia-induced cardiomyopathy, which is potentially reversible when treated (Martin & Lambiase 2017). It is well-known that atrial flutter and atrial fibrillation cause an increased risk of embolies, especially when untreated. Recent research has shown that SVT is associated with higher prevalence of embolic stroke (Sharma et al. 2019). AVRT can cause pre-excited atrial fibrillation, which can lead to high ventricular rates or ventricular fibrillation; if left untreated, this can lead to cardiac arrest and sudden death (Brugada et al. 2019; Farkowski et al. 2014; Lane et al. 2015). For those with pre-excited AVRT (a combination with atrial fibrillation) who did not undergo catheter ablation, sudden death in 2.4 cases per 1,000 person (DeSimone, Naksuk & Asirvatham 2018).

History of treatment

Through history, people have lived with illnesses, including various problems with their hearts. The traditional history of medicines focuses on physicians and medical science, with new methods, diagnostic techniques, and clinical experiences serving as tools in the fight against illness, suffering, and death (Johannisson 2013). Treatment of tachycardia can be traced back to the 17th century, when vagal manoeuvres, still recommended for self-care, were used to stimulate vagal receptors in the heart to restore its normal rhythm (Jacobs, Bossy & Patel 2018). The introduction of ECGs in 1893 provided objective information about the heart, and they remain an essential part of evaluation for patients with cardiac conditions (Boehmer et al. 2021; Brugada et al. 2019). Objective information gives HCPs measurable signs, such as heart rate or an arrhythmia, that reflect the symptoms patients feel. The therapeutic potential of catheter techniques for treating SVT was recognized in the 1970s (Oral & Morady 2024). Catheter ablation involves creating cardiac lesion in the myocardial tissue to eliminate the source of the arrhythmia and progresses through three stages: thermal injury (via freezing or heating), haemorrhage and inflammation, and fibrosis (Oral & Morady 2024). The first successful catheter ablation was performed in 1981, significantly improving the patient's quality of life. In Sweden, Sahlgrenska University Hospital in Gothenburg pioneered electrophysiological study and catheter ablation in 1991. As the time of writing, the treatment is available in 11 specialized national clinics (Sigurjónsdóttir 2023). Electrophysiological study, typically performed under local anaesthesia, are invasive diagnostic procedures and often precede catheter ablation during the same session (Brugada et al. 2019; Lane et al. 2015).

Treatment options

International guidelines direct HCP's in how to manage patients with symptoms from recurrent tachycardia/SVT (Brugada et al. 2019). These guidelines have algorithms for the assessment, including effective, safe, and curable treatments for SVT as AVNRT and AVRT. The anamnesis the patient gives, itself is characterized by and indicative of AVNRT and AVRT, even without tachycardia documented by ECG or other types of heart rhythm supervision. Arrhythmia diagnosis is based on documentation of the tachycardia on ECG but is sometimes inconclusive or unable to capture an episode of tachycardia due to the unpredictable nature (Brugada et al. 2019). The 12-lead ECG is a non-invasive method, but it may provide a diagnostic challenge for specialist with limited experience due to the critical knowledge required for ECG interpretation (Boehmer et al. 2021; Schläpfer & Wellens 2017).

Under *non-acute* circumstances, patients with arrhythmias such as AVNRT and AVRT needs access to clear information to make informed decisions about treatment and its

impact on symptoms and quality of life may change following these treatments (Boehmer et al. 2021; Brugada et al. 2019; Lane et al. 2015). For patients with specific arrhythmias as AVNRT and AVRT, the main goal of treatment is to decrease symptoms and improve health and quality of life. Treatment typically follows a stepwise approach: (1) Self-care-related management (e.g., Valsalva manoeuvre[2]) can be initiated independently or with guidance from HCPs at any level of healthcare (Appelboam et al. 2015; Brugada et al. 2019); (2) pharmacological treatment aims to reduce the frequency and duration of SVT episodes (Brugada et al. 2019); and (3) catheter ablation, is considered a first-line curative option for AVNRT/AVRT when symptoms are frequent or prolonged, or medication is poorly tolerated (Brugada et al. 2019; Oral & Morady 2024).

In *acute* cases, stabilization is prioritized (Brugada et al. 2019; Lane et al. 2015). If blood pressure is adequate, intravenous medication may be used to restore the rhythm. In more severe cases, such as those with low blood pressure or pre-excited SVT, electrical cardioversion is required in settings with cardiology and anaesthetic expertise (Boehmer et al. 2021; DeSimone et al. 2018). While acute interventions are effective and standardized (Brugada et al. 2019), they offer only temporary relief. From a patient perspective, being helped in an acute situation is essential and brings a rapid and immediate improvement in health. However, when the patient returns home, the underlying cause of the tachycardia remains. Long-term management requires coordinated care across healthcare levels, emphasizing accessibility and timely transitions between different primary and specialist cardiac care (SOU 2020:19).

The background provides the context for this thesis, which aims to describe the complexity of living with and getting help for recurrent tachycardia/SVT. The next chapter presents the theoretical perspectives and concepts of the research area through the literature.

[2]Valsalva maneuvers i.e. bending one's head down, inhaling deeply, putting cold water on one's face, clearing one's throat, coughing, or straining at an early stage can interrupt the SVT.

Theoretical perspectives and concept

This thesis, situated within caring science as an academic discipline, takes its scientific and theoretical point of departure in human lived experience, where the patient's perspective is central to the investigation of health, suffering, and well-being. To deepen the understanding of what it is like to live with and seek care for recurrent tachycardia/SVT, a lifeworld perspective grounded in phenomenological philosophy has been applied. Phenomenology encompasses several foundational concepts and theoretical assumptions that are valuable for understanding the humans and their relationship to the world, including intentionality, the lived body, and the intersubjectivity of consciousness. The following section presents the lifeworld as a theoretical foundation, followed by discussions on the lived body and caring. The concepts of health, well-being, and suffering will also be explored.

Lifeworld as a theoretical foundation

Lived experiences, understood from a lifeworld perspective, are grounded in modern phenomenology by Husserl (1929/1977, 1939/1973). Edmund Husserl (1859–1938), claimed that the development of scientific objectivity had created a profound separation between science and the lived experience, turning science into a theoretical construct detached from daily life. As a response, human science emerged to reconnect with the subjective, lived world, what Husserl called the lifeworld, and this perspective became central to phenomenology (Husserl 1929/1977).

Ontology and Human Existence

Lifeworld as ontology offers a philosophical understanding of human existence grounded in lived experience (Husserl 1939/1973). Ontology can be understood as the science of being in general, answering questions of 'what,' such as 'What is a human' and 'What is existence' and their meaning (Dahlberg, Dahlberg & Nyström 2008). The lifeworld is subjective and individual, constituting the prerequisite for and source of all experiences throughout human existence (Husserl 1929/1977). The focus is not on the subject or object but on the relationship or 'in the-between' them–how the subject experience the object in the world. Heidegger further developed the theory of lifeworld by providing a scientific model to describe and interpret the existential world inhabited by all humans (Heidegger 1926/1962). Through birth, human beings exist within the lifeworld, where experiences are shaped by cultural and historical traditions, forming the

basis for understanding themselves and the world (Heidegger 1926/1962; Husserl 1939/1973). Human beings are not responsible for the fact that they live; instead, they have responsibility for how they live (Heidegger 1926/1962). Merleau-Ponty (1945/2023) further developed the theory of the lifeworld, emphasizing that humans access and relate to the world through their lived body, as discussed later in this section. Central to Merleau-Ponty's philosophy is the concept of *reversibility*, which emphasizes the intertwining of the individual and the surrounding reality. From an ontological perspective, the human being is whole and inseparable, simultaneously subject and object, especially in bodily experiences (Merleau-Ponty 1945/2023). This means that, while the body can be examined and studied, for example, through an ECG, the findings must be understood in relation to the person who lives with the illness, including how they deal with the impact of recurrent tachycardia/SVT.

Epistemology and Meaning-Making

Epistemology is the science of knowledge, answering questions of 'how,' for example 'How can science describe the lifeworld' and 'How is scientifically valid knowledge possible' (Dahlberg et al. 2008). In phenomenological research, phenomena are studied not as pure objects but as 'things' with meaning. According to Husserl (1929/1977), it is people's experiences that give things their meaning. The concept of *intentionality* means how the person perceives and understands the world as something, and that consciousness is always directed towards something (objects, events) that has meaning. All aspects of life involve an intertwining of subjective and objective meanings. Intentionality is linked to *natural attitude,* which can be understood as how the world presents itself as simply there, given to us in ordinary experiences and available in a state of unconsciousness. In everyday life, individuals unreflectively take themselves and their life for granted. This is referred to as the natural attitude, which frames how experiences are encountered in daily life (Dahlberg et al. 2008; Sundler, Lindberg, Nilsson & Palmér 2019). Within our natural attitude, lived experiences are not constantly analyzed, which makes an awareness of the natural attitude important in phenomenology (Sundler et al. 2019).

Lived body

In the context of caring science and the aim of this thesis, the concept of the lived body offers a crucial view for understanding the existential and embodied dimensions of living with recurrent tachycardia/SVT. Merleau-Ponty's (1945/2023) philosophy challenges the biomedical view of the body as merely a biological entity, instead presenting it as the very condition for experiencing and engaging with the world. The body is not something one has, but something one is–a lived, subjective whole through which meaning is created (Merleau-Ponty 1945/2023).

For individuals living with recurrent tachycardia/SVT, this embodied existence is disrupted. The condition brings sudden and unpredictable bodily sensations, such as palpitations, dizziness, and uncertainty about one's own future, which intrude upon the tacit certainty of health (Carel 2021; Gadamer 1996). These episodes can evoke a sense of *homelessness* in one's own body, where the body no longer feels familiar and trustworthy. This loss of stability (Gadamer 1996) challenges the individual's existential basis and alters their access to life and the world (Dahlberg et al. 2008). From a lifeworld perspective, such disruptions are not merely physiological events but deeply individual experiences that affect the whole person. The lived body becomes a site of vulnerability where the individual must navigate between moments of control and loss, and familiarity and alienation. This movement reflects Gadamer's notion of health as silent (Gadamer 1996), only noticed in its absence, and highlights how illness makes the body visible in a new way, often distressing way. Furthermore, the lived body provides access to both personal and shared experiences. In caring encounters, acknowledging the patient as a lived body means recognizing the existential meaning embedded in their symptoms, fears, and coping strategies. It calls for a caring approach that is sensitive to the patient's embodied reality, where clinical interventions (e.g., ECGs, medication) must be understood in relation to the person's lived experience of recurrent tachycardia/SVT.

Caring

Caring science, as a discipline, explores human existence in relation to health, suffering, and care. It highlights the patient's perspective and acknowledges them as an expert in their own life situation and well-being (Arman et al. 2022). Intersubjectivity forms the foundation of caring, where the interactions between the patient and HCP centre on supporting growth, health, and well-being (Dahlberg et al. 2008). According to Husserl (1929/1977), intersubjectivity is the conscious interchange between two people's dialogue of thoughts and feelings, as facilitated by empathy. Intersubjectivity refers to how we understand, communicate (dialogue), and connect with each other (to be present). Further, the intertwining between the individual person and the surrounding (social) reality understood as the person's impact of the reality. Merleau-Ponty (1945/2023) described intersubjectivity as the relation between two living bodies as a subject and an object. Another person's lifeworld can be recognized to some extent but never fully understood (Palmér, Nyström & Karlsson 2023). When understanding the meaning of lived experiences, it is essential to consider the lifeworld, bodily existence in the world, and how we interact with others (Sundler et al. 2019).

Caring dialogues means having an openness to gain insight into the other person's lifeworld, how life, health, illness, and caring appear for the person in question (Ekebergh & Lindberg 2020; Hörberg 2020). It is in the meeting between HCPs and the patients that caring is expressed, where the unique patient has valuable knowledge about

themselves and their own needs, expectations, and preferences (Dahlberg & Segesten 2010). Dahlberg, Todres, and Galvin (2009) argued that current patient-led approaches, centred on consumerism and pursuit of choice, can obscure a deeper understanding of what person-led care could entails. This focus risks diverting attention away from patients' lived experiences, well-being, and suffering, including the existential dimensions of care. As an alternative, they presented a model of lifeworld-led care that encompasses three key dimensions: a philosophy of the person, a view of well-being beyond illness, and a philosophy of care aligned with these principles. This approach repositions patient not as consumers competing for services, but as individuals with rich, storied lives who seek expert support when needed (Dahlberg et al. 2009).

Within caring science, there is an ethical requirement to provide 'the best possible care', which requires interpretation of the situated context and a sensitive approach to the patient's perspective (Dahlberg & Segesten 2010). Lifeworld-orientated ethics are grounded in the patient's narrative as a basis for dialogue about health and life situations (Arman et al. 2022). However, research shows that this ideal is often challenged in practice, particularly in episodic conditions as SVT, where the patient's lived experience risks being overlooked. Therefore, this thesis takes the patient's perspective as a starting point for developing care. To understand and develop caring in the context of recurrent tachycardia/SVT, it is essential to consider how relationships are formed in care. From a lifeworld perspective, the distinction between an *encounter* and an *interaction* is central. While encounters may be brief and lack depth, interactions involve mutual engagement and responsiveness, better addressing patients' needs (Kwame & Petrucka 2021). Caring dialogues require intentionality and a reflective attitude, enabling HCPs to support the patients through empathy, trust and meaningful participation, key aspects of understanding what it is like to live with and seek for recurrent tachycardia/SVT. To explore how caring can be developed in relation to patients living with this condition, this thesis draws on lifeworld-led care, grounded in phenomenological philosophy (Dahlberg et al. 2009). This approach emphasizes human existence as dynamic and vulnerable, acknowledging both agency and openness to change. In practice, it means being present to the patient's lifeworld, listening to narratives, embracing uncertainty, and allowing oneself to be affected. Such responsiveness supports ethically grounded care and enables meaningful patient participation, aligning with the aim to understand and improve caring from the patient's perspective.

Health, well-being, and suffering

In this thesis, health, well-being, and suffering are understood as existential dimensions of human life, central to the patient's lived experience of recurrent tachycardia/SVT. Health is not merely defined by the absence of illness but as a dynamic and multifaceted state that reflects the individual's ability to maintain life balance, engage in meaningful life projects, and experience vitality (Dahlberg & Segesten 2010; Arman et al. 2022). From a lifeworld perspective, health is shaped by how individuals perceive and relate to their everyday existence, and is always situated in time, context and personal meaning (Galvin & Todres 2013).

Well-being, closely intertwined with health, refers to what matters to the person and includes existential aspects such as freedom, vulnerability, and the capacity to find peace and movement in life (Dahlberg et al. 2009). It is not a static condition but a possibility that emerges through lived experience. In the context of recurrent tachycardia/SVT, well-being may be challenged by unpredictability, fear, and limitations in life, yet it may also be supported through caring interactions that confirm the patient's lifeworld. Suffering, as a counterpart to well-being, is an inevitable part of human existence. When suffering arises from illness, it disrupts the person's sense of self, dignity, and continuity in life (Arman et al. 2022). Suffering is not only biological, such as warning signal (e.g., pain), but also existential, related to loss, insecurity, and the inability to live as before. For patients with an episodic condition as SVT, suffering may be intensified by episodic symptoms, uncertainty, and lack of recognition in care.

Moreover, suffering can be caused by care itself, which Eriksson (1994, 2018) termed 'care-suffering'. This occurs when patients feel unheard, unseen, or disrespected, especially in situations where help is repeatedly sought but not received. In such cases, the absence of responsive and ethically grounded care adds a layer of suffering that is avoidable and deeply impactful (Berglund et al. 2012; Dahlberg 2002). Understanding health, well-being, and suffering from a lifeworld perspective is essential to this study's aim: to describe how it is to live, with and being cared for, recurrent supraventricular tachycardia. It highlights the need for care that is attuned to the patient's existential reality, where the body as both lived and examined are considered, and where suffering is not ignored nor reduced but met with openness, presence, and respect.

Rationale

Recurrent tachycardia/SVT is a prevalent cardiac condition that can significantly disrupt daily life and deeply affect individuals' experiences of health and well-being. When experiences of the condition are hard to manage on their own, people turn to healthcare with the expectation of receiving help. Despite the episodic nature of the tachycardia, the condition remains elusive in clinical settings, often leading to patients' experiences of being dismissed or misunderstood when seeking care. Previous research highlights a troubling pattern: patients' report that their concern is not adequately acknowledged, and the effects of SVT on their everyday lives are overlooked. The unpredictable and episodic nature of the condition contributes to repeated healthcare visits for the same symptom. These frequent visits may, in turn, affect patients' trust in healthcare and contribute to increased suffering. Simultaneously, HCPs face challenges in diagnosing and managing SVT, including difficulties in interpreting ECGs and providing proper treatment. These clinical uncertainties can result in inefficient resource use and inconsistent care.

From a caring science perspective, care grounded in the patient's lived experiences is essential for promoting health, and well-being and alleviating suffering. However, scientific knowledge about the patient's perspective of living with and receiving care for recurrent tachycardia/SVT is insufficiently explored. This gap contributes to HCPs' uncertainty and limits the development of responsive, equitable, and sustainable care strategies. The care provided to patients with an episodic condition as SVT requires urgent development to meet both clinical and existential needs.

Despite the conditions prevalence and its significant impact on daily life, current care practices often lack a structured and person-centred approach. In this context, it is essential to make the patient perspective visible and to actively involve patients in the co-creation of innovative care models. The absence of patient participation in care development risks maintaining a system that fails to address the lived realities of those affected by SVT. Without integrating patients' experiences, values, and preferences, care risks becoming fragmented, inequitable, and unsustainable. Moreover, the lack of standardized management pathways contributes to inconsistencies in care delivery, which may undermine both patient trust and healthcare efficiency.

From a caring science perspective, sustainable care must be grounded in both the patient's lifeworld and the healthcare system's capacity to respond meaningfully. This dual perspective highlights the need for a care model that is not only clinically effective but also empathetic, inclusive, and resource conscious. Addressing this gap requires a shift toward participatory care development, in which patients are recognized as co-creators of knowledge and practice.

This thesis seeks to problematize the current state of recurrent tachycardia/SVT care by emphasizing the need for more responsive and sustainable approach, one that integrates the patient perspective into the design of future care strategies. Through a lifeworld-oriented view, the research aims to contribute to the development of care that is both ethically grounded and practically viable.

Aim

The overall aim of this thesis is to describe how it is to live, with and being cared for, recurrent supraventricular tachycardia, with emphasis on the patient perspective and how to develop the care given.

Specific aims of the studies were:

I. To explore healthcare utilization for outpatients with episodes of tachycardia visiting healthcare centres and/or emergency departments

II. To describe the phenomenon catheter ablation as experienced by patients who were treated while awake

III. To describe patient participation in healthcare as experienced by patients with supraventricular tachycardia

IV. To describe how areas for improvement in the care of patients with supraventricular tachycardia can be identified and prioritized using the experience-based co-design approach[3]

[3] Experience-based co-design (EBCD) will be further presented and discussed in the section methods.

Methods

The following section outlines the methodological foundation of the study. It begins with a presentation of the research approach and establishes the epistemological and theoretical underpinnings that guide the inquiry. This is followed by a description of the design and methodological approach, detailing how the study was structured to address its aim and research questions. Finally, the section concludes with an overview of the data collection and analysis procedures, highlighting the strategies employed to ensure methodological rigor and trustworthiness.

Research approach

In this thesis, an overall inductive approach is applied with the intention of generating new knowledge based on empirical research in the care of patients with recurrent tachycardia/SVT. Emphasis is placed on the patient's perspective and the improvement of caring practices that respond to their lived experiences. An inductive approach is useful for a research area with limited research from a patient perspective, such as this one.

The four studies draw on two distinct scientific traditions: phenomenology and positivism. Although these traditions differ fundamentally in their epistemological foundations, they both refer to the same phenomenon, the human being, and together offer a coherent understanding of the world. Each tradition contributes unique strengths and limitations (Flanagan & Beck 2025), and their integration provides valuable insights into the phenomenon of recurrent tachycardia/SVT.

The phenomenological approach focuses on lived experiences, with an intention to understand meaning from the first-person perspective rather than provide explanations. In parallel, quantitative methods enabled the identification of descriptive and comparable patterns in the healthcare system at an aggregating level. By combining both qualitative or quantitative characteristics of the phenomenon of interest, this thesis offering a relating perspective: the depth of individual experience and the breadth of healthcare system-level patterns. The phenomenon in question is the experience of living with and seeking care for recurrent tachycardia/SVT. The inductive approach enables openness and flexibility in the research process, allowing the phenomenon to guide methodological choices. This justifies the selection of a lifeworld-orientated theoretical framework, which is central to the thesis.

To follow the phenomenon

Based on the findings of an earlier study (Nordblom et al. 2017), new questions emerged regarding the patient's healthcare journey before, during, and after catheter ablation for tachycardia/SVT. The study highlighted patients' struggles to access appropriate care and described how the unpredictable nature of SVT episodes disrupted daily life and well-being. Despite the availability of effective treatment, many patients reported long delays in receiving a diagnosis or referral. One key question that arose was: How common is it for patients with recurrent tachycardia/SVT to seek unplanned care in primary healthcare and emergency departments? This question became the starting point for Study I, which aimed to quantify healthcare utilization and identify patterns in care-seeking behavior, assessing whether this represents an isolated phenomenon or a common reason for unplanned visits to primary care and/or emergency departments.

The findings from Study I, revealed disparities in access to care and referral practices, which motivated further exploration of the patient experience. Despite existing knowledge of catheter ablation as a treatment for arrhythmias, the patient perspective remains unexplored. Therefore, it was important to include patients with experiences of being treated for recurrent tachycardia/SVT (II). Although existing research has described the procedure as painful and stressful, this perception was not reflected in clinical practice. This study became important due to the need of updated, nuanced, and experience-based knowledge from the patient's perspective in treatment. This study had a distinct temporal focus, spanning from the moment patients were informed about the procedure of catheter ablation until the period following the ablation. The patients' narratives in Study II clearly revealed a lack of involvement in their own care. This absence highlighted participation as a vital aspect of the healthcare experience, making it a coherent and meaningful focus to pursue in the following study. Study III focused on the experiences of patient participation when seeking help and receiving care for this episodic condition. It was evident when the patients share their experiences of encounters with healthcare; some of them had done this repeatedly for years and reported that their concerns had not been acknowledged. Building on the findings from Studies I-III, which explored healthcare utilization, patient experiences of catheter ablation, and participation in care, Study IV represents a logical and necessary step toward improving clinical practice. While the earlier studies highlighted the challenges and existential dimensions of living with recurrent tachycardia/SVT, they also revealed gaps in continuity, communication, and patient involvement across healthcare levels. Study IV was designed to translate the insights from Studies I–III into actionable change through participatory methodology, experience-based co-design [EBCD]. By engaging both patients and HCPs in a collaborative process, the study aimed to co-create improvements grounded in lived experience and responsiveness to real-world clinical contexts. This progression from descriptive and phenomenological understanding to participatory

developments reflects a methodological movement and supports the thesis's overarching aim: to describe how it is to live, with and be cared for, recurrent SVT, with emphasis on the patient perspective and how to develop the care given. EBCD thus serves as a bridge between research and the practice, ensuring that the knowledge generated is not only theoretically robust but also clinically relevant and ethically grounded.

Design and methodological approach

The current thesis consists of four studies to answer the overall aim, and they are based on diverse designs and methods for data collection and analysis (Table 1.).

Table 1. Overview of the study design.

Study design	Aim	Sample	Data collection	Data analysis
I Descriptive and comparative	To explore healthcare utilization for outpatients with episodes of tachycardia visiting healthcare centers and/or emergency departments	2 373 patients	Registry and medical records, i.e., retrospective data	Descriptive and comparative statistics
II Descriptive	To describe the phenomenon catheter ablation as experienced by patients were treated while awake	12 patients	Lifeworld-interviews	Reflective Lifeworld Analysis
III Descriptive	To describe patient participation in healthcare as experienced by patients with supraventricular tachycardia	17 patients (from study II + supplementary interviews)	Lifeworld-interviews	Reflective Lifeworld Analysis
IV Descriptive	To describe how areas for improvement in the care of patients with supraventricular tachycardia can be identified and prioritized using the experience-based co-design approach	4 patients in 2 workshops, 7 healthcare providers in a 5-day process for improvement	Individual qualitative interviews, workshops and SIPOC-process	Reflexive Thematic Analysis with a lifeworld approach

The epistemological stance guiding this thesis is grounded in a phenomenological approach, with the purpose of understanding the lived experience of patients with recurrent tachycardia/SVT and how they manage their symptoms, navigate care, and

find meaning in their health journey, which informed the methodological choices. The different studies contribute descriptions from various stages of the care process with approaches that follow the phenomenon. First, they highlight care-seeking patterns in outpatient settings at an aggregating level, providing a broader, more generalizable view of the patient journey. Second, on an individual level, they provide insights from patients regarding their participation in healthcare and their experiences during catheter ablation treatment. Finally, they offer descriptions of the development of supportive interventions for patients seeking care for recurrent tachycardia/SVT.

Study I is based on empirical data and prioritize generalizable patterns over individual variation (Flanagan & Beck 2025). Originating with August Comte in the 19th century, the positivistic tradition assumes that reality is objective and exists independently of human perceptions or social context. This approach advocates for the application of scientific methods that can be understood independently of subjective interpretation (Crotty 2015). However, it also acknowledges that that each data point represents a person with a lived experience of the phenomenon, reminding us that statistical patterns must be interpreted with sensitivity to the human stories behind them.

Qualitative research embraces complex existential and social contexts, focusing on health, well-being, and individuals' capacity to pursue life projects despite illness (Dahlberg et al. 2008). Studies II and III applied a descriptive design using the reflective lifeworld research [RLR] approach, characterized by its focus on meaning and its orientation toward phenomena being awake during treatment with catheter ablation (II) and patient participation in care (III).

Methodological Approach: Reflective Lifeworld Research

Methodology is the scientific method used to answer questions such as 'how', 'In what way can we openly describe human lifeworld and human phenomena?' Based on phenomenological philosophy and a lifeworld-theoretical foundation, Dahlberg, Dahlberg and Nyström (2008) developed the RLR approach. The overarching aim of this methodology is to describe and clarify lived experience in a way that deepens understanding of human existence and experiential meaning. Central concepts in this approach include the lifeworld, the lived body, intentionality, and reversibility. A fundamental methodological principle is the phenomenological attitude, characterized by openness and bridling, meaning a reflective stance that questions pre-understanding and allows the phenomenon to reveal itself (Dahlberg et al. 2008).

To examine and describe the experience of living with recurrent tachycardia/SVT, seeking healthcare, and undergoing treatment, it was essential to turn to those who had lived these experiences. This approach aligns with the principles of phenomenology (Dahlberg et al. 2008). Through lifeworld interviews, Studies II and III aimed to describe

the reality and subjectivity experiences shaped by context (Finlay 2011). The intention was to understand the meaning of lived experiences from the first-person perspective, as participants can explain their experiences in their own word, which helps correcting the researcher´s potential misunderstanding. By analyzing and describing the essential meanings of the phenomenon, these studies sought a deepened understanding in relation to its specific context (Dahlberg 2006a). Dahlberg (2006a) argues that essences belong to the lifeworld and exists within the intentional relationship between the phenomenon and the human being. To perceive and understand the meaning that phenomena carry, openness to what presents itself is necessary.

Study IV applied a descriptive design using a participatory method based on EBCD (Bate & Robert 2006), which emphasizes collaboration between engaged patients and HCPs to improve healthcare services. The study consisted of two main phases, inspired by Twamley (2020): two Workshops with patients and a five-days development process with HCPs from specialist care. The data generated from these phases were analyzed using reflexive thematic analysis. The choice of reflexive thematic analysis was motivated based by the nature of the phenomenon under study and the suitability of the data for thematization rather than constructing an essence (Sundler et al. 2019). While this approach does not examine the lifeworld phenomena in the same depth as RLR (used in Studies II and III), it aligns with the phenomenological orientation of the thesis by maintaining a focus on meaning and lived experiences. Reflexive thematic analysis enabled a broader exploration of the participants' narratives, particularly in a collaborative context involving both patients and HCPs. This method was well-suited to the EBCD framework, allowing for the identification of patterns and themes that could inform practical improvements in care while still respecting the subjective and experimental dimensions of the data.

Methodological Approach: EBCD

The EBCD process aims to identify areas of care provision that require improvement through collaboration between individuals with experience of a specific condition and HCPs (Bate & Robert 2006; Robert 2013). While the EBCD approach is flexible, its core components include the collection of service user experience data and a joint event involving both service users and providers (Green et al. 2020). In Study IV, only two of three intended phases were completed. The final phase, an event bringing together service users and providers, was not conducted. These changes were carefully reflected upon, and Study IV is therefore considered a first step in a broader process. It offers valuable insights and lays the groundwork for a follow-up study, ideally conducted in a primary care context where patient interactions are central.

The *phenomenological method* used in Studies II, III and IV is guided by three interrelated principles: openness, questioning pre-understanding, and adopting a

reflective attitude. With lived experiences in focus, *openness* involves a curious and sensitive stance toward the lifeworld and the phenomenon, requiring the researcher to be observant and attentive to how experiences are expressed (Dahlberg et al. 2008). Pre-understanding is shaped by our lived experiences and traditions (Gadamer 1996) and includes assumptions that can obscure new insights. Genuine understanding requires to restrain our pre-understanding and remain open to 'the other', the *otherness*, meeting what is unfamiliar without immediately reducing it to what is already known, which can be understood as adopting what Dahlberg et al. (2008) describes as bridled attitude. To *questioning the pre-understanding* means reflecting on one´s own beliefs and assumptions to become aware of natural attitudes and deepen understanding (Dahlberg & Dahlberg 2003). This attitude involves a shift from the everyday, taken-for-granted way of seeing the world to a more reflective and open way of engaging with the phenomenon. The goal is to understand phenomena as they are lived, experienced by the individual, without assumptions or judgements. A *reflective attitude* helps researchers shift from everyday life understanding to a more critical and open stance with the data, questioning how meanings arise and ensuring they are grounded in the participants' experience (Dahlberg et al. 2008).

Bridled understanding in the research

Through self-reflection and awareness, the PhD candidate's cultivate sensitivity to experience in a bridled understanding, allowing fresh meanings to appear from familiar data (Dahlberg et al. 2008). This paragraph provides an informal description of my ways of adapting to the methodological principles in the studies.

My own *personal* experience of recurrent tachycardia consists of short, non-persistent tachycardia with fluttering in the neck, appearing infrequently for as far as I can remember. Vagal maneuvers have helped me every time so far, so it has never become an issue, except for managing thoughts about the tachycardia becoming persistent. This experience may be seen as an advantage for understanding the phenomenon at hand, provided it is bridled; on the other side, it may have an unreflected-upon impact on my understanding of living with the condition. My understanding of the *patient perspective* mainly derives from my clinical experience as a registered nurse in a cardiology department, working with adult patients from varied backgrounds. Before the EP-lab opening in Skaraborg Hospital of Skövde in 2010, patients with SVT were rarely admitted; they were typically treated in the emergency department and discharged. Consequently, my first insight into this patient group, especially those with SVT, was largely theoretical.

To manage my pre-understanding during the research process, I needed to practice a *phenomenological attitude*. The phenomenological attitude in RLR encourages openness to meaning, helping researchers avoid defining what is indefinite in a lived experience, a phenomenon in relation to the lifeworld (Dahlberg et al. 2008). I needed to be aware of my *natural attitude,* which can be questioned through reflective self-dialogue, to critically examine my own feelings and experiences, to slow down the process of understanding, and to bridle (Dahlberg et al. 2008). By adopting and having a reflective attitude, it was possible to go beyond unexamined assumptions, opening the way to new insights and deeper knowledge (Berglund & Ekebergh 2025).

During the analysis in Study II, my perspective was shaped by my professional role as a nurse in the EP-lab, my natural position. I focused on interpreting the events in the room and the meaning behind the HCPs' communication during the procedure. This became an obstacle between my process of understanding and the phenomenon, not having an openness to the individual patient's lived experience. Therefore, I took a step back and restarted the analysis with the patient perspective in focus, approaching the phenomenon with curiosity and sensitivity. This process was repeated several times and was facilitated by critical reflective dialogues with my supervisors and peers.

During Study III, I made a conscious effort to remain open to patients' described experiences of participation in their own care, especially when they spoke of non-participation. Their reflections offered profound insights into what it means to be involved in care, and many described a lingering sadness over lost time and missed opportunities for quality time. These accounts affected me deeply. As a PhD candidate, I had to navigate my own emotional responses while also acknowledging my position as a representative of the healthcare system. This dual role required careful reflection to ensure that I could humbly and respectfully share their experiences without overshadowing them.

Study IV marked a turning point in my approach to research, introducing a collaborative stance that involved patients and HCPs as active partners. Although I began my PhD studies as a novice researcher, I had already gained experiences through individual lifeworld interviews in Studies II and III, as well as a facilitator in group interviews in other research projects. My background as a registered nurse provided me with both practical and theoretical insights into hospital care, although my experience with primary care and general healthcare was initially limited. During the EBCD workshops, many reflections focused on the interaction between general healthcare and specialist care. These discussions challenged my assumptions about the distinctions between different level of healthcare. Gradually, I came to realize that the core of healthcare is the patients, and regardless of the setting, the patient's needs remain central. The patients had the whole picture of the process, while HCPs saw only occasional part. This realization

helped me move beyond rigid boundaries and embrace a more integrated, patient-centered approach, where the patient's need guide the care, regardless of the setting.

My bridled understanding to this specific research area and the patient perspective has been a long journey, like a huge puzzle where every piece of the puzzle is an insight and the beginning of new knowledge. It is a process that continues to progress, driven by curiosity, reflections, and an open mind.

Data collection and analysis

Data collection for Studies I-IV was conducted between January 2020 and September 2025. The PhD candidate's of this thesis conducted all data collection.

Study I

Study I employed a quantitative design using retrospective registry data. Data from a 24-months period (2017-2018) were analyzed to examine differences in healthcare utilization based on sex and age, as well as to compare pattern between groups. A hypothesis was tested, proposing that no differences in search patterns existed between the sexes at healthcare facilities.

Sample selection

This study was conducted in southwestern Sweden, with an approximate population size of 214,000 inhabitants aged ≥18 years (50,5% male) (Statistics Sweden 2017). A period of 24 months was selected in collaboration with hospital statisticians in the research and development center at Skaraborg Hospital, Sweden. The benchmark for the period was based on previous years' reported visits to the emergency department by the patient group. At the time of the study, this area had two county hospitals with emergency departments and 15 communities, each with one or several healthcare centers. The inclusions criteria specified outpatients aged ≥18 years who were diagnosed by a physician as having a specific or nonspecific arrhythmia with at least one of the selected ICD-10-SE codes, described in the next section.

The selection process of ICD-10-SE codes

The study included both undiagnosed patients and those with confirmed diagnosis. To identify outpatients with clinical presentations of arrhythmia in medical records and the primary care register 'VEGA', a selection of ICD-10-SE codes was used (WHO 2011). The process of selecting ICD-10-SE codes was conducted in collaborating with a medical secretary in the cardiological department and the hospital statisticians and checked with a specialist in cardiology (electrophysiologist). The PhD candidate's first initial selection expanded in dialogue with the medical secretary, and the sample included codes of symptom and signs related to heart arrhythmia, in categories of non-specific (R-codes) or specific diagnosis (I-codes): R000 'Tachycardia unspecific', R002 'Palpitations', I471 'Paroxysmal supraventricular tachycardia', I479 'Paroxysmal tachycardia, unspecific', I498 'Other specific heart-arrhythmia', I499 'Heart-arrhythmia, unspecific'. For patients visiting the emergency department, another ICD-10-SE code if interest was found: U999 'Diagnostic information is missing'. The high frequency of heart-related interventions and subsequent hospitalizations for further investigation formed the basis for interest in this final code.

Data collection

Data collection was conducted at an aggregated level, including data from the medical journal and registry. Encrypted aggregated data from the primary healthcare register 'VEGA' was sealed with a special code for access and only valid for a limited time (three months). Patients were identified using their identification number, duplicates were removed (e.g., visits that were registered more than once the same date and healthcare facility), and then data were anonymized without compromising the scientific integrity, with information retained about age, sex, and ICD-10-SE code. Authorization for withdrawal of ECG was obtained from the hospital lawyer for 100 individual ECGs, with the intention to evaluating the assessment of the ECG and the diagnosis by the physician in the emergency department.

Validation of heart-rhythm

From the study population, a smaller stratified random sampling was conducted to estimate the incidence of missed arrhythmias (diagnoses) in relation to the ECG assessment. The decision on the size of the subsample was based on the accuracy of the sample, which was decided based on 95% confidence intervals[4] (CIs). A representative distribution across age groups and sex was determined using a random generator in the Excel software program (Microsoft, Office 365 version). This stratified random sample included 100 patients admitted to the emergency department with unspecific ICD-10-SE codes (R000, R002 and U999). The intention of the analysis was to find arrhythmia as AVNRT or AVRT (ICD-10-SE codes: I45.6A and I47.1, respectively). Each ECG was

[4] The CI gives the range of values within which a population parameter is likely to lie at specified probability (Flanagan & Beck 2025).

anonymized, having tasks about gender, age, and the physicians' assessment (with ICD-code). To interpret the ECG, an algorithm was used and then confirmed by a specialist in cardiology (electrophysiologist).

Data analysis

Descriptive and comparative statistics were used to analyze retrospective data (from journals and registries) to identify patterns of care-seeking behavior and differences within the patient population. Descriptive statistics were applied to summarize and describe the main characteristics of the dataset, which included both categorical (qualitative) and numerical (quantitative) variables (Flanagan & Beck 2025). The key methods were measures of central tendency (mean, median, and mode) and measures of variability (standard deviation and range). These measures help to understand the distribution of variables and can be illustrated with histograms (not presented in this article).

This analysis was conducted on aggregated data, and descriptive statistics were used to assess the patients' visits, stratified by sex, frequency, and level of care (healthcare centers and emergency department) using mean values and 95% CIs. Comparative statistics were used to test hypotheses, such as an assumption about the relationship between categories (in this study, sexes), and to compare groups and subgroups within the population. Key methods included analysis of variance (ANOVA) for comparing means between groups, chi-square tests for comparing categorial variables, and the use of confidence intervals and *p*-values to assess statistical significance (Flanagan & Beck 2025).

To show difference between sexes, the population was divided into 10-year age groups (Flanagan & Beck 2025). To find the statistical significance of differences, an ANOVA was used, for example, to compare differences in means of three or several groups or samples. The incidence of arrhythmias was included as one factor, as the number of unique patients per 10,000 inhabitants, and one-factor ANOVA was used. For variables that were not normally distributed, the non-parametric Mann-Whitney U test was used. The chi-square test was used to compare categorical variables and find differences between sex, age, and search term of patterns for each healthcare facility as well as the proportions. A p value < .05 was considered statistically significant. Statistical analysis was performed using SPSS/WIN v24.0 software.

The purpose of these analyses was to identify differences and patterns between groups. More advanced statistical methods, which can be used to evaluate treatment outcomes and support evidence-based practice and clinical guidelines, were not used in this thesis.

Analysis of assessed ECGs

In the entire population there was a high number of visits (n = 2424) classified with the unspecific symptom codes R000, R002, and U999. The cases attending the emergency department (n = 392) consisted of 366 unique patients. A random sample was collected from this group of patients' medical records, consisting of ECGs distributed into four groups stratified by sex (female and men) and age (18–65 years and ≥66 years). Additionally, biometric data from a stratified sample (n = 100) were analyses to assess physicians' evaluation of heart rhythm based on ECG readings.

Study II and III

These studies aimed to add nuance to the existing body of knowledge and were conducted with an open and reflective attitude throughout the research project (planning, organizing, and analyzing data). Reflective lifeworld interviews were conducted to capture patients' experiences and increase understanding of the phenomenon (Dahlberg et al. 2008). In Studies II and III, participants were recruited from one specialist clinic that receives referrals from several regional hospitals, ensuring a broad representation. When preparing for the interview, the participant was given the opportunity to choose the time and location, even considering the current pandemic and post-pandemic situation (COVID-19). Some preferred to come to the hospital, others preferred their home, and a few opted for a digital or phone interview (Rautalinko 2023). The time and setting of the interview are important for several things, including privacy (being undisturbed), comfort, and a sense of security, especially when the environment is unfamiliar. The first contact was important, and the PhD candidate's intention was to be open and friendly and to invite a calm and respectful presence. At the beginning of each interview, the participant was informed about the framework and purpose of the conversation. Participant received advance information about the study's aim, giving them time to reflect before the interview began. The PhD candidate's role was to remain open and curious about their individual experiences, without preconceived expectations, and to be prepared with follow-up questions when needed. Further, ready to respond to negative emotions with kindness and flexibility, and to address medical or technical questions related to treatment or management after the interview, if the participant wished. The sociodemographic and clinical characteristics of patients taking part in Studies II and III were collected and presented in Table 2.

Table 2. Sociodemographic and Clinical Characteristics of patients in contacts with healthcare in front of treatment with catheter ablation.

Patient	Primary, secondary healthcare level	Sexes, and ages in years	Time from self-rated onsets of symptoms (months)	Own strategy to interrupt palpitations	Pharmaco-logical treatment (before ablatio	Diagnosis (after ablation)
P1	Primary Secondary	Female, 65	432	No	No	AVRT[b] with an overt delta-wave
P2	Primary Secondary	Female, 53	84	No	Yes	AVNRT[c]
P3	Secondary	Male, 55	3	No	Yes	AVNRT
P4	Primary Secondary	Male, 59	492	No	Yes	AVRT with an overt delta-wave
P5	Primary Secondary	Female, 53	45	No	No	AVNRT
P6	Primary Secondary	Female, 46	240	No	No	AVNRT
P7	Secondary	Female, 63	14	No	Yes	AVNRT
P8	Primary Secondary	Female, 89	180	No	Yes	AVNRT
P9	Primary Secondary	Male, 63	144	No	Yes	AVNRT
P10	Secondary	Female, 21	96	No	No	AVNRT
P11	Secondary	Male, 35	33	No	No	AVRT & AVNRT
P12	Primary Secondary	Male, 68	144	No	Yes	AVNRT
P13	Secondary	Male, 74	38	Yes	No	AVNRT
P14	Primary	Female, 63	120	No	No	AVNRT
P15	Secondary	Male, 63	360	No	Yes	AVNRT
P16	Secondary	Female, 35	120	No	No	AVNRT
P17	Primary	Male, 55	156	No	No	AVNRT
		Average 56.6 years of age	Mean of 159months (3–492)			AVNRT (14) AVRT (2) AVRT + AVNRT (1)

[1]AVNRT = atrioventricular nodal reentry tachycardia, [2]AVRT = atrioventricular tachycardia

The typical participant was 56-year-old women. She had suffered for SVT episodes for 13 years, seeking help both in primary healthcare and lately more often in emergency care. She had medication on a regular basis but did not practice self-care management to break the tachycardia. In most of the interviews, the conversation was summarized toward the end to give participants space to add or clarify anything they felt was important. On a few occasions, to conclude, the participants were invited to reflect on how they experienced the interview (Rautalinko 2023).

Sample selection

Three to 12 months after catheter ablation for AVNRT and/or AVRT, 27 patients received an invitation to participate in the study via a letter with a self-addressed stamped envelope, and 10 patients declined. Seventeen participants were recruited over two occasions, within the original research group, in a primary gathering, with 12 participants, and with a supplementary dataset, with five participants (Cheng & Phillips 2014; Heaton 2008). Data for Study II were collected between December 2021 and March 2022. The material was assessed as rich in meaning, and content related to patient participation were preserved for further analysis. This allowed data from two separate collections to be used in Study III. To complement the existing data, five lifeworld interviews were conducted between April and June 2023 specifically for Study III.

Study III was guided by a secondary qualitative analysis which involves an analytic expansion of existing data and promotes a more comprehensive use of the material (Beck 2019; Cheng & Phillips 2014; Heaton 2008). The interviews were conducted, on average, five months after catheter ablation. The interviews varied from 20 to 93 minutes, with an average of 62 minutes.

Data gathering

The data gathering for Study II began with lifeworld interviews focused on participants' experiences of treatment, and Study III focused on patients' participation in healthcare. Initially, two pilot interviews were conducted, which were considered rich in meaning and were therefore included in the data collection. All interviews in started with the open-ended invitation "Tell me about your experiences during treatment with catheter ablation' in Study II and "Tell me about your experiences of participation in your own care". Thereafter, follow-up questions were posed to explore further (e.g., Tell me more, Give an example, How did you feel when. and What do you mean by) and to gain deeper insight into the phenomenon. All interviews were conducted, audiotaped, and transcribed verbatim by the PhD candidate. There was one exception: an interview conducted without audio recording due to a technical mishap, during which notes were taken throughout to document the conversation.

Data analysis

The analysis was an iterative, repeated, constant commuting between whole–parts–new whole. The process began with becoming familiar with the data as a whole, and then the various parts begin to appear, the meaning units, a careful division into smaller segments with respect to the meaning. In this part of the process, an understanding of the data began to arise, with an intention to find, unpack, and understand the meaning (Dahlberg et al. 2008). To highlight the various parts of the data, a structure was made of meanings that seems to belong to each other, and clusters formed a temporary pattern of meaning. In this part of the analysis process, it was important not to let the pre-understanding prevail and determine the understanding of the phenomenon in advance. This was done by going back and forth between closeness and distance and between parts and the whole of the text with a goal to be surprised and see something new, the otherness, characterized by a conscious approach of openness and bridling. In Study II and III, the analysis was repeated several times to ensure depth and accuracy. A movement between figure and background was the applied to illuminate the essence of the phenomenon, meaning that the PhD candidate shifted focus between specific details (figure) and the broader context (background) to better understand and clarify the core meaning of patient participation. The nuances and variations in the data of 'participating' and 'not being participated' were assessed as belonging to the same phenomenon and became clearer when this way of understanding the data was adopted (Dahlberg et al. 2008; Merleau-Ponty 1945/2023). The essence is the most abstract level of the description of the phenomenon and can be understood as the most invariant structure of meaning for the phenomenon in the actual context, answering the 'what'. After the essence was identified, its constitutes were described: this is the description on a more concrete level and forms the foundation of the essence, concretized and contextualized by quotations from the interviews (Dahlberg et al. 2008).

Study IV

There is limited evidence on effective strategies for improving care delivery and accessibility and addressing unmet patient needs for those with episodic tachycardia. Therefore, the Study IV research question focuses on identifying areas for improvement in the current management of patients with recurrent tachycardia. Grounded in patients' lived experiences, the study uses a participatory framework inspired by Twamley (2020) and based on EBCD (Bate & Robert 2006) Fig. 1.

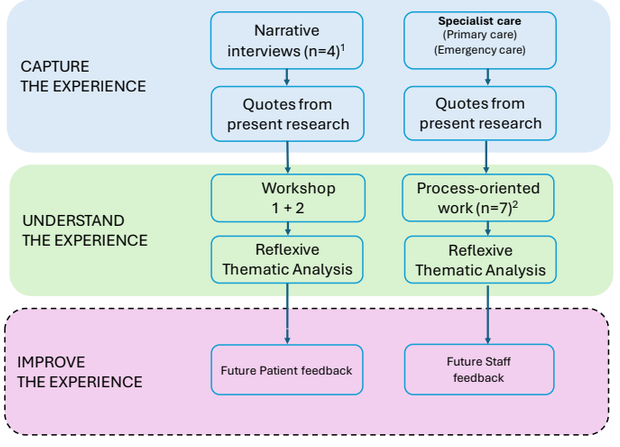


Fig. 1. Study flow chart, [1]patient representative, [2]healthcare professionals. Figure inspired by original by Twamley, Monks and Beaver 2023.

A structured two-phase EBCD methodology was applied, involving participatory workshops with patients and collaborative process development with HCPs. The purpose was to include participants with various experiences to gain multiple perspectives.

Sample selection

To reach individuals interested in contributing to the development and improvement of healthcare, contact was taken by the PhD candidate with an initiative coordinated by the Västra Götaland Region [VGR]. The designated contact person (gatekeeper) provided contact details (after obtaining permission) for four individuals with individual experiences of recurrent tachycardia and interactions with healthcare services. Their involvement was motivated by shared interest in collaboration and healthcare development. These 'patient representative,' referred to as *patients*, were invited to individual interviews to share their experiences with recurrent tachycardia in support of ongoing improvement efforts. After the interviews, four adults (three women and one man) were invited and confirmed their willingness to participate in two workshops and were formally included in the study.

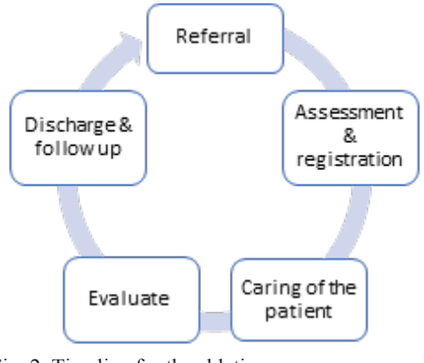
Seven *HCPs* were purposefully selected to ensure representation across all aspects of the ablation process, thereby enabling a comprehensive identification of relevant areas

for improvement. The team consisted of one medical secretary, two cardiologists, two biomedical scientists, and two nurses - all with extensive experience in cardiology.

Data gathering

In Phase 1, individual interviews (30–45 minutes) were conducted with the patients, giving them the opportunity to describe their individual experiences of sudden palpitations/tachycardia and their motivation to contribute to improving care. These interviews provided a foundation for the upcoming workshop, enabling patients to reflect on their experiences and later focus on identifying and capturing key issues opportunities for improvement in healthcare. All interviews were conducted and transcribed verbatim by the PhD candidate.

Seven HCPs and one process work facilitator were gathered for a 5-day collaborative improvement process-oriented workshop. To understand the ablation process for specialist care, a mapping was conducted using a cause-and-effect (fishbone) diagram (Kumah et al., 2024), for a timeline before, during, and after intervention with catheter ablation. It is presented in a simplified form in a circular flow in Fig.2.



1. Referral of a patient with documented or suspected arrhythmia in need of further assessment for decisions on intervention
2. Assessment and registration of the patient
3. Caring of the patient, ablation treatment
4. Evaluate intervention
5. Discharge and follow up

Fig. 2. Timeline for the ablation process.

Phase 2. Two workshops were conducted, in April and September 2025, held as digital meetings, due to patients' health status, geographic distance, and preferences. In the *first* workshop, a PowerPoint titled "Capturing the experience," including quotes from earlier research (II and III) and the patients strengths from previous involvement in healthcare improvement, were used to initiate dialogue. The discussion was facilitated with guided reflections and follow-up questions were posed to support deeper engagement. The *second* workshop was based on preparatory materials reviewed by patients in advance.

Their immediate and sustained engagement shifted the PhD candidate's role to that of a more passive facilitator, primarily listening and ensuring space for participant-led reflection, and occasionally guide the conversation back to the workshop purpose (Rautalinko 2023). The evolving role illustrates the reflexive nature of qualitative research, such as reflective thematic analysis, where the researcher's presence and interaction are part of the knowledge construction process (Sundler et al. 2019).

Next, to identify the ablation process for HCP, a timeline was described in the specific stage of a SIPOC. The SIPOC is a tool for visual overview over a process to map key elements, identify inefficiencies and reflect potential areas for improvement (Daly et al. 2021; Nikita & Singh 2025). Reflections during the SIPOC sessions led to the identification of two key areas for improvement: *information* and *communication*, including *medical responsibility*.

The data were derived from patients' reflections in Workshops 1 and 2, as well as the documentation generated through process-oriented workshop in specialist care settings. The resulting transcript text were extensive, reflecting the richness and volume of the material.

Facilitating the workshops. The PhD candidate and a management developer facilitated the process. During workshop 1, the PhD candidate was active in the conversation, mainly leading the discussion and asking follow-up-questions when needed. During this workshop 2, the role as facilitator differed somewhat; to listen actively, ask follow-up questions when needed, ensure everyone had space to speak, and occasionally guide the conversation back to the workshop's purpose. The PhD candidate took part in the discussion with openness and sensitivity, aiming to minimize their influence on the data (Sundler et al., 2019).

Data analysis

The analysis of data involved a reflexive thematic analysis (Sundler et al., 2019) with a lifeworld approach and a motivation to follow the phenomenon: areas for improvement identified in care. The analytical approach in this study is inductive, based on data reflecting the lived experiences of patients with recurrent tachycardia/SVT and their encounters in healthcare, with focus on the time of treatment in specialist care setting and catheter ablations. The analysis is reflective and seeks to illuminate meaning through a systematic and thoughtful approach (Sundler et al., 2019). The themes derived from the analysis are data driven and grounded in both the participants' experience and the empirical material. The process began with a reading to become familiar with the data and to explore how meanings could be understood. The focus was on discovering unique and novel aspects of experiences rather than confirming what was already known. The next step involved identifying nuanced meanings—those that differed from one another

but remained interrelated. These meanings were marked and described briefly with notes in the margins. Rather than emphasizing interpretation or frequency, the aim was to describe and deepen the understanding of the complexity of meaning within the data. Throughout the process, the first author engaged openly with the material, identifying patterns of meaning and exploring how these could be organized into coherent themes. Finally, the generated findings were rewritten as themes and structured into a meaningful whole (Sundler et al., 2019).

Ethical consideration and reflections

The following section presents ethical considerations, accompanied by reflections that emerged before, during, and after the research process. To meet the ethical requirements aligned with caring science and lifeworld-led care (Dahlberg et al. 2009), it was necessary to engage in a development process together with the patients.

The PhD candidate's responsibility and endeavor with the research was to follow, protect, and promote for research to ensure that it was carried out in accordance with good research practice (Swedish Research Council 2024), according to the prevailing Swedish legislation (SFS 1998:204; SFS 2003:460), and that the investigation conformed with the principles outlined in the Declaration of Helsinki (WMA 2024). The ethical principles beneficence (to do good), non-maleficence (do no harm), autonomy (respect self-determination), and justice are further described in the next section.

Permission for Study I - IV was obtained from the Ethical Review Board of Uppsala, Sweden (Dnr: 2019-03295) with an additional application 21-01-2020 for Study I, concerning extraction of data from the VEGA register. For Study I, the registry protocol was approved, and the need for written consent was waived by the Ethical Review Board of Uppsala, Sweden, due to the retrospective nature of the study.

To fulfil the information requirement in Study I–IV, personal contact was established with the head of the cardiac clinical, who was informed verbally and in writing of the specific aims in the thesis and asked for approval to conduct the respective sub-study. Between 2019 and September 2025, this contact was updated and approved annually. Approval to contact patients in Study II, III, and IV was obtained from the department manager (both past and present).

Potential patients received a letter of invitation to take part, included the PhD candidate's contact details and a self-addressed stamped envelope. The reply letter was followed by telephone contact to confirm or, in some cases, withdraw participation. All patients received written information, which was repeated verbally before the interviews. They were assured that participation in the study were completely voluntary and would not affect their care in any way (autonomy). The patients could choose to end their participation at any time. The consent requirement: The written information holds the aim of the study, potential risks, and benefits of participating, and the patients were free to withdraw from the study without giving reasons. Informed consent was obtained from each participant in Studies II, III, and IV. All participants interviewed were offered contact with and support from a counselor at the cardiology clinic (non-maleficence). The use of letter invitations meant long response latency in some cases, and after three

weeks, telephone calls were made to remind recipients of the invitation. The first contact could have been conducted in another way, such as by email, to save time. On the other hand, this letter-invitation gave the patients time to make a thoughtful decision to take part in the study and share their experiences. Some patients needed two dialogues before they agreed to or declined participation in the study. A reason for declining was not required.

During the interviews, there were repeated occasions when patients expressed relief and appreciated being able to talk about their experiences with someone who listened and interested un the subject (beneficence). Some expressed that they had not talked with others about their experiences before. In one interview (on the phone), there was a technical mishap, and a new time for interview was offered, but the patient was determined to proceed. They were ready to finally be able to talk to someone about the context and did not want to miss the opportunity (autonomy). During the interviews, the patients shared personal and often emotionally significant narratives about their lives and encounters with the healthcare system. Their openness reflected a notable trust in the interviewer and a strong willingness to contribute to the study. Although participation was entirely voluntary and patients had access to a counselor at the clinic, reflections appeared after the interviews on how the patients' stories might have continued and how they were doing now. These interactions contributed to a deeper engagement in the research and reinforced the motivation to improve healthcare practices for patients with recurrent tachycardia (justice). There was moment when patients talked about difficult experiences, or expressed sadness over lost time in life, and/or broke down in tears. The patient reacted emotionally on memories being stirred up in ways that surprised them, and that they had not reflected on earlier. In these moments, to the best of the PhD candidate's ability, attempted to remain in a research position but also to listen as a fellow human being (Dahlberg et al. 2008). In these moments, patients were allowed to take the time they needed and only continued when (and if) they were ready. There were also patients who express their gratitude for the whole care process and for whom everything just went on smoothly–the way it should be for all patients.

Following the Declaration of Helsinki (WMA 2024), the patients were guaranteed confidentiality. Names and identification numbers were known only to the PhD candidate's through personal contact during the data collection. All interviews were transcribed by the PhD candidate, and the transcripts held no personal identifiers. No identifying information was disclosed in the publication. The phenomenon-orientated RLR approach focuses on the meaning in the patients' narratives (Dahlberg et al. 2008). This involves an abstraction process that reduces the risk of identification.

The collected data are preserved according to the regulation by the research principal of Skaraborg Hospital Skövde, Sweden. The utilization requirement means that the collected data will not be used for commercial purpose but only used for research purposes. Data collection was managed together with the healthcare statistician at the hospital to guaranteed confidentiality during analysis. A sub-analysis holding ECG data was assessed as personal and considered vulnerable. This was done with help from the healthcare statistician to guarantee confidentiality. To enable later review, every ECG was marked with a code, and the code list was kept locked in a sealed envelope.

The potential risk was discussed with the PhD candidate's supervisors and was addressed in the ethical application. It concerned possible discomfort for physician assessing ECG rhythm and validating diagnosis. However, the benefit of the project, aimed at improving the care process, was considered to outweigh this risk. For patients undergoing ECGs, no additional risk was identified, aligning with the principle of justice.

Another ethical issue was the relationship between the PhD candidate and the patients who took part in the studies. Dependency: the PhD candidate, work as a registered nurse in the ablation team at the clinic where patients with SVT were cared for. Ablation is a planned health and medical activity, with scheduled days for ablation procedures with or without anesthesia during surgery. In the dual role as a researcher and a clinical nurse, ensured not having participate in the care of patients included in Studies II and III, nor those who were being considered for inclusion. In practice, the PhD candidate collaborated with patients treated for arrhythmias other than those relevant to the research project. In Study IV, participants were recruited through an initiative by the VGR aimed at improving healthcare services. These individuals, referred as patient representative, had personal experiences of recurrent tachycardia. This was the first time the PhD candidate had met them.

During course of this education and the work on this thesis, the PhD candidate's has continued clinical practice at 50% and this arrangement required flexibility in adjusting work shifts with colleagues. This generally worked well, although it may have caused additional stress for both colleagues and managers at times. Hopefully, it will bring benefits, with added skills and an impact on learning and developing the organization.

Findings

Healthcare utilization

A total of 2,719 visits with 2,373 unique outpatients were included in the study. The flowchart of the study process is presented (Fig.3.).

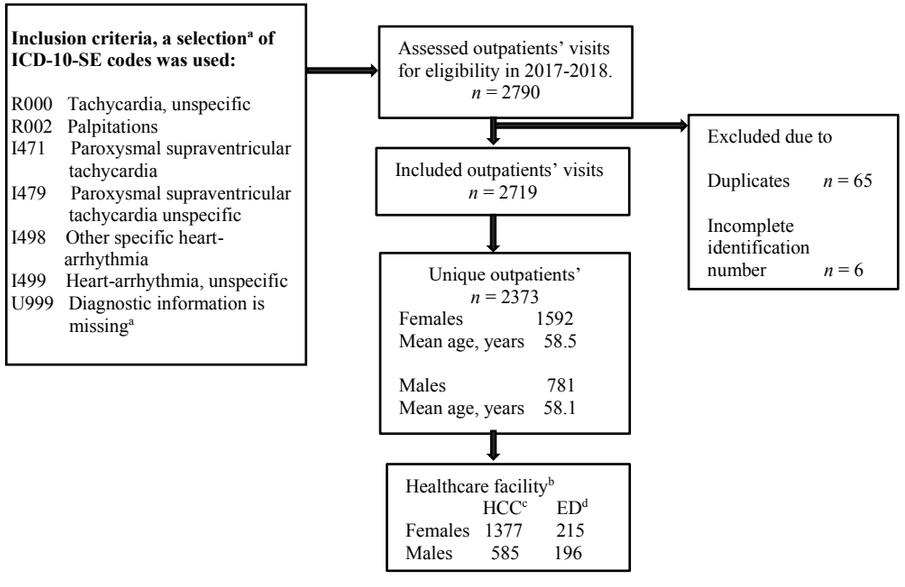


Fig. 3. Flowchart of the study process. [a]Selected ICD-10-SE code motivated of the high incidence of measures related to the heart rhythm, [b]first index visit, [c] Healthcare centre. [d]Emergency department.

The main findings showed a significant difference in the total number of visits between females and males (68% vs. 32%, $p < .001$). Table 3 presents the number of visits to healthcare centers and emergency departments distrusted by gender and age. Table 3.

Table 3.

	Total Group	*Visits to HCC*	*Visits to ED*
Visits	*n=2790*	*n*=2295	*n*=495
Women (%)	1893 (68)	1630 (58)	263 (10)
Men (%)	897 (32)	665 (24)	232 (8)
Unique persons age	*n=2373*		
Women mean (range)	58.5 (18–99)		
Men mean (range)	58.6 (18–96)		
Age 18–65	*n*=1383 (58)		
Women (%)	931 (67)		
Men (%)	452 (33)		
Age ≥66	*n*=990 (42)		
Women (%)	661 (67)		
Men (%)	329 (33)		

Of the 2,719 visits, 82% were at healthcare centers, and 18% were at emergency departments. When analyzing unique patients (n = 2,373), significant differences were seen between females and males in the numbers of visits to healthcare centers ($p < .001$) and visits to emergency departments ($p < .001$). Outpatients at the emergency department were older (Fig. 4). The hypothesis was that no differences in search patterns would exist between the sexes at healthcare facilities. The findings indicated a significant difference in the healthcare facilities visited by the patients, with differences observed between the sexes ($p = .001$), leading to the rejection of the hypothesis.

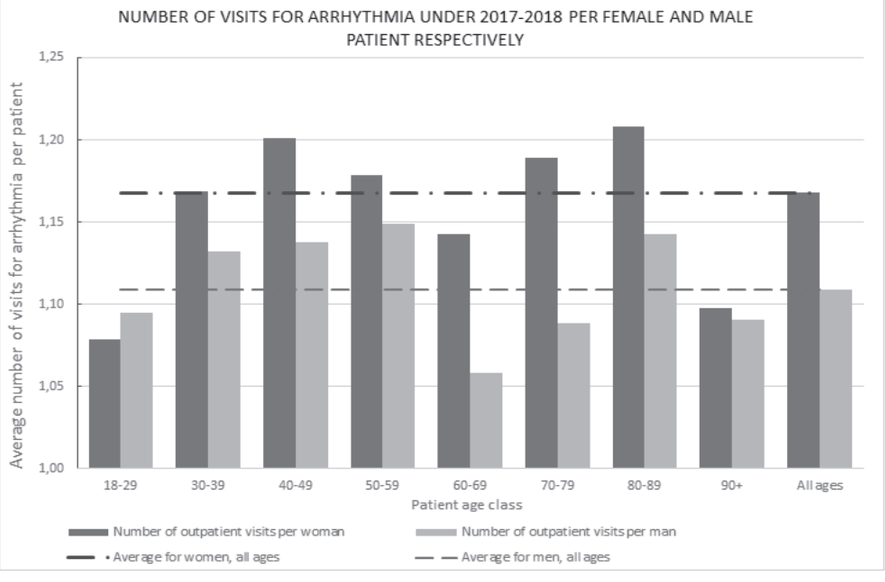


Fig. 4. Outpatients' visits (n = 2719) to healthcare centre and/or emergency department due to episodes of tachycardia in groups stratified by sex and age (18-99 years).

At an aggregated level, 1.12% (112 of 10,000 inhabitants) had visited a healthcare facility because of recurrent tachycardia at least once over a period of 24 months in 2017–2018. The average number of visits for females of all ages was 1.17, and it was 1.11 for males. A clear difference was seen between sexes; of the 10,000 inhabitants, 151 females and 73 males ($p < .01$) had visited a healthcare facility at least once because of the condition.

A total of 277 patients had 623 recurrent visits at healthcare center and/or emergency department, with a range 2–9 visits per patient, and the visits were more common among females ($p = .001$). In this group, there was a higher frequency of visits to healthcare center ($n = 487$) than to emergency departments ($n = 56$). Additionally, 35 patients (20 females and 15 males) made repeat visits to both healthcare center and emergency center, consisting of 80 visits (mean 2.3 visits).

The patients ($n = 480$) attending the emergency department were found to have a high rate (95%) of hospitalization. No significance differences were seen in this group according to sex or age, although hospitalizations were more common among patients aged ≥66 years. In the entire population, the typical patient was a female aged 66 years or older, with unplanned visits in primary healthcare due to recurrent tachycardia.

During this period of 24 months, 292 patients were referred to cardiologist in specialist care. Three were referred from primary healthcare, and the remaining 289 were referred internally from the hospital. Of all the referrals, 57% were females, and the highest proportion of referrals were in the 60-69-year age group.

In a group of outpatients admitted to emergency departments with unspecific ICD-10-SE codes (R000, R002, or U999), ECGs from 100 unique patients were analysed using a stratified random sample. The analysis of ECGs found 5% (Cl 1.9%-10.6%) of arrhythmias as potential AVNRT or AVRT, of which 4% occurred in females. The remaining ECGs were atrial fibrillation/atrial flutter (56%), sinus-rhythm (26%), and other arrhythmias (13%).

Foreign movement in one's own body

The aim was to describe the phenomenon catheter ablation as experienced by patients who were treated while awake. The findings are presented in essence, remaining faithful to their original meaning and structured according to the identified constituents in a condensed format. For a comprehensive account of the findings, please refer to the published article.

Essence: Catheter ablation, as experienced by patients who are treated while awake, involves relying on another's expertise and entails being safe and confident; on the other hand, it also entails being unprepared and vulnerable. Vulnerability includes putting oneself in the hand of others, being simultaneously objectified and confirmed. Being awake during catheter ablation implies following instructions, being actively passive, trusting and demanding to achieve simultaneously, and striving to regain health. Sensation of foreign movements in the body when the catheters are inserted into and placed in the heart, thereby leading to experiences feelings and curiosity and being terrified, endured by shifting the mental focus away from one-self. Curiosity entails the ability to distance from one's own body in the moment, while terrifying experience entails existential fear and anxiety. In addition, communication between staff creates both curiosity and uncertainty. It is about creating an individual story of the event, built on ideas and knowledge. The foreign environment and context instils a sense of disorientation that reinforces vulnerability. After the monitors are turned off, there is a pride, gratitude, and joy at having endured the treatment and a hope for a future without the obstacles brought on by the tachycardia.

Thus, the phenomenon includes the four constituents, 1) relying on expertise in a foreign environment, 2) enduring foreign movement and sensations in the body, 3) actively passive cooperation in striving to be cured, and 4) being simultaneously objectified and confirmed. The four constituents are summarized and presented with selected quotes.

Relying on expertise in a foreign environment

Relying on expertise in a foreign environment means trusting the knowledge and professionalism of the ablation team, with the expectation of being well treated and receiving help to deal with the condition. It includes striving to regain health and hopeful belief in the future, in opportunities instead of obstacles, caused by tachycardia. The foreign environment in a hospital means listening to the technical communication between staff in the EP-lab and a noise that can be filtered if the atmosphere in the room says that everything is normal, while also wondering what the communication implies. As one patient reflected:

> And so, someone in the control room said 17, yes good, and then they burned a little on 17, and so they kept on. And then they said 324 and I wondered what that was. 324, what is that? Further in or longer out or what? Up? Down? I do not need to know, but that was what I was thinking. (P4)

Enduring foreign movement and sensations in the body

During the procedure, the patient reported experiences of foreign sensations and movements inside the body and heart. Treatment was endured by shifting the mental focus from themself to something else, a strategy used by runners, athletes, and by meditation practitioners. During the procedure, experiences of short, repeated palpitations, which were familiar but slightly different from their usual episodes of tachycardia, were described as sensational, scary, and exciting. One patient reflected on how she endured this:

> There was one time that I wanted to stop the whole thing; it was very hard in the end, they would stress my heart, and I felt it in my whole body, almost as if my heart were popping out of my mouth. But it was not for a long period, and I felt that I could handle this. (P11)

A burning sense during treatment was experienced differently and could go unnoticed in certain patients or turn into discomfort and border on pain for short periods for others. The burning sense was experienced as an itchy, warm feeling in the chest, not purely unpleasant but more like drinking a hot beverage, felt along the esophagus.

Actively passive cooperation in striving to be cured

During procedure, experiences were reported of a kind of cooperation between the patient and the surgeon, with the common goal of curing the condition, and can be understood as necessary for relieving the symptoms of the tachycardia but also includes shortcomings. Actively passive cooperation was experienced as trusting the process; on the other hand, it was demanding and difficult to follow instructions to lie completely still. There were limited opportunities for patient to speak and ask questions during the procedure, which amplified their experience of vulnerability and being left in the hand of others. One patient articulated how she experienced a (lack of) support and expressed vulnerability:

> I felt completely left out, which meant that I had to concentrate in not thinking it was disgusting and… I knew they were in control; they had all the stuff and there was everything so… they did know how my heart felt, but they did not know how I felt. (P5)

Being simultaneously objectified and confirmed

Being objectified and exposed in a vulnerable situation implies being unprepared, accepting an intervention without having sufficient information and with unanswered questions about the unknown what occurs, and experiencing feelings of being left out. The opportunity to share the joy of being treated was not given space, and numerous questions remained unanswered. The lack of patient perspective was articulated by one patient in the following manner:

> I experienced the aftercare as very spartan. I thought it was a big cut at first, but it was exceedingly small… but I felt a little… abandoned, a little lonely. I wanted to share the inherent peace I experienced after the procedure to treat something that has bothered me for so many years. (P10)

The procedure entails a surrealistic experience of being objectified when seeing one's own heart visualized on the monitor, which can be both exciting and frightened. There was experiences of relief and confirmation when tachycardia was seen at the monitors; that this was real and could not be explained by stress or anything else, and this confirmation strengthen self-esteem. The occasionally stressful moment during the procedure, it strengthened them to avoid future episodes of tachycardia, which made the effort worthwhile.

Being taken seriously

The aim was to describe patient participation in healthcare as experienced by patients with supraventricular tachycardia. The findings are presented in essence, staying true to their original meaning and structured according to the identified constituents, in a condensed format. For a full account of the findings, please refer to the *manuscript*.

Essence: Participation in healthcare, as experienced by patients with SVT, involves a currency of trust that is hampered by lack of continuity. Participation is prevented by the lack of continuity, while life continues without regard for those whose lives are on hold in an 'existential waiting room.' The existential waiting room is characterized by a trust in healthcare and a hope for treatment of the unpredictable condition that significantly impacts daily life. Effective participation in their own care allows patients to resume their lives but is hampered by inconsistent involvement. This phenomenon fosters a transition towards increased existential safety, beginning when patients are believed. Knowledge and a joint struggle for objective evidence and appropriate treatment are crucial. Participation manifests as a sense of trust in being taken seriously as a whole person, bringing hope for help with their unreliable heart. When participation is not facilitated, it results in powerlessness and broken trust in the healthcare system, even if suitable treatment is offered.

Thus, the phenomenon includes 1) being taken seriously – a joint struggle 2) trust in an uncertain situation, 3) lack of continuity, and 4) knowledge – a transition to existential safety. These are summarized and presented with selected quotes.

Being taken seriously - a joint struggle

The need for objective evidence involves a joint struggle with healthcare to have the tachycardia documented on the ECG, but for some patients, it feels like a fight on their own. One patient articulated how he experienced a lack of support (in a sustained episode of tachycardia), being ignored, and not respected as a person with a life:

> When I them about this, they responded, 'It is not dangerous.' Well, I can say this is serious for me. Not dangerous?! Sit here and have this tachycardia in several hours, then you see it yourself. (P 11)

Being reassured that the condition is not dangerous is a relief, but at the same time, it can make people feel as though their condition is downplayed and not being taken seriously, especially if the message does not include information that the condition is treatable. Participation occurs when patients engage in the decision-making, are aware

of treatment options, and understand the significance these options have for their well-being.

Trust in an uncertain situation

Participation can be understood as trusting HCPs and relinquishing responsibility for one's care, which also staying attentive to the procedure. One patient described this during treatment with ablation:

> I experienced the ablation as quite effortless-I handed over the responsibility of myself to the expertise. I don't like pain, but if everything seems normal in the operating room, then I keep cool. (P9)

Trust in an uncertain situation was described as particularly difficult because of the elusive heart condition, when the tachycardia suddenly stops, and patients are told 'come back if the symptoms return'. Being neglected when searching for help resulted in frustration due to the lack of participation and support and left a lingering lack of trust in healthcare.

Lack of continuity

Trust, which is central for participation, fluctuates in interactions with different HCPs and is hindered by a lack of continuity. A lack of participation expresses itself in experiences of being ignored, especially when there is a lack of continuity in care. This discontinuity disrupts the development of trusting relationships and contributes to a sense of existential insecurity. Patients describe a resignation, a quiet giving up, when their efforts to be heard are repeatedly met with unresponsiveness. The repeated need to recount one's medical history becomes not only exhausting but also symbolic of a fragmented continuity that does not recognize the person behind the symptoms. One patient reflected on how she dealt with this lack of continuity:

> I did not manage it in the end. Just not being believed in… there were so much other stuff they were good at, but in the end, I did not manage to repeat my story again. (P2)

The insecurity following a lack of participating in the examination, or not even having an examination, resulted in existential fear of serious condition, experiences of powerlessness, and decreased trust in healthcare; a feeling of knowing something was wrong but not being aware of how to manage the symptoms and condition.

Knowledge - a transition to existential safety

Knowledge of the condition, illness, and treatment, included the ability to make decisions when further treatment was appropriate, supported by the HCPs, meant the possibility of changing existential uncertainty and feeling safer. A patient with previous negative experiences of participation described the turning point when she felt more secure:

> Just to hear what this is about, and they were checking 'Do you get what this means?' and 'Do you want us to send this referral?' and yes, there I think the security in me entered just by having knowledge and being involved in the decision. (P2)

Participation emerged with increased security for patients after they received a diagnosis, as communication with healthcare eased, such as when calling for an ambulance when tachycardia was persistent. The meaning of participation was clear when patients, even after successful treatment, described a lingering sadness of lost years and quality time due to frustrated unanswered questions and not being treated earlier when there was a cure for the condition.

Improving care for patients with SVT

The aim was to describe how areas for improvement in the care of patients with supraventricular tachycardia can be identified and prioritized using the experience-based co-design approach. The participants were patient representatives, referred to patients, and HCPs from specialist care. The findings are presented in themes, staying faithful to their original meaning, and structured according to the identified sub-themes in a condensed format. For a full account of the findings, please refer to the *manuscript.*

Confidence-building support

The patients reflected on the importance of confidence-building support and alternative forms of support that promoted their confidence. They emphasized the need to acknowledge the patient as an expert in their own life and as an active partner in care, able to express and determine what kind of support they needed during important interactions. This might include having a trusted person present or being allowed to record the conversation to memory aid, since stress and anxiety significantly impair memory, making such support essential for informed decision-making. The experiences in among the patients vary from being able to choose based on their preferences to not receiving any assistance and being neglected, with the conversation instead directed at their next of kin. Patients also discussed the importance of dialogue in which the interaction between the patient and the healthcare provider is trust-building and responsive to the individual's needs. It was considered important that the information given reflected their needs at the time; otherwise, it could be a burden and more frightening than supportive. Their reflections emphasized the purpose of the dialogue: to determine the patient's need for support. The conversation should be guided by the patient's own questions, enabling healthcare providers to meet the individual where they are, rather than "bombarding them with information". It was acknowledged that some individuals may not wish to receive all available information:

> I do not want to know, do not give me information I do not want to hear
> because it's going to give me big concern; I cannot sleep. (P4)

The patients reflected on trust-building dialogue, characterized by the HCP beginning the conversation with an open question and the patient indicating how deeply they wanted to go into it. Some patients wanted to have the full picture clear, so it was considered important to find a balance. The patients underlined that they believe on the dialogue, and that it was about trust to healthcare, and one patient continues:

> I have never had a groin procedure, I do not know how I can move.
> How shall I continue to live my life? (P4)

The group reflected on the importance of using time well during interactions with specialist care. In cases of persistent tachycardia, the patients suggested that there should be a service with direct contact with the aim to avoid unnecessary healthcare visits, or in case of emergency, a referral to emergency department.

HCPs' reflections

The HCPs discussed and reflected on a proposal for a nurse-led pre-ablation clinic and investing improvements for both patients and the clinic. This would respond to patients' need for trust and availability and being able to ask questions to someone knowledgeable in the area. The nurses should have close collaboration with the cardiologists responsible for the ablation department. The competence was there, but the participants reflected on the proposal could be hard to implement when it required new resources, mainly time. As one HCP's reflected:

> The patients need opportunity to ask about practical things and other concerns,
> and we must check in their motivation for the intervention,
> and support the patient to be prepared for the ablation procedure. (P5)

The proposal was submitted to the clinic management for a decision. The group discussed and reflected on various opportunities to provide support before and during ablation procedure, such as informative films or virtual reality (VR) glasses to support relaxation and even reduce pain perception. The HCPs' primarily focused and reflected on the referral process, emphasizing the importance of establishing a solid foundation. As the referral often represents the first point of contact between specialist care and the patient, they play a crucial role in building relationships based on trust. A key factor in ensuring the success of the intervention is referring the right patient—those who are motivated and understands the reason for the referral. It is essential that patients are informed not only about the benefits of the treatment but also about potential disadvantages, and that they have a realistic expectation of the treatment outcome. When this part of the process is handled correctly, the likelihood of utilizing available operating times increases, which in turn has a positive impact on accessibility.

Tailored information

The patients' reflections were united regarding the content of the information: It should be tailored. Verbal or written information should be clear and reassuring, and the group agreed that avoiding medical terms was essential, as patients commonly do not understand medical terminology. Adequate information was deemed important; the patients needed to know about the severity, followed by the possibility being investigated to assess the symptoms, otherwise patients described being neglected:

> They say, ‘You don’t need to be worried’, and that I just must take it easy.
> How on earth is it possible to respond that way? Do they even know? (P3)

The patients reflected on the type of information that should be provided at various levels of healthcare. They emphasized the value of clear, simple language and practical guidance before and after the intervention, such as “What should I do beforehand? What happens afterward? What should I consider? How should I live?” They noted that it was helpful to know, for example, whether driving and heavy lifting should be avoided for a few days. At the same time, one participant emphasized the following:

> You don’t need to be zealous with the details on the intervention
> because how interesting is it? (P4)

The group reflected on the challenge of balancing the amount of information at the time of referral. However, opinions varied regarding how much details were needed. The patients continued how the information should be handed over, and all agreed that it should be a topic in the dialogue with someone at the unit responsibility for the intervention planned; otherwise, the information risked being incorrect and not tailored.

HCPs’ reflections. The HCPs emphasized the importance of health literacy in enabling patients to understand and engage with health information. A key challenge identified was the timing and content of information provided prior to referral. In some cases, specialist care providers had to spend valuable time correcting or clarifying information given by other healthcare professionals. During consultations in specialist care, it was considered essential to offer patients a clear overview of what to expect, including who held the medical responsibility and whom to contact before the intervention. The HCPs also noted the limited ability of specialist care to influence the quality of information provided at other levels of healthcare, underscoring the need for improved coordination and communication across healthcare providers to support patient understanding and continuity.

Substantial communication

The patients reflecting on how communication gaps, unclear messaging, and a lack of transparency in the flow of information contributed to uncertainty in an already vulnerable situation. The patients reflected on the challenges of being cared for in a multicultural society, where language and generational barriers can lead to conceptual misunderstandings. Furthermore, the patients felt that referral confirmation should be mandatory, as current practices varied between ablation departments within VGR. Such confirmation would not only demonstrate patients’ interest in the intervention but also serves as an indication to HCPs that the patient was motivated—or may require further dialogue and information. It could also represent the first verbal contact between the patient and the specialist care responsible for the planned intervention. And as one patient reflected:

> I think that the impose referral-confirmation is a part of a stage-created routine,
> for me as a patient it means that I can process given information,
> and can collect questions for the next conversation. (P2)

The patients emphasized the importance of internal communication within healthcare, noting that while patients may not be aware of it, such dialogue can significantly impact the timing of investigations. They agreed that it is not the patient’s responsibility to understand or manage the resources required for their care, this falls to HCPs. Regarding questionnaires, the patients suggested avoiding their current format unless they clearly benefit the individual patient’s care and management.

HCPs’ reflections. The HCPs reflected on the need for improved internal communication, particularly regarding the information required from the referring provider when making a referral to specialist care. Referrals needed to provide a substantial medical history, as these were identified as a key factor in assessing whether an intervention should take place. Important aspects included referral confirmation and clear information about medical responsibility during the waiting period. Another key reflection was the necessity for patients to be given contact details in case any changes, updates, or issues arose. This was considered important for planning and rescheduling, especially when an ablation appointment was canceled and another patient needed to be scheduled. The HCP group reflected on digital portals as a possible way to present information but noted that maintaining and updating these platforms might require more effort than the benefit they provide.

Comprehensive understanding

Karin's lived experience as ethical and existential challenge in healthcare

The following text is a descriptive summary of the main findings from Studies I–IV of this thesis. One of the four studies contains numeric descriptive characteristics, and the other three contain qualitative characteristics, and these were translated into the fictional character Karin as a representative of the most common patient. The story begins with Karin and ends with others she has met along the way. In the second part, Karin's story is explored through the theoretical framework of the thesis.

Karin is a 57-year-old woman. She lives with an elusive heart condition characterized by unpredictable episodes of tachycardia, leading to an obstructive uncertainty and an inhibited existence due to worry about when the next episode will occur. She longs for things she has done previously in her life, such as going to events in different cities. She has not done this for a long time, afraid that the episode will occur during the event or the journey.

When episodes of tachycardia are persistent, Karin seeks help in unplanned visits to primary healthcare. On those occasions, she sits in the waiting room for long periods of time. The unpredictable episodes have been a part of her life as long as she can remember, but have progressed over the past few years, becoming more frequent and persistent. This has led to repeated visits and encounters with different HCPs, resulting in fragmented participation due to the lack of continuity. Despite this uncertainty, Karin still maintains a supportive trust in the healthcare system.

Finally, Karin finds someone who is engaged and recognizes her condition, leading to a referral to specialist care. Karin relies on their expertise, even though sha has insufficient information, not being fully prepared for being awake during treatment with catheter ablation. In the operating room, she is actively passive, experiencing foreign sensations and movement inside her body and heart. Karin endures the procedure by shifting her mental focus, striving to be cured, and trusting the process. She thinks about others she has met in the waiting room at the primary healthcare center and the emergency department who have talked about repeated visits striving for sustainable help with the condition. Some have waited months for a sustainable help, often younger men, while others like as herself have fought a frustrating battle for years, even decades. The relief of having been successfully treated is mixed with a lingering sadness about lost quality time in life.

Karin's narrative offers profound insight into how recurrent tachycardia/SVT disrupts the existential rhythm of everyday life. Her experience exemplifies a transition from the natural attitude, where health and bodily function are taken for granted, into a state of vulnerability and increased bodily awareness. In line with Gadamer´s (1996) notion that "health is silent," illness renders the body visible and problematic, challenging one´s sense of 'home-likeness' and trust in one's own body.

Through Merleau-Ponty's (1945/2023) philosophy of the lived body, Karin's experience is not merely a clinical case but an existential transformation. The body is not an object to be examined but the very medium through which the world is accessed, and meaning is made. Her state of being actively passive, conscious during treatment yet uninformed and fearful, reveals the tension between being a subject of experience and an object of medical intervention. This duality disrupts her intentional structure and leaves her existentially exposed. The concept of reversibility (Merleau-Ponty 1945/2023) that emphasizes the intertwining of the self and the surrounding reality becomes relevant here. Before the treatment, Karin needs to solve situations for herself, to refrain from doing what she wants to do, which leads to an inhibited existence. She is limited to social participation due to her condition, restricted geographically, and does not have the same access to the world as before. Even after the treatment, the absence of prominent symptoms continues to shape her lived experiences, needs to find trust to her lived body again.

Karin's suffering is multifaced. She endures illness-related suffering through fatigue, unpredictability, and disrupted life routines. Simultaneously, she experiences care-related suffering, encounters with HCPs who fail to recognize or respond to her needs. Eriksson's (1992, 2018) concept of care-suffering is central here: suffering that arises not from illness itself, but from the way care is delivered, or withheld. Karin's repeated experiences of disbelief, objectification, and lack of relational continuity contribute to a sense of powerlessness and existential insecurity.

Her story also reveals a deeper structural issue: the existence of effective care that remains inaccessible, particularly for her as a woman. Karin's tireless search for care she is entitled to, care that exists and can heal, highlights the gendered dimensions of healthcare access and recognition. Her struggle becomes symbolic of a broader ethical failure within the healthcare system.

From a lifeworld-oriented ethical perspective (Arman et al. 2022; Dahlberg & Segesten 2010), Karin's narrative calls for a reorientation of care practices. HCPs are ethically obligated to provide care that is responsive, dignified, and grounded in the patient's life story. This requires openness, attentiveness, and a willingness to be surprised by the patient's narrative. The patient's story becomes a vital epistemological tool for understanding suffering and guiding care.

Phenomenological epistemology (Husserl 1929/1977; Sundler et al. 2019) emphasizes that meaning arises through lived experiences and intentionality. Karins's inability to interpret bodily signals or understand the treatment process disrupts this intentional structure, leaving her in a state of existential homelessness. As Carel (2021) and Binder (2022) argue, illness is not merely a biological disruption but a threat to one's entire existence, prompting reflection on finitude, loss, and injustice.

In summary, Karin's story is once individual, relational, and universal. It reveals the existential and ethical dimensions of suffering and care and challenges healthcare to move beyond clinical efficiency toward lifeworld-led care, ethically grounded, and sustainable care. Such care must integrate the patients' lifeworld, recognize them as co-creators of knowledge and healing, and be rooted in empathy, intersubjectivity, and a deep understanding of suffering as a lived experience.

Discussion

This section presents a discussion of the findings in relation to the overall aim of the thesis: to describe how it is to live, with and being cared for, recurrent supraventricular tachycardia, with emphasis on the patient perspective and how to develop the care given. Methodological considerations are also addressed, including the qualitative and quantitative characteristics of the data.

Discussions of the findings

The findings showed that patient participation was hindered by lack of relational continuity as they sought help repeatedly in different healthcare facilities. Further, they revealed a significant difference between genders and age groups in total visits in healthcare centres and/or emergency departments. Challenges in obtaining proper assessment and treatment were evident, with women being more frequently represented in healthcare centres. Despite high hospitalization rates from emergency departments, referrals to cardiology specialist care were significantly low, especially from healthcare centres. The patients described experiences of care-suffering as stuck in an 'existential waiting room,' which undermined trust and gave them a sense of not being taken seriously. Undergoing catheter ablation while awake was described as driven by a strong desire for restored well-being, with reliance on medical expertise. A profound sense of being cared for was expressed; the heart was monitored and protected, but the human aspect, personhood, was left unattended. This paradoxical experience gave rise to a quiet endurance: a willingness to be actively passive, allowing foreign sensations and movements within the lived body and heart. A state of vulnerability and security emerged when the heart was objectively observed, yet the inner being remained unseen. Being treated opens opportunities for life projects that were previously not realistic to implement. Finally, the patients and HCPs jointly identified areas for improvement, particularly within specialist care, involving patients care before, during and after catheter ablations.

A summary based on the results initiates each of the following subsections, and thereafter, the findings from each study are marked with I, II, III or IV for clarity in the discussion.

Unequal access to sustainable treatment

The findings show when patients no longer can manage the unpredictable, recurrent episodes of tachycardia in their own, they turn to healthcare for support. These symptoms are often experienced as something foreign within the lived body, an unfamiliar disruption that was not present before to that extent and now interferes daily well-being and the patient's lifeworld. Patients' place their hope and trust in healthcare, believing that this unfamiliar condition is something only HCPs can understand and treat. Unfortunately, patients describe experiences of being dismissed or misunderstood when seeking help. If this pattern continues, it risks eroding patients' trust in the healthcare system (III). Patients' narratives consistently reflect a struggle to access appropriate care, such as self-care for managing the symptoms, but even after successful treatment, patients express lingering sadness over lost quality time in life, questioning why they did not receive catheter ablation earlier. This emotional residue suggests an existential impact that extends beyond the clinical success of ablation (II).

The thesis highlights important ethical consideration regarding the equal provision of care. This consideration of equal provision is illuminated of patients' repeated visits to outpatient care for the same complaint (I). The findings (II, III) reveal substantial variation in access to treatment, with waiting times ranging from 3 months to as long as 41 years. This highlights inconsistency in the management of recurrent tachycardia/SVT, suggesting the HCP–patient interactions may significantly influence how quickly appropriate treatment is initiated. This inconsistency in management aligns with Oliviera et al.'s (2022) findings that catheter ablation as a first-line treatment for SVT is not discussed with patients. While catheter ablation was not available 41 years ago, it has been an established treatment option in Sweden since 1991 (Sigurjónsdóttir 2023). This underscores the importance of timely recognition and referral, and the crucial role of the individual physician, in the capacity of a referrer, in ensuring equitable access to care (III, IV).

Patients who are well informed should be empowered to choose treatments that align with their preferences, capabilities, and life circumstances (IV). This includes the option to engage in self-care and postpone other treatment interventions until later in life. Available options may include pharmacological treatment or catheter ablation, particularly when symptoms are frequent or medication poorly tolerated. Although the prerequisite for participation in one's own healthcare process may differ between healthcare settings, accounts from patients interviewed (III, IV) suggest that participation is not limited or determined by geographical location. Beyond the fact that participation in one's own care is mandated by law (SFS 2017:30) and supported by international guidelines (WHO 2013), patients' experiences of participation contribute

to a sense of autonomy and personal responsibility. This, in turn, can reduce the negative influence of powerlessness and suffering (Berglund et al. 2012; Eldh 2006; Johansson & Ekebergh 2006; Nordgren 2008).

When the individuals are dismissed by HCPs as capable of interpreting their own body/health, HCPs can cause care-suffering, an extra dimension of suffering in addition to their illness (Eriksson 2018). Care-suffering is a negative event caused by HCPs which could have been avoided (Dahlgren 2002). This may cause the patient to avoid seeking healthcare when it is necessary (III), the trust to healthcare is eroded. The patients described how they received support and encouragement from next of kin to seek help from healthcare again and ultimately received the care they needed. The avoidance of seeking care due to previous interactions has been studied in other care context, for both genders, and as a reason to postpone surgery (Swahnberg, Thapar-Björkert & Berterö 2007).

In this study, the complexity of patients' experiences was highlighted (III) as they navigated the healthcare system, where the absence of a coherent care structure posed significant challenges to patient participation and shared decision-making. These findings highlight the need to deepen HCPs' understanding of patients' lived experiences and the relational aspects of care, insights that are essential for developing more responsive, patient-centred SVT care. They also point to the importance of developing cohesive care models, such as lifeworld-led care or person-centred care, to better support patients in managing episodic conditions such as SVT.

Sex and age-related differences in care

The findings revealed that most of the patients were female (I) and primarily sought care at healthcare centers, and while the number of referrals was remarkably low, women were referred even less frequently. Although the findings primarily highlight elderly women, it is important to emphasize that the concerns this condition causes, such as discomfort and even suffering, are evident regardless of age or gender, based on patients' narratives.

It is concerning that access to SVT treatment varies by gender, age, and geographical location. This pattern aligns with previous research showing that women are more likely to receive accessible, lower-cost primary care, while men tend to receive specialist inpatient care (Friberg et al. 2016). Recurrent visits to healthcare centres and emergency departments (I) highlight significant shortcomings in the current management of patients with recurrent tachycardia/SVT. In 2017-2018 there were 292 referrals (I); 57% were female outpatients, which at first suggests that the number of referrals is relatively equal

for both sexes. However, given the percentage of women who presented with this condition in healthcare facilities (68%), the referral rate must be considered. This aligns with previous research showing a significantly longer history of symptomatic SVT for females before a catheter ablation intervention compared with males (Rosengren et al. 2018). Although this study did not explicitly apply a gender theory framework, it would have been valuable to explore whether these differences stem from deep-rooted societal beliefs and assumptions about gender (SKR 2019). Future research could benefit from integrating gender theory to better understand how gendered norms and expectations shape healthcare-seeking behaviour, diagnostic pathways, and the legitimacy of patient experiences.

A key challenge in healthcare is identifying episodes of tachycardia for further assessment. However, this should not hinder the management of patients, especially when their narratives clearly indicate the nature of their condition. It is realistic to presume that the requirement to capture tachycardia on ECG results in an unnecessary delay of referral to specialist care for both men and women (Carnlöf et al. 2017). HCPs must also consider the validity and reliability of the techniques used to monitor heart activity. Encouragingly, developments in self-monitoring technologies, such as smartwatches and other wearable devices, are already underway and show promising potential for patients (Fernstad et al. 2024; Hillmann et al. 2022; Svennberg et al. 2022). A recent position paper highlighted several important findings: Women have a 2-3 times higher risk of developing AVNRT compared than men, SVT is more prevalent in the luteal phase of the menstrual cycle, and women report a greater impact on quality of life than men. Importantly, catheter ablation for SVT has been shown to be equally successful and safe for both sexes (Linde et al. 2018). These findings make it even more difficult to understand why women are referred to specialist care at a lower rate.

Health, as a lived experience, is deeply personal and shaped by existential, social, and biological dimensions. For patients with recurrent tachycardia/SVT, the unpredictability of symptoms disrupts their sense of bodily trust and familiarity, which caring science describes as a ‘homelike being-in-the-world’ (Dahlberg et al. 2009). Patients reported inhibited existence (II, III), in which the heart can no longer be trusted, and a sense of insecurity appears, an obstructive uncertainty, and patients may feel estranged in their own bodies, leading to vulnerability and a search for support. However, the experience of seeking care is not equal for all. Gender and age emerge as significant factors that influenced how patients are perceived, listened to, and treated (Carnlöf et al. 2017; Wood et al. 2007). Younger people often report being dismissed or having their symptoms attributed to anxiety or stress rather than being taken seriously as cardiac concerns. Older, women for example, may face assumptions that their symptoms are simply part

of aging, leading to underdiagnosis or delayed treatment. These patterns reflect deeper societal biases that shape clinical interactions and decision-making (Carnlöf et al. 2017).

From a philosophical standpoint, questions about epistemic injustice are raised when individuals are wronged in their capacity as experts of their own bodies and experiences (Merleau-Ponty 1945/2023). When HCPs fail to recognize or validate a patient’s narrative due to age or gender, they contribute to a form silencing that undermines person-centred care (Ekman 2022). When vulnerability arises with a sense of being strange or homeless in one's own body, life-suffering may appear. This may have consequences for access to life, restricting the person’s social activities, such as through a fear of driving or taking care of their grandchildren alone (Nordblom et al. 2017; Withers et al. 2015).

Being taken seriously

This thesis findings highlights existential concerns that need to be taken into consideration for care. Patients reported that they experienced being taken seriously when HCPs listened to them and treated them with respect. Participating in one’s own care involves understanding the importance of capturing tachycardia on an ECG, something that requires coordinated efforts between the patient and the healthcare system, as it often demands immediate action and can be challenging. In several reported cases (II, III), the patients had tried for years to capture their tachycardia episodes on an ECG. In some instances, they needed to be in an upright position during the recording, as lying down caused the tachycardia to stop and the heart rhythm to return to normal. This highlights the dual challenge of capturing the tachycardia but also interpreting the rhythm, a finding highlighted in Study I by the assessed ECGs. Challenges like this has been noticed in prior research; for example, Johnson et al. (2025) tested an artificial intelligence [AI] algorithm designed for direct-to-physician reporting of ambulatory ECGs. The results favoured the AI model in identifying critical arrhythmias. AI-only analysis could potentially reduce costs, improve access to care, and enhance outcomes for patients requiring ambulatory ECG monitoring (Johnsson et al. 2025).

On the other hand, a strong focus on objective parameters risks diminishing the significance of the patient’s narrative and their experience of symptoms. When patients experience, that they are not being taken seriously, it can lead to substantially delays in assessment and treatment for condition such as SVT and may evoke existential questions about life and death. These experiences deserve attention in clinical care to support patient health and well-being, and in research to inform the development of caring practices (Palmér et al. 2023).

In Study II, the patients described their experiences during treatment with catheter ablation. While they felt reassured that the ablation team were taken care of their heart as a physical organ, they also described a lack of concern for how they themselves were experiencing the situation. This disconnect can be understood through Merleau-Ponty's concept of reversibility, which emphasizes the intertwined relationship between the individual and their surrounding reality (Merleau-Ponty 1945/2023). When healthcare focuses solely on the body as an object, without acknowledging the patient's lived experience, the mutual exchange between HCP and patient is disrupted. In a similar situation (II), patients overheard internal staff communication, such as sequence "200-200-250." Some patients interpreted these numbers as the heart rate and found it a "cool thing to experience," while another believed they were about to die, thinking, "hopefully they manage to save my life." In moments like these, care may lack authenticity, as the human being are not treated as a whole, simultaneously a subject and object. These descriptions reflect experiences of care-suffering, which could be avoided through interactions with communication that informs and prepares the patient for what will happens during the ablation procedure (II, IV).

Another finding that needs to be discussed, due to the concept of reversibility, is the notion of being "actively passive" (II). This notion gradually emerged through an open and reflective attitude, with careful consideration on the patient experience during catheter ablation, with a deep focus on understanding their vulnerability. It became clear that the patients experienced this situation differently; some entered a relaxed state, while others struggled to do so. Those who achieved a relaxed state described using personal strategies, particularly meditative practices such as yoga or endurance techniques from physical activity, which they found helpful. After the interviews, when the procedure was explained in more detail, the patients became aware of the collaboration aspect of the interaction with the physician. Several expressed that they could have been better prepared if they had known in advance about this "actively passive" form of collaboration. During catheter ablation, patients need to lie still and remain relaxed, being actively passive; otherwise, the procedure might be jeopardized, and the physician might have to end it prematurely to avoid compromising the patient's safety. To the best of the PhD candidate's knowledge, this has not been described before Study II and would likely contribute to an increased awareness of what the treatment requires for the patient.

The severity of illness is shaped not only by clinical parameters but also by the degree of suffering it causes, how it disrupts the person's life, and how the individual is able to cope (Jølstad 2023). While adaptation can sometimes reduce perceived severity, certain conditions, such as recurrent tachycardia/SVT, may resist adaption, leading to persistent suffering. Jølstad (2023) also noted that perceptions of illness severity often influence

healthcare prioritization and resource allocation. From a philosophical perspective, this raises ethical concerns: When suffering is not visible or easily measurable, there is a risk that the patients are not taken seriously. In cases of recurrent tachycardia/SVT, it is worth reflecting on whether the condition is sometimes downplayed by HPCs, potentially leading to missed opportunities for timely referral to specialists (II, III). This suggests a need to move beyond a purely biomedical assessment and instead adopt a more holistic view that recognizes the patient's lived experiences as a legitimate form of evidence.

Health and suffering are intertwined in a dialectic movement, two aspects of the same process (Eriksson 2018). It is possible to experience health during moments of illness, such as recurrent episodes of tachycardia/SVT. One question is whether a focus on symptoms and potential diagnosis risks objectifying the patient and leading to care that does not address the patient's actual needs (II, III). On the other hand, once patients finally receive a diagnosis, it can facilitate communication with significantly others, such as next of kin, colleagues, employers, HCPs, and emergency services.

This thesis underscores the profound significance that patients attribute to receiving a diagnosis (III). Patients perceive a diagnosis as vital for affirming the legitimacy of their condition and or helping them feel believed rather than dismissed. This aligns with Svenaeus (2013, 2018), who argued that medical designations–the diagnosis–give suffering legitimacy and meaning. However, while a diagnosis can be empowering, it should not overshadow the patient's lived experience. From a lifeworld-orientated ethical perspective, the diagnosis is only one part of the whole that constitutes the patient's life situation (Arman et al. 2022). True understanding and support require attentiveness to the patient's narrative, where vitality is seen as a dynamic process shaped by relationships, context, and meaning–not merely by clinical labels.

Lifeworld-led care

This thesis calls for a reorientation of SVT care that incorporates existential and relational dimensions of health alongside medical considerations. A genuinely person-centred approach requires active efforts to address inequalities through trust-building, attentive listening, and the inclusion of all patients, regardless of gender or age. Despite widespread implementation in Sweden, person-centred care has not achieved the intended outcomes (Ekman 2022). Person-centred care and caring science offer complementary insights by emphasizing the patient's perspective, aiming to promote health and well-being and alleviate suffering. Lifeworld-led care adopts an existential view of the human being as constantly evolving, necessitating openness to patients' narratives and experiences. It offers a direction for care that acknowledges both human

agency and vulnerability. Within this framework, in collaboration with other HCPs, the nurse plays a central role in interactions for building trust, facilitating meaningful dialogue, and supporting patient participation throughout the care process. This enables ethically and existentially grounded care and strengthens patient participation (Dahlberg et al. 2009).

The finding across the studies in this thesis highlight the complexity (I) and emotional burden of living with recurrent tachycardia/SVT (II, III, IV). A lifeworld-led approach to care, grounded in the patient's lived experience, offers a valuable framework for responding to these challenges (Ekebergh & Lindberg 2020; Galvin & Todres 2013; Holmberg 2021). This existential model is particularly suited to understanding the existential dimensions of health, suffering, and well-being (Dahlberg et al. 2009). Lifeworld-led care emphasizes the importance of understanding the lifeworld: the patient as a person with a unique life context, beyond clinical symptoms, shaped by time, space, relationships and bodily being. Health is understanded as a movement: not just the absence of illness but also the ability to pursue meaningful life projects (II, III, IV). For patients with recurrent tachycardia/SVT, this means acknowledging the uncertainty, fear, and disruption that unpredictable tachycardia episodes cause in daily life (II, III, IV), as well as the frustration of not being believed or taken seriously when tachycardia is not captured as a sign on the ECG (III).

The notion of the 'existential waiting room' identified in Study III reflects how life can feel on hold or paused when care is delayed or fragmented. Feeling stuck in this waiting room is caused by a lack of continuity and illustrates how patients can be leaved in a suspended state, where life is paused and trust in the healthcare system is strained. Lifeworld-led care as a model could help to understand how delayed treatment can lead to existential suffering, even later, when physical symptoms are resolved (Dahlberg et al. 2009; Ekeberg & Lindberg 2020). It also supports the idea that being taken seriously and timely care are essential not only for the physical recovery but for restoring existential balance (II, III, IV).

A lifeworld-led approach to care highlights the nurse's essential role in ensuring continuity, building relational trust, and facilitating meaningful dialogue throughout the patient journey (Dahlberg et al. 2009). Nurses actively listen to patient's narratives, validate individual experiences, and collaborate with patients to develop care strategies that reflect their needs and preferences (Ekebergh & Lindberg 2020). This includes supporting shared decision-making and helping patients according to their priorities, such as methods for documenting SVT episodes and navigating the healthcare system. An approach like this aligns with the development and clinical outcomes for patients with atrial fibrillation (Wijtvliet et al. 2020; Yu, Xu & Lei 2024). This approach aligns with the principles of EBCD used in Study IV, where patients and HCPs collaboratively

identified areas for improvement, emphasized the importance of confidence-building support, tailored information, and substantial communication. The idea of an arrhythmia nurse was mentioned by Withers et al. (2015) in the context of patients with SVT and has been realized in nurse-led clinics focusing on atrial fibrillation (Holmlund 2024; Wijtvliet et al. 2020; Yu, Xu & Lei 2024). However, to the best of the PhD candidate's knowledge, such a model had not previously been implemented as a nurse-led pre-ablation clinic in Sweden. As a result of this thesis work, this model is now established at the Skaraborg Hospital, Sweden.

In line with a lifeworld-led approach and the findings in Study IV, nurses contribute to quality improvement by providing timely information in interactions at each stage of care. They ensure that information is tailored to the individual patient and is practical, balanced, and delivered from the responsible unit, minimizing patient anxiety and information overload. Direct communication with knowledgeable nurses was emphasized by patients (IV) as an important complement to written materials and digital portals, ensuring that patients receive nuanced, individualized guidance that may not be fully conveyed through written or digital information alone. Before interventions such as catheter ablation, a nurse-led pre-ablation clinic enables patients to ask questions and receive individualized guidance, supporting both patient well-being and clinic efficiency. Close collaboration between nurses and cardiologists is vital for optimal outcomes (IV).

In summary, lifeworld-led care offers a holistic response to the needs of the patients with recurrent tachycardia/SVT. It supports the development of more integrated, patient-centered practices that recognize the emotional, existential, and relational dimensions of living with an episodic condition (Dahlberg et al. 2009; Ekebergh & Lindberg 2020; Galvin & Todres 2013) and are applicable in different context of healthcare (Holmberg 2021).

Methodological considerations

In following section, individuals who took part in the studies are referred to as participants. This section will explore methodological considerations related to both qualitative and quantitative characteristics of data. Particular attention will be given to questions of evidence, including how different types of data contribute to understanding of the phenomenon of interest.

Qualitative characteristic of data (Studies II, III and IV)

Questions of evidence are discussed in this section in relation to the selected qualitative methods and the consideration taken. Phenomenology offered an opportunity to make the patients voices heard and to deepen the understanding of their experiences through the lifeworld approach, which was a primary concern of the PhD candidate. Recurrent narratives from clinical practice revealed that patients often feel unheard and not taken seriously. Phenomenology offers a non-dualistic, non-reductionistic, and holistic view of human existence, emphasizing lived experiences as central to understanding meaning in health and illness (Dahlberg et al. 2008). A strength of qualitative research lies in its well-established ontological and epistemological foundation, which contribute to the robustness of its evidence base (van Wijngaarden, van der Meide & Dahlberg 2017). In the method section of this thesis, both epistemological assumptions and methodological principles guiding the studies' implementation are presented (II, III, IV).

Questions of evidence according to the lifeworld approach, in notions as objectivity, validity, and generalizability can be understood in terms of openness, meaning, and essence (Dahlberg et al. 2008; van Wijngaarden et al. 2017). *RLR*, with its phenomenological approach, does not follow a fixed set of procedural rules. Rather, it serves as a methodological framework that supports thoughtful reflection and considerations in reaching scientific knowledge (Dahlberg et al. 2008). Findings derived from RLR can make an important contribution to research that employs other methodological approaches by adding both depth and meaning (II, III). Such findings may, for example, provide explanations for *why* certain patterns emerge in quantitative data (I), thereby illuminating underlying dimensions that cannot be captured through numerical measures alone. In this way, RLR enriches research conducted with different methods by offering complementary insights, enhancing interpretative possibilities, and supporting a more comprehensive understanding of the phenomenon studied.

Objectivity in qualitative research as phenomenology means confirmability and refers to the fact that the findings represent the patients' voices. From a lifeworld-theoretical and phenomenological perspective, this requires a phenomenon-oriented approach characterized by openness, sensitivity, and a reflective stance. Maintaining objectivity in this context acknowledges and starts from connection instead of detachment, in a disciplined attentiveness to the phenomenon, allowing it to reveal itself without being prematurely defined (Dahlberg et al. 2008; van Wijngaarden et al. 2017). As Dahlberg et al. (2008, p.339) claimed, researcher is, and cannot be anything other than, subjects within the lifeworld, who are intentionally involved in the exploration of any phenomenon.

The greatest challenge was adopting an alert, self-aware and reflective openness to practice throughout the research (II, III). This involved continuously reflecting on the PhD candidate's own pre-understandings and questioning personal assumptions, to remain open to the phenomenon and allow new meanings to emerge. In other words, to step aside from the natural position as a nurse and move into the position of a researcher while embracing a phenomenological attitude (Dahlberg et al. 2008). This approach was different from the PhD candidate's previous experiences; it was tentative and time consuming yet ultimately rewarding, and it allowed meanings to emerge that had previously gone unreflected upon. Before and during the implementation of the studies, the PhD candidate and the research group had discussions whether others should also conduct interviews. The PhD candidate's prior understanding in the EP-lab (II) was seen as a strength, offering valuable insights into catheter ablation procedures and the technical environment. This familiarity enabled a deeper understanding of the participants' reflection. However, this pre-understanding also posed a risk of overlooking subtle nuances and meanings in the data.

As far as known, Study II is one of the first in over 20 years to describe patients' perspective during electrophysiological examination and catheter ablation treatment for SVT, such as AVNRT and AVRT. This may be considered as a strength of the study. The participant who declined to reschedule because they had waited so long to share their experiences reflects a recurring theme: the desire to share their experiences. The participants expressed relief at finally being able to talk to someone who listened and had expertise in the area. In several interviews, there was curiosity from the participants about the specific environment of the electrophysiological lab, such as its technical aspects, while others had concerns about what really happened during the procedure. During these moments, the methodological principles of openness, flexibility, and reflection helped the PhD candidate to hold back the reaction to explain what really happened and instead, with curiosity, ask follow-up questions to preserve focus on the experience described. This dilemma was solved by having dialogue after the interview,

which was appreciated by the participants, who said that this was something that they wanted to know beforehand as patients to be better prepared for the procedure.

During the lifeworld-interviews (II, III), it became evident that silence can be a helpful approach. Allowing participants to linger in their thoughts often led to new insights that surprised them, as these reflections had not previously arisen. By *bridling*, the PhD candidate refrained from steering the conversation, enabling the participants to follow their own thoughts and reflections. At the same time, preconceptions were held back, maintaining openness to the phenomenon as it presented itself. This approach allowed meanings to emerge more authentically from the participants' lived experiences, for a depth of understanding that could not have been achieved through direct questioning alone. This enhances the phenomenological *sensitivity* of the study, ensuring that the findings are grounded in the participants' own expressions and contexts. Together, these practices strengthen the *trustworthiness* and dept of the analysis, supporting both *reliability* and *transferability* in qualitative research (Dahlberg et al. 2008; van Wijngaarden et al. 2017).

Throughout the research process, the research team in each study (II, III) supported the PhD candidate in the development into the role of researcher. Their reflective discussions, diverse perspectives, and expertise were invaluable, particularly in helping the PhD candidate guard against bias, maintain a phenomenological attitude through reflections, and refrain from deciding too quickly (bridling). To ensure *reliability*, the research team continuously ensured the rigor of the data by engaging in critical reflection. Manuscripts were peer-reviewed during research education seminars, and feedback from colleagues and professors contributed to refining the analysis. Additionally, reviewers from the scientific journal (II, III) provided constructive input that strengthened the final versions. These steps enhanced the *credibility* of the findings.

The participants (II, III, IV) represented a diverse sample of adults of varying ages and gender, living in both rural and urban areas. Their education backgrounds ranged from primary to academic levels. This diversity was considered representative of the broader population from a Swedish healthcare perspective, contributing to the objectivity and relevance of the findings. It was somewhat more difficult to include younger people under 30 years of age, which can be seen as a limitation. All lifeworld interviews (II, III), including the workshops (IV), were conducted according to participants preferences: at their homes, at the hospital, by phone, or via digital meeting. Reflections on the interview setting suggest that the most important factor is creating a confident and relaxing environment that allows participants to be fully present in the moment. Interviews conducted in these different formats may have influenced how openly participants shared their experiences, potentially affecting depth and consistency.

Validity in qualitative research refers to the relevance and meaningfulness of findings for those affected—in this case, patients living with recurrent tachycardia/SVT. It also involves transparency throughout the research process, including clear epistemological and methodological foundations (Dahlberg et al. 2008; van Wijngaarden et al. 2017). In RLR, validity means ensuring that the phenomenon studied is truly the one intended, and that it is approached with openness and rigor. It is closely tied to meaning, as it concerns how individuals describe and experience a phenomenon within their lifeworld. Both objectivity and validity demand a consistent alignment between the research question, methodological choices, and data collection (Dahlberg et al. 2008; van Wijngaarden et al. 2017). The participants (II) were invited due to the inclusions criteria including adults with the experience of catheter ablation treatment. A specific timeframe was applied: a minimum of three months after the procedure to allow a healing period, and a maximum of 12 months to reduce the risk of memory lapses. The timeframe offers several important dimensions for capturing important dimensions for capturing meaningful reflections on the treatment experience.

As the PhD candidate saw it, a short delay between the experience and the interview allows participants time to reflect and process their experiences while keeping them vivid and accessible. In Study III, the inclusions criteria were consistent with Study II, except for the timeframe, due to the research question focused on patient participation in seeking care for recurrent tachycardia. The PhD candidate observed that participants who received timely and effective care tended to provide shorter, more straightforward narratives, often with fewer emotional nuances. These interviews reflected satisfaction with healthcare interactions. In contrast, participants who had endured prolonged and frustrating efforts to access appropriate care, regardless of how long ago these events occurred, shared vivid, rich, detailed narratives marked by existential burden. Their experiences remained emotionally present, suggesting that the suffering associated with delayed or inadequate care had not diminished over time. These interviews provided deep, nuanced descriptions of the participants' lived experiences with recurrent tachycardia/SVT (II, III). This suggest that the phenomenon had a lasting existential impact, reinforcing the relevance and authenticity of the data. Including individuals with both smooth and challenging care experiences allowed for variation in the data, supporting a more comprehensive understanding of the phenomenon. There may be limitations regarding validity: Although vivid memories can indicate lasting impact, retrospective accounts may be influenced by time and emotion, which can affect the accuracy of details. The PhD candidate's dual role as a nurse and researcher may have introduced subtle bias, despite efforts to maintain a bridled stance.

Questions of evidence according to reflexive thematic analysis differs slightly in goals and how to conceptualize and present evidence, and in notions of validity and rigor,

understood in terms of reflexivity, credibility and transferability (Sundler et al. 2019). *Rigor* refers to scientific quality of the research and is closely linked to how the study is presented and how *validity* is ensured throughout the thematic analysis process (Sundler et al. 2019). *Reflexivity* involves critically examining how the researcher engages with the data and influences the understanding of and development of themes. Employing two methodological approaches presented a challenge, particularly in transitioning from the bridled openness of RLR (II, III) to the more active engagement in reflexive thematic analysis (IV). In Study IV, objectivity was redefined, and the PhD candidate played an active role in reflecting on the data, evidence was understood as constructed through reflexive engagement rather than discovered, and themes were developed (Sundler et al. 2019).

The findings (IV) should be understood in relation to the settings in which data were collected, digital workshops for the patient representative and a hospital setting for the HCPs. The PhD candidate was actively engaged throughout all phases of the study and approached the dual role both researcher and facilitator with openness, sensitivity, and conscious effort to minimize the influence on the data through the selection of questions, interpretation of responses, and decisions about what is presented. A further complexity lies in the PhD candidate's embeddedness in the same healthcare context being studied, which may shape both the interactions and the analytical view. Moreover, the nature of the data, workshops with patients versus process-orientated engagement with HCPs, can be critiqued for differing in character and depth. However, in this study, the combination is considered justified, as it enables a multifaceted understanding of care development from both experimental and professionals perspectives. Reflexive thematic analysis was chosen to explore patterns of meaning grounded in the participants narratives. The themes are data-driven and illustrated with quotes, supporting the abstraction of knowledge while enhancing the potential transferability of the findings beyond the study context. Throughout, the intention has been to remain open to participants' experiences and to actively seek *otherness*, perspectives that challenge assumptions and contribute to a deeper understanding of care.

Generalizability in qualitative research, such as RLR, means that the finding should be meaningful beyond the specific participants involved while remaining contextual (Dahlberg et al. 2008). From a positivistic perspective, a small sample size may be seen as a limitation for generalizing findings. However, from a lifeworld-theoretical and phenomenological perspective, the strength of the finding lies not in the number of participants, but in the depth of the descriptions and the search for meanings (Dahlberg et al. 2008). The challenge is to present the findings as a general structure of meaning, one that captures both the essential characteristics of the phenomenon, what makes it what it is, and the individual variations, often illustrated through participants quotes that

highlight nuance and variety. In Studies II and III illustrative quotes are presented with an intention to support the text of the findings. *Usability* refers to how research findings can be applied in practice. It involves considering how findings can inform and guide care, based on coherent and well-reasoned reflections about the limitations and possibilities for implementation (van Wijngaarden et al. 2017).

All participants (II, III, IV) were Swedish speakers, although several had origins in other countries. This linguistic homogeneity may limit the generalizability, as it excludes perspectives from individuals who might experience and express their healthcare experiences differently due to language barriers or cultural nuances. This absence highlights an important area for future research, as their voices remain underrepresented.

Credibility, a question of evidence in reflexive thematic analysis used in Study IV, refers to the meaningfulness and transparency of the findings presented. To support credibility, the PhD candidate attempted to clearly describe the method used and to report on methodological decisions and considerations throughout the study. The themes described have been supported by illustrative quotes to ensure the consistency between the described meanings and the data (IV). Additionally, the PhD candidate provided information about the research setting to helps readers understand the context in which the findings were generated (Sundler et al. 2019).

In Study II, the context involved participants' experiences of undergoing catheter treatment while awake. These findings may be transferable to similar contexts, such as procedures for other kinds of arrhythmia or cardiac catheterization during coronary angiography. The study provides insights into how patients perceive and cope with these procedures, offering guidance on how to better support them in similar care contexts. In Study III, the focus was on the participants' experiences of participation in their own healthcare, which often involved repeated interactions across levels of care and with multiple HCPs. The findings from Study III, situated in a prolonged context of frequent healthcare encounters, may to some extent be transferable to other patients who struggle to receiving appropriate and timely care. It is also important to consider that findings in phenomenological studies should not be regarded as final; rather, they represent an ongoing conversation shaped by context (Dahlberg et al. 2008) and new research questions.

Study IV is a reflexive thematic analysis and differs slightly from Study II and III with their RLR approach. *Transferability* refers to the usefulness and relevance of the finding, they must be understandable, recognizable, and relevant to a more specific or broader context than original study (Sundler et al. 2019). The participants in Study IV, represent two different perspectives of the care for patients with recurrent tachycardia. The patient representatives were recruited with the criteria of having experiences with recurrent

tachycardia, representing patients, and the HCPs selected had experiences of providing care to patients with recurrent tachycardia, selected to represent all aspects of the ablations process. While the strategy to recruit mainly from one clinic can be criticized for limiting transferability, the patient representatives' narratives reflect experiences across the VGR.

In Study IV, the focus was on patients experiences and interactions during the period surrounding the referral decision and subsequent specialist care. This phase represents a crucial part of the overall care process for individuals with SVT. The findings may offer guidance for improving care for these patients, particularly in relation to communication, coordination, and expectations during transitions in care. Although the Study IV is specific to patients with SVT, several identified issues, such as unclear referral processes, fragmented communication, and lack of continuity, are relevant on a broader level and not limited to this patient population. These insights may therefore be transferable to other areas of healthcare in which similar challenges exist and can inform the development of more integrated and person-centered care models.

Quantitative characteristic of data (Study I)

Questions of evidence are discussed in the following section in relation to the selected quantitative methods and their related considerations. Study I was situated within the positivistic tradition and aimed to explore healthcare utilization at both the meso-level (the healthcare system) and the micro-level (the individual). To examine patterns in seeking unplanned care for recurrent tachycardia, existing data from medical records and registries were used. The quality of the study depends on the relevance and accuracy of the collected data, as well as whether the chosen analysis methods effectively address the research questions. In quantitative research, evidence is typically evaluated in terms of validity, reliability, and generalizability (Flanagan & Beck 2025).

Validity refers to how well a study measures what it intends to measure and reflects the overall quality and lack of bias in its design and findings. High-quality, accurate, and complete data are essential for drawing reliable conclusions, as any inaccuracies or bias can undermine validity. Therefore, it was crucial that data collection was conducted accurately and consistently (Flanagan & Beck 2025). There are some strengths and limitations due to using retrospective data. As a strength, the data has already been collected which is cost effective and time efficient compared to other designs, such as prospective data collection.

Retrospective studies often use data from large populations, and in Study I, a period of 24 months was chosen to optimize the analysis of healthcare utilization for this

population. Another strength is that data reflects actual clinical practice, which can enhance the validity of the findings. The generation of a hypothesis can help identify patterns that may inform future studies. The limitations of using retrospective data include concerns about the data quality and completeness; data may be missing, inaccurate, or inconsistently documented, such as the assessment and use of ICD-10-SE codes. There is no way to control or influence how data were collected, which may limit the ability to account for confounding factors (Flanagan & Beck 2025).

The PhD candidate's endeavor to collect data to examine unplanned visits for outpatients seeking for symptoms of tachycardia, for both diagnosed and undiagnosed patients. To determine the relevant variables for data collection, the PhD candidate developed a comprehensive list encompassing variables such as visits type, patient age and gender, selected ICD-10-SE diagnostic code, and date of visit. The list of variables was the same for both sources: medical records at the hospital and the VEGA primary care registry. The initial step in the data analysis process involved familiarization with the collected data. This included identifying and removing duplicates or incomplete entries. Next, the data were reviewed according to the inclusion and exclusion criteria. Given the size of the dataset, this step was particularly time consuming. A collaborative dialogue was held with staff at the hospital's research and development center, where the PhD candidate received valuable guidance on selecting suitable statistical analysis for the dataset. A limitation of the study is that referrals may have reached specialist care through channels not captured in the data. Targeted efforts were made to identify potential communication pathways for referrals, but some may still have been missing.

Reliability is a prerequisite for validity. In quantitative research, it refers to measurement accuracy and repeatability: the ability to obtain the same findings using the measurements. The reliability of a study depends on how the data are collected. In retrospective studies, reliability may be affected by inconsistent documentation or missing data (Flanagan & Beck 2025). A strength of this study (I) is the robust sample size and its use of comprehensive registry data, which enhances the reliability of the findings. Reliable studies are reproducible, which strengthens the credibility of the findings and supports evidence-based practice. Interestingly, during the time this study was being prepared for publication, other studies from other part of the Western world, were published on the same topic and within the same research area (Chew et al. 2021; Sacks et al. 2020a; Sacks et al. 2020b). Their results aligned closely with the findings of this study, further supporting its relevance and reliability.

Generalizability in quantitative research depends on both validity and reliability being well established. It refers to the extent to which the findings can be transferred to other individuals or contexts, although some caution should always be exercised when making such assumptions (Flanagan & Beck 2025). This study (I) was performed in a Swedish

context, which may limit its generalizability to other countries and healthcare systems. To help readers assess whether the findings are generalizable to other settings, the process has been described as thoroughly as possible. Additionally, the study is timely and highlights critical areas for improvement in arrhythmia management.

Language, clarity, and grammar improvements in parts of the thesis coat text were supported by Microsoft 365 Copilot AI tools. All content was rigorously reviewed and endorsed by the PhD candidate, who takes full responsibility for the final text.

Conclusions

This thesis in caring science offers increased and in-depth knowledge of what it is to live with and seek care for recurrent tachycardia/SVT through the eyes of the patients, from a lifeworld perspective. It emphasizes the patients' perspectives to understand their lived experiences and highlights how caring practices can be developed to better meet their needs. The findings underscore that medical and technical solutions alone are insufficient. There is a clear need to improve the relational aspects of care, particularly in terms of how patients are listened to and supported.

A recurring theme throughout this thesis is the lack of adequate follow-up care after initial contact with the healthcare system. This gap reflects unequal access to sustainable treatment, influenced by factors such as gender and age. The patients reported not being listened to and described experiences of suffering that point to systematic disparities in care. These insights call for a more holistic and equitable approach to caring, one that integrates both clinical expertise and genuine human connection.

Patients with recurrent tachycardia/SVT seek care with trust and hope for a relief from a condition that unpredictably disrupts daily life and causes profound suffering. However, identifying arrhythmias remains challenging, and current management often falls short, leading to repeated unplanned visits and care-related suffering. Early and proper assessment is essential not only for patient well-being but also for healthcare efficiency and must address disparities related to sex and age.

Despite frequent primary care visits, referrals to specialist care remain rare, possible due to outdated perceptions of catheter ablation. However, recent research, including patient perspectives from this thesis, shows that ablation is often a valuable intervention, confirming that SVT is a treatable condition and offering renewed possibilities. The patients emphasized the need for informative and caring dialogue, especially before, during, and after ablation. Their experiences revealed fragmented interactions across various healthcare levels, where continuity was lacking. Participation, grounded in trust, was undermined by this discontinuity, leaving patients in an 'existential waiting room,' hoping to be seen as whole individuals.

Contributions to new knowledge

This thesis has contributed descriptive knowledge on a general and individual level concerning an elusive condition, SVT, which affects and disrupt daily life for adult

patients of all ages. All studies (I-IV) were conducted in a Swedish context, and participant were recruited from one clinical center (II and III), which might be seen as a limitation of the findings. However, it is important to keep this research in motion to be develop and improve current management and strengthen patients' health processes in a way that is meaningful to them.

Study I contributes to the field of cardiology, particularly in understanding healthcare utilization for arrhythmias. It advances the conversation around the necessity for tailored healthcare solutions in cardiology and serves as a call to action for addressing observed disparities in care access.

Study II contributes to the field of cardiology, particularly in understanding patients' perspectives before and during treatment with catheter ablation for SVT. The findings highlight the emotional and existential dimensions of being awake during a physically invasive procedure. Study II fills a gap in the research on patient perspectives in modern catheter ablations procedures, which has evolved significantly since earlier studies in the 1990s.

Study III contributes to highlighting the complexity of navigating the healthcare system for patients, where the lack of a coherent care structure creates challenges for patient participation and shared decision-making. This study underscores the need for a deeper understanding of patients' lived experiences and the relational aspects of care. It also points to the importance of developing cohesive care models, such as lifeworld-led care, to better support patients in managing episodic conditions such as SVT.

Study IV contributes to the field of cardiology by demonstrating how the EBCD approach can be effectively applied to identify patient-centred improvements in the care of individuals with recurrent tachycardia/SVT. Although the study focuses on one segment of the care pathway, specialist care surrounding catheter ablation, it reveals broader insight into the relational aspects of healthcare. Reflexive thematic analysis uncovered a key finding: Patients value being recognized as individuals beyond their diagnosis. While standardized information and general instructions were useful, the participants consistently emphasized the importance of personal contact, highlighting the enduring value of human interaction in healthcare delivery.

Implications of this thesis

This thesis highlights the need of support and involvement in all levels of healthcare, emphasizing the importance of addressing sex- and age-related differences to ensure equal care. The findings underscore the necessity of early assessment for potential recurrent arrhythmias and the value of informative, supportive conversations for patients undergoing catheter ablations. Repeated encounters at various levels of healthcare and with numerous HCPs results in unstructured care, making it difficult for patients to feel that they have been taken seriously, especially when tachycardia is undocumented. A diagnosis validates patients' experiences, serving as a bridge to being believed and providing direction for treatment. Increased participation can be achieved through a joint effort to determine the diagnosis, grounded in a mutual trust in the patient's competence and narrative. From a patient perspective, the lack of actively engaged healthcare professionals suggests a need for improved collaboration within interprofessional teams, incorporating comprehensive and patient-centred care.

Implications for local practice

This thesis has identified and explored potential areas for improving patient care, such as referral patterns from healthcare centers to specialist care (I, III). Further, it explored the patient perspective concerning experiences during catheter ablation, which may be of interest for other electrophysiological centers developing care in this specific timeline of the care process, such as nurse-led pre-ablation clinic (II-IV).

Implications for wider healthcare

Considering the aging global population and increased focus on personalized medicine, Study I could influence future health policies and guidelines. The study raises broader questions about the integration of primary and specialist care, particularly with regard to varying healthcare resources. Study III highlight challenges in identifying potential arrhythmias and underscore the need for improved early assessments strategies. New structured management needs to be sustainably implemented at all levels of healthcare. Any improvements benefit both patients and the healthcare system while also addressing differences related to sex and age.

Future research

Study I underscores a critical need for the adaption of health services to suit differing patient needs, which, if addressed, could vastly improve clinical outcomes related to tachycardia management. Future research could build upon these findings by exploring interventions to balance these disparities and improve patient outcomes. The referral rate to cardiology specialist care was significantly low, especially from primary healthcare and compared to the high proportion of hospitalizations from the emergency departments, and this circumstance deserves further investigation.

Study II suggest that phenomenological insights can guide improvements in patient-centred care and ethical practice. It highlights the need for supportive, informative communication before, during, and after treatment with catheter ablation for SVT. Future research could further examine the different strategies used of the patients during the ablation procedure and the physical and mental strategies that helped patients endure the discomfort during electrophysiological examination and treatment with catheter ablation.

Study III identified nurses, with their specialized competencies, as an underutilized resource in the care of patients with recurrent tachycardia/SVT. Given that patients today often navigate multiple levels of healthcare and encounter various HCPs, future research should explore the potential role of nurses as consistent points of contact for patients throughout the care continuum. Such research could investigate how nurses might serve as guiding anchors, from initial contact in primary care through to specialist care, thereby enhancing continuity, coordination, and patient-centeredness in the management of SVT care.

Study IV identified potential areas for improvements, especially during the time of referral and interactions with specialist care. This study represents an important step in exploring collaborative approaches to improving care for patients with recurrent tachycardia/SVT. The findings offer valuable insight into patients' and HCPs experiences. A logical next step is to conduct a follow-up study that includes the final phase, a joint service user-HCP event, to fully realize the co-design potential. This continuation should be situated in a primary care context, where many patients first seek help and where early recognition, and continuity of care are critical. Such a study could deepen the understanding of patients care and support the development of more responsive, patient-centered practices across healthcare levels.

The overall findings of this thesis highlight how patients navigate the healthcare system, revealing deficiencies in care that affect patient participation, continuity, and responsiveness to individual needs. These insights point to the importance of continued research aimed at developing more holistic and patient-centered care for patients with recurrent tachycardia/SVT. Although catheter ablation has proven effective in improving quality of life for many patients with AVNRT, emerging research suggests that long-term risks may persist. Recent studies (Andreasen et al. 2022; Paludan-Müller et al. 2025) challenge the view of AVNRT as a benign condition, showing associations with cardiomyopathy, heart failure across all age groups, and increased mortality, particularly among younger patients.

Furthermore, the patient perspective on non-response to ablations remains underexplored. Understanding the experiences of those who do not benefit from ablation is essential for refining treatment strategies and ensuring equitable care. Continued research is needed to strengthen the evidence base, address disparities related to gender and age and develop sustainable care models that support both responders and non-responders. By integrating clinical outcomes with patient narratives, future studies can contribute to the advancement of caring practices that are not only effective but also deeply attuned to the lived experiences of those affected by SVT.

Summary in Swedish

Svensk sammanfattning

Att leva med plötslig hjärtklappning, supraventrikulär takykardi (SVT), kan för många innebära utmaningar att få rätt vård i rätt tid. SVT är ett återkommande och många gånger svårfångat tillstånd med snabb hjärtrytm, vilket kan leda till upprepade kontakter med olika nivåer inom hälso- och sjukvården under lång tid. Avhandlingens övergripande syfte var att beskriva hur det är att leva med och vårdas för återkommande SVT, med fokus på patientperspektivet och hur vården kan utvecklas.

Metoder
Avhandlingen har en vårdvetenskaplig grund och en induktiv ansats. Livsvärldsteorin användes för att förstå patienternas erfarenheter. Fyra delstudier genomfördes.

Studie I: Kvantitativ, retrospektiv design. Beskriver 2719 oplanerade vårdbesök, i primärvård och på akutmottagningar, där patienter sökte akut på grund av symtom på snabb hjärtrytm, analyserade med beskrivande och jämförande statistik.

Studie II och III: Kvalitativa, fenomenologisk metod med livsvärldsperspektiv. Studie II fokuserar patienters erfarenheter av kateterablation, och Studie III patienters erfarenheter av delaktighet i vårdprocessen. Intervjuer genomfördes med 12 respektive 17 patienter.

Studie IV: Erfarenhetsbaserad co-design (EBCD) med fyra patienter i två workshops, och sju vårdpersonal från kardiologisk specialistvård, i ett process-orienterat förbättringsarbete under fem dagar. Reflekterande tematisk analys användes för att identifiera utvecklingsområden.

Huvudresultat
För patienter med återkommande hjärtklappning, kan det vara en kamp att bli tagen på allvar av sjukvården. Särskilt i primärvården är antalet vårdbesök ojämnt fördelat mellan könen, och remisser till hjärtspecialist är ovanliga. Delaktighet i den egna vården försvåras av bristande kontinuitet och avsaknad av planering för nästa steg, vilket skapar en känsla av att livet pausas i ett ”existentiellt väntrum”. Trots detta finns tillit och hopp kvar, men bemötandet är avgörande. Att bli sedd som en kapabel person med ett liv utanför vården är viktigt. I ett utvecklingsarbete med patienter och sjukvårdspersonal i specialistvård framkom att patienterna föredrog att få prata med någon kompetent om tillståndet, framför att få till sig information på annat sätt. Att genomgå behandling med kateterablation upplevs som en känslomässig process där patienten litar på vårdens expertis, samtidigt som patienten försöker återfå sitt välbefinnande. Behandlingen bekräftar att tillståndet är fysiskt och går att behandla, vilket förändrar synen på framtiden till möjligheter - i stället för de hinder i vardagen som hjärtklappningen inneburit.

Konklusioner
Avhandlingen lyfter fram att patienter med hjärtklappning behöver mer stöd och möjlighet att vara delaktiga i sin vård – oavsett vårdnivå. För att vården ska vara jämlik är det viktigt att ta hänsyn till de skillnader som ses i sjukvårdens nuvarande hantering av dessa patienter kopplade till kön och ålder. Patienterna betonar vikten av att få tidig bedömning och att ha stödjande samtal med vårdpersonal, särskilt före, under och efter behandling med kateterablation. Många upplever att vården är splittrad, med flera olika vårdkontakter, vilket ger intrycket av att inte bli tagen på allvar - särskilt när hjärtklappningen inte är diagnosticerad. Att få en diagnos ger patienten en bekräftelse på symtomen, underlättar kommunikation och ger riktning för behandling. Delaktighet kan stärkas genom samarbete mellan patient och vårdpersonal, där patientens berättelse och resurser tas på allvar.

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Health care centre and emergency department utilization by patients with episodes of tachycardia

Ann-Katrin Nordblom[1,2*], Gabriella Norberg Boysen[2,3], Mia Berglund[4] and Anna Kjellsdotter[4,5]

Abstract

Background: Outpatients seek to visit health care facilities for episodes of tachycardia-related signs and symptoms. The challenge for physicians is to balance a proper initial assessment and avoid overlooking a possible arrhythmia. This common clinical situation affects individuals and health care utilization, and effective management may substantially affect health care resources. This study aimed to explore health care utilization for outpatients with episodes of tachycardia visiting health care centres (HCCs) and/or emergency departments (EDs).

Method: This retrospective study used data of adult outpatients (≥ 18 years) who were assessed by a physician as having a specific or nonspecific diagnosis of arrhythmia between 2017 and 2018, and data were retrieved from medical records and a regional registry database. Data was analysed with appropriate statistical analyses to identify disparities between sex, age and terms of search pattern for each health care facility. Analysis of variance was used to test disparities between the sexes, and one-factor ANOVA was used for the incidence of missed arrhythmias.

Results: A total of 2719 visits with 2373 outpatients were included in the study. The result showed a significant difference in the total number of visits ($n = 2719$) between female and male patients (68% vs. 32%, $p < .001$). In the 60–69- and 70–79-year age groups, females had significantly higher frequencies of visits than males ($p = .018$). A significant difference was also observed between sexes in terms of which health care facility they tended to visit ($p < .001$). Ninety-five percent of the outpatients visiting EDs were hospitalized. When estimating the incidence of missed arrhythmias (diagnoses) in relation to assessments, the results showed a 5% missed diagnosis involving potential atrioventricular nodal re-entry tachycardia and atrioventricular re-entry tachycardia. Moreover, the referral rate was low, especially from HCCs to cardiologists.

Conclusions: This study shows a significant difference in total visits in HCCs and/or EDs by patients of different sexes and indicates the need for improved care for outpatients with episodes of tachycardia. Sex- and age-related differences must be addressed with an aim of providing equal care. Finally, the low rate of referral from HCCs to cardiologists compared to the high proportion of hospitalizations from EDs, deserves further investigation.

Keywords: Episodes of tachycardia, Arrhythmia, Health care centre, Emergency department, Sex and age differences, Retrospective study

Background

Episodes of rapid heart rate with tachycardia-related signs and symptoms are a reason why people seek medical attention at health care centres (HCCs) or emergency departments (EDs) [1–3]. The episodes may affect

*Correspondence: ann-katrin.nordblom@vgregion.se
[1] Department of Cardiology, Skaraborg Hospital Skövde, 54185 Skövde, Sweden
Full list of author information is available at the end of the article

patients' daily lives, as well as their need for medical assistance, generating consequences for individuals (repeated investigations/visits, social disadvantages, and economic costs) [4–6] and society (costs to the national economy and the consumption of health care resources) [5, 7, 8]. The severity of the episodes and the presence of signs and symptoms is highly variable, depending on the patient's heart rate, duration of tachycardia, underlying heart disease, and individual experience [1, 9]. Supraventricular tachycardia (SVT) is a generic term for atrial arrhythmias, including condition such as atrioventricular nodal re-entry tachycardia (AVNRT) and atrioventricular re-entry tachycardia (AVRT). SVT affects approximately 0.17–0.20% of the Western population [10–12]. These arrhythmias are benign, except in rare situations [1, 9, 13]. They may occur at any age; although they are common in young adults, they do not emerge in some patients until they are elderly. Females are diagnosed with AVNRT more frequently than males (70% vs. 30%); the opposite is true for AVRT (45% vs. 55%) [1, 14, 15]. The signs and symptom are often recognizable for the patient from previous episodes and may be associated with palpitations, neck pounding, light-headedness, chest discomfort and presyncope, and rarely syncope [1, 3]. Symptoms, such as fatigue and/or polyuria, may occur during or after an episode of tachycardia and may last for hours or even days [4]. The clinical characteristics of AVNRT and AVRT are the abrupt onset and sudden termination of regular tachycardia [1, 3]. Episodes may be more frequent with longer durations over time and may exert a severe, negative effect on a patient's quality of life with an increased symptom burden [1, 9]. Previous research has shown a negative effect on patients' daily lives [6, 14–16] and patient frustration due to repeated, time-consuming visits to health care services and increased utility of health care resources [3, 6, 14]. Patients have experienced not being taken seriously by physicians, with their signs and symptoms explained as stress or mental instability [4, 6, 14, 15]. The challenge for physicians is to balance a proper initial assessment and estimation of the likelihood of a relevant underlying arrhythmia or other possible explanation [1–3]. Electrocardiograms (ECGs) with ongoing SVT show a characteristic tachycardia pattern, while this finding is valuable for the assessment, it can be challenging since the episode may be terminated spontaneously before 12-lead ECG is recorded [4, 15]. Overlooking a possible arrhythmia may cause a delay in proper first-line treatment for AVNRT and AVRT, for example, vagal manoeuvres as self-management [1, 3, 5, 17, 18] and a delay in referral for a cardiologist opinion [14, 15]. Patients need information about how their symptoms and quality of life may change following these treatments to enable them to make informed decisions about treatment options [1, 18, 19]. Catheter ablation therapy represents a potentially curative therapy, with a 95–97% success rate for AVNRT and a 95% rate for AVRT [1, 14, 18], compared to lifelong drug treatment [1, 18]. Following catheter ablation, a significant improvement is observed in a variety of symptoms and quality of life indices [10, 13, 19], as well as decreases in medical and health care costs [20, 21]. However, studies of health care utilization at both HCCs and EDs for outpatients with episodes of tachycardia (potential SVT) are limited [5, 15]. Hence, effective management of outpatients with tachycardia may substantially affect the utilization of health care resources [2, 21]. This study aimed to explore health care utilization by outpatients with episodes of tachycardia visiting HCCs and/or EDs. The hypothesis is that no differences in search patterns exist between sexes at health care facilities.

Method

Sweden has a long tradition of health data registration based on the personal identity number that each citizen is assigned at birth or when attaining citizenship. This retrospective registry study was conducted in southwestern Sweden with an approximate population of 214 000 inhabitants aged ≥ 18 years (50.5% male) [22]. This area has two county hospitals with EDs and 15 communities, each with one or several HCCs [22]. The HCC constitutes the first level of care; it is considered an entry point for patients with new health problems and, if necessary, collaborates with other levels of care and specialists to coordinate patient care and treatment [23]. Since 1992, the International Classification of Diseases and Related Health Problems (ICD-10) [24] has been used to statistically classify groups of diseases, health problems and causes of death in medical records. The 10th Revision Swedish version (ICD-10-SE) [24] was used in this study. Permission was obtained by the Ethical Review Board of Uppsala, Sweden (Dnr: 2019–03,295 with additional application 21-01-2020). The permit includes that need for written consent was waived, due to the retrospective nature of the study. The investigation conforms with the principles outlined in the Declaration of Helsinki [25].

Data collection

Data were collected using statistical data for outpatients´ unplanned visits to HCCs and EDs during the period from January 2017 to December 2018. Data were selected from a registry (regional administrative health care database) and medical records. Initially, the outpatients were identified by their identification number, and then participant data were anonymised, but these changes did not distort the scientific meaning. The inclusion criteria were outpatients aged ≥ 18 years who were diagnosed by a physician as having a specific or nonspecific arrhythmia that included at least one of the selected ICD codes described in the next section. The exclusion criteria were a known diagnosis of atrial fibrillation or atrial flutter (ICD-10-SE: I480, I481, I482, I489) [24].

Selection of ICD-10-SE codes

Selected ICD-10-SE codes were used to identify potential outpatients with symptoms and signs related to episodes of tachycardia (potential SVT) [24]. The sample comprised R-codes of nonspecific symptoms related to tachycardia and the I-codes with nonspecific or specific diagnoses related to SVT, as follows: I471, 'Paroxysmal supraventricular tachycardia'; I479, 'Paroxysmal tachycardia, unspecific'; I498, 'Other specific heart-arrhythmia'; and I499, 'Heart-arrhythmia, unspecific.' The nonspecific symptom R-codes were identified as common in the medical record for the patient group of interest and considered important to identify patients without a diagnosis of arrhythmia, as follows: R000, 'Tachycardia, unspecific' and R002, 'Palpitations.' Among the outpatients visiting EDs because of arrhythmia, another ICD-10-SE code of interest was identified—U999, 'Diagnostic information is missing'- because of the high incidence of measures related to the heart and resulting of hospitalization for further investigation.

Validation of heart-rhythm

Random sampling was conducted using 100 outpatients admitted to EDs with unspecific ICD-10-SE codes (R000, R002 and U999) to estimate the incidence of missed arrhythmias (diagnoses) in relation to the ECG assessment. The accuracy of the sample was determined based on 95% in confidence interval (CIs). It was distributed as a percentage by age group and sex using a random generator in the Excel software program (Random Generator at Microsoft Excel, Office 365). The intention was to identify arrhythmia as AVNRT or AVRT (ICD-10-SE codes: I45.6A and I47.1, respectively) [24]. The inclusion criteria were adherence to the criteria and confirmation by the electrophysiologist. A review of the records was performed for all potential cases using an algorithm based on standard ECG criteria for SVT to interpret ECG and then identify the potentially eligible arrhythmia. The criteria were as follows: (1) paroxysmal occurrence (sinus and episodes of tachycardia), (2) narrow QRS complex configuration or pre-excited bundle branch block, (3) variation in successive RR ≤ 40 ms, (4) ventricular rate ≥ 120 bpm, (5) no evidence of AV dissociation and (6) no identifiable P-waves preceding the QRS complex during tachycardia [11]. The ECG identified as potentially eligible AVNRT or AVRT was then confirmed by the electrophysiologist.

Data analysis

Descriptive statistics were used to assess the participants' visits after stratification by sex, age, frequency, level of care (HCC and ED) by calculating mean values and 95% CIs. The difference between sexes was pronounced even in the 10-year age groups. Analysis of variance (ANOVA) was used to determine the statistical significance of differences. We included one factor, incidence of arrhythmias, as the number of unique patients per 10 000 inhabitants, and one-factor ANOVA was used. The non-parametric Mann–Whitney U test was used for the variables that were not normally distributed. The chi-square test was used to compare categorical variables and identify disparities between sex, age and terms of the search pattern for each health care facility, as well as the proportions. A p value of ≤ 0.05 was considered statistically significant. Statistical analysis was performed using SPSS/WIN v24.0 software.

Results

This study was conducted in a geographical area with inhabitants ages ≥ 18 years (male 50.5%, female 49.5%) and was designed to explore the current situation for adult outpatients with episodes of tachycardia visiting HCCs and/or EDs (Fig. 1).

In total, 2790 visits were eligible for the study; of these, 65 were duplicates and six were excluded due to an incomplete identification number. Hence, 2719 visits were included, consisting of 2373 outpatients, of which 1592 (67%) were female and 781 (33%) were male. Of the 2719 outpatient visits, 82% were at HCCs, and 18% were at EDs. The differences between sexes were pronounced when the sample of outpatients was divided into 10-year age groups. By extracting demographic data for sex and age groups from Statistics Sweden for 2017 [22], we were able to calculate the number of patients per 10 000 inhabitants in each age group. At the aggregate level, 112 out of 10 000 inhabitants had at least one visit to an HCC or ED because of episodes of tachycardia in 2017–2018; thus, 1.12% of the inhabitants visited a provider at least once. The results showed a significant difference in the total number of visits ($n = 2719$) between female and male outpatients (68% vs. 32%, $p < 0.001$). A significant difference was observed between sexes; among the females, 151 of 10 000 had visited at least once because of the condition, whereas the corresponding number among males was 73 ($p < 0.01$). When analysed by the average and unique persons, female outpatients had 1.17 visits, and male outpatients had 1.11 visits. In the 60–69- and 70–79-year age groups, females had significantly higher frequencies of visits than males ($p = 0.018$) (Fig. 2).

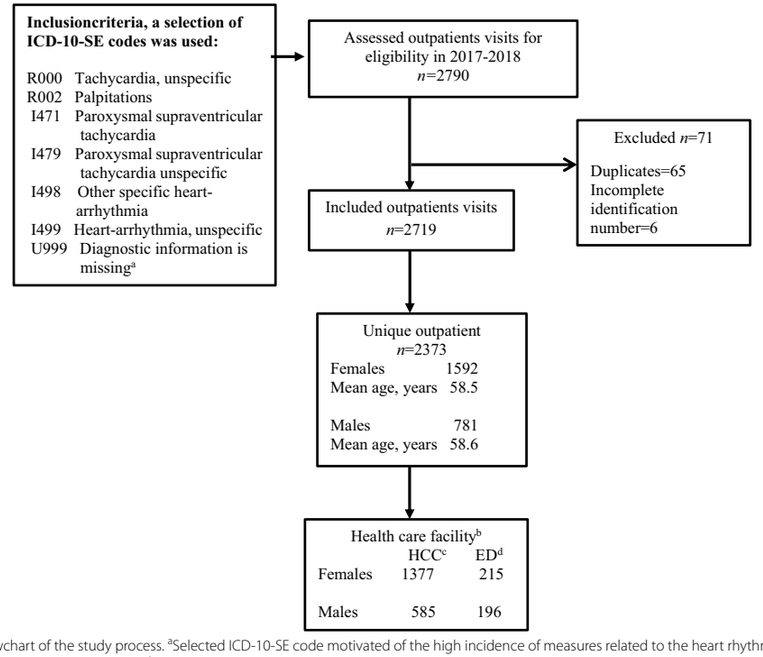

Fig. 1 Flowchart of the study process. [a]Selected ICD-10-SE code motivated of the high incidence of measures related to the heart rhythm, [b]first index visit, [c]health care centre, and [d]emergency department

A significant difference ($n=2719$) in the type of health care facility outpatients visited was observed between the sexes ($p<0.001$). A significant difference between the unique outpatient ($n=2373$) female and male visits to HCCs and visits to EDs was also observed ($p<0.001$). Further, a significant difference between sexes was observed among the age groups who visited HCCs ($p<0.001$). However, more females than males in the ≥66-year age group ($p<0.001$) sought care at EDs, but the opposite result was obtained for the 18- to 65-year age group. In general, the outpatients who sought care at EDs were considerably older than those seeking care at HCCs (Table 1).

A range of 1–9 visits per person was recorded for the 2373 outpatients. A comparison of visits to health care facilities resulted in a number of 1.12 visits to HCCs and 1.06 visits to EDs. The most frequently used ICD-code was R002 (Palpitations), which was assessed in 1759 visits from 1569 outpatients, with a quota of 1.12 (Table 2).

A total of 277 outpatients with episodes of tachycardia had 623 recurrent visits at HCCs and/or EDs. These outpatients had ≥2 visits in under 24 months, with a range 2–9 visits per outpatient; the visits were more common among females ($p=0.001$). This result shows a higher frequency of visits to HCCs (487) than to EDs (56). Moreover, 35 outpatients (20 females and 15 males) visited both HCCs and EDs, with a total of 80 visits and a mean number of 2.3 visits (Table 3).

Four hundred fifty-four outpatients (248 females and 206 males) were hospitalized among 480 visits, corresponding to 95% of the population recurrently visiting EDs due to episodes of tachycardia. No significant difference in hospitalization was observed between the sexes, either in the whole sample or after stratification by age group. For outpatients admitted from EDs ($n=454$), the ICD code U999 was most common diagnosis ($n=336$), followed by I499 ($n=61$) (Table 4).

Three outpatients visiting HCCs were referred to a cardiologist; referral for 289 outpatients occurred internally at the hospital. Regarding the total numbers of referrals for outpatients, 166 were female and 126 were

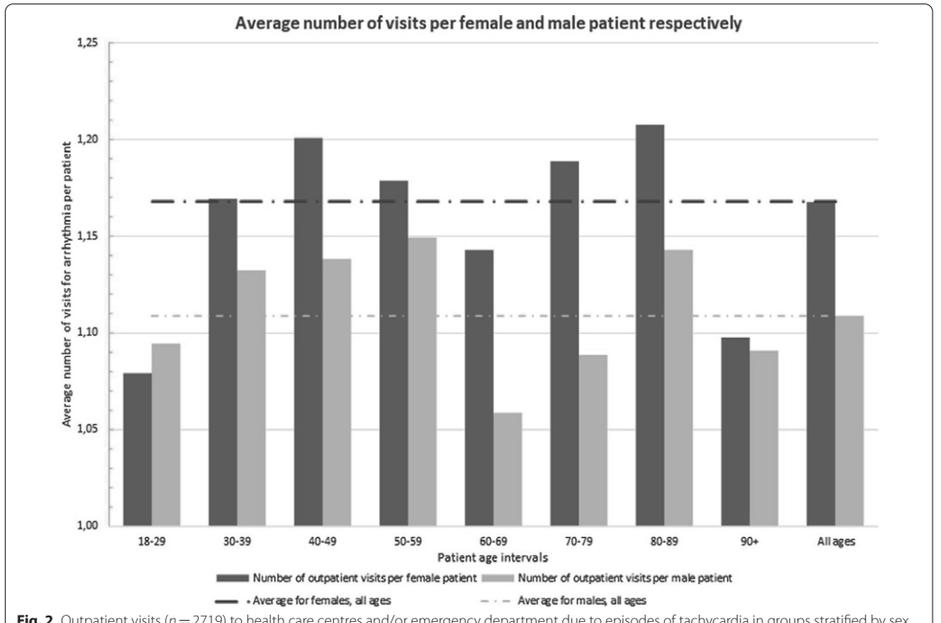

Fig. 2 Outpatient visits ($n=2719$) to health care centres and/or emergency department due to episodes of tachycardia in groups stratified by sex and age (18–99 years)

Table 1 Outpatient visits to HCCs[a] and/or EDs[b] stratified by sex and age

	Total	Visits to HCCs	Visits to EDs	*P* value
Visits	*n=2719*	*n=2239*	*n=480*	
Female (%)	1857 (68)	1596 (71)	261 (54)	<.001[d]
Male (%)	862 (32)	643 (29)	219 (46)	
Unique outpatients[c]	*n=2373*	*n=1962*	*n=411*	
Female (%)	1592 (67)	1377 (70)	215 (52)	<.001[d]
Male (%)	781 (33)	585 (30)	196 (48)	
Mean age of females, years (SD)	58.5 (18.9)	56.0 (18.1)	73.3 (16.6)	<.001[e]
Mean age of males, years (SD)	58.6 (18.4)	54.3 (17.9)	70.6 (13.7)	<.001[e]
Age 18–65 years	*n=1383*	*n=1283*	*n=100*	
Female (%)	931 (67)	891 (69)	40 (40)	<.001[d]
Male (%)	452 (33)	392 (31)	60 (60)	
Age ≥66 years	*n=990*	*n=679*	*n=311*	
Female (%)	661 (67)	486 (72)	175 (56)	<.001[d]
Male (%)	329 (33)	193 (28)	136 (44)	

[a] Health care centre

[b] Emergency department

[c] First index visit

[d] The chi-square test was conducted to compare categorical variables between groups

[e] Mann–Whitney test was employed to compare continuous data between groups

Table 2 The ICD-10-SE[a] codes used as diagnostic description at HCCs[b] and EDs[c]

ICD-10-SE code	Diagnostic description	Visits to HCCs *n* (%)	Visits to EDs *n* (%)	Patients treated at HCCs *n*	Patients treated at EDs *n*	Number of visits per patient
I471	Paroxysmal supraventricular tachycardia	55 (2)	8 (2)	50	7	1.11
I479	Paroxysmal tachycardia, unspecific	43 (2)	6 (1)	40	6	1.07
I498	Other specific heart-arrhythmia	49 (2)	6 (1)	46	6	1.06
I499	Heart-arrhythmia, unspecific	60 (3)	68 (14)	50	68	1.08
R000	Tachycardia, unspecific	309 (14)	15 (3)	287	15	1.07
R002	Palpitations	1723 (77)	36 (8)	1534	35	1.12
U999[d]	Diagnostic information is missing	0 (0)	341 (71)	0	316	1.08
Total		2239	480	2007	453	1.11
Number of visits per unique patient		1.12	1.06			

[a] International Classification of Diseases and Related Health Problems, 10th Revision, Swedish version

[b] Health care centres

[c] Emergency departments

[d] U999 was only reported in the documentation for EDs

Table 3 Recurrent visits to HCCs[a] and/or EDs[b] by outpatients stratified by sex and age

Recurrent visits, *n* = number of visits (%)	Total *n* = 623	Visits to HCCs *n* = 487	Visits to EDs *n* = 56	Visits to both HCCs and EDs *n* = 80
Unique persons (%)	*277*	218 (78.7)	24 (8.7)	35 (12.6)
Age 18–65 years	*n* = 162	*n* = 143	*n* = 4	*n* = 15
Female (%)	118 (73)	107 (75)	2 (50)	9 (60)
Male (%)	44 (27)	36 (25)	2 (50)	6 (40)
Age ≥ 66 years	*n* = 115	*n* = 75	*n* = 20	*n* = 20
Female (%)	92 (80)	65 (87)	16 (80)	11 (55)
Male (%)	23 (20)	10 (13)	4 (20)	9 (45)
Number of visits per person (range)	2.2 (2–9)	2.2 (2–9)	2.3 (2–4)	2.3 (2–5)

Recurrent visits = an outpatient with ≥ 2 visits due to recurring tachycardia

[a] Health care centres

[b] Emergency departments

Table 4 Hospitalization for outpatients visiting EDs[a], stratified by sex and age

	Hospitalization No	Hospitalization Yes	Total group
Visits	*n* = *26*	*n* = 454	*n* = 480
Female (%)	13 (50)	248 (55)	261 (54)
Male (%)	13 (50)	206 (45)	219 (46)
Age 18–65 years	*n* = 18	*n* = 103	*n* = 121
Female (%)	10 (56)	42 (41)	52 (43)
Male (%)	8 (44)	61 (59)	69 (57)
Age ≥ 66 years	*n* = 8	*n* = 351	*n* = 359
Female (%)	3 (38)	206 (59)	209 (58)
Male (%)	5 (62)	145 (41)	150 (42)

[a] Emergency departments

male, with the highest proportion of referrals occurring in the 60–69-year age group (44 females, 33 males).

Of the 2719 visits to HCCs and EDs, 2424 visits were classified with the nonspecific ICD-10-SE symptom codes R000, R002 and U999 (Table 2). In the group visiting EDs, 392 visits consisting of 366 unique outpatients were identified (Table 5). Due to limited access to data from HCC, a random sample was collected from the group of outpatients' records admitted to EDs. This random sample consisted of ECG from a total of 100 unique outpatients distributed into four groups based on sex and age. The analysis of ECGs identified 5% (CI 1.9%-10.6%) of arrhythmias as potential AVNRT or AVRT, of which 4% occurred in females. The remaining ECG analyses

Table 5 Documentation for outpatient at ED[a] with unspecific codes R000, R002 and U999

Patient	Age 18–65 years *n* = 92 (%)	Age ≥ 66 years *n* = 274 (%)	Total *n* = 366 (%)
Female	38 (41)	155 (57)	192 (53)
Male	54 (59)	119 (43)	172 (47)
ECG-rhythm	*n* = 28 (%)	*n* = 72 (%)	*n* = 100 (%)
AVNRT/AVRT	4 (14)	1 (1)	5 (5)
Atrial fibrillation/flutter	15 (54)	41 (57)	56 (56)
Other arrhythmia	2 (7)	11 (15)	13 (13)
Sinus	7 (25)	19 (27)	26 (26)

[a] Emergency departments

were atrial fibrillation/atrial flutter (56%), sinus-rhythm (26%) and other arrhythmias (13%) (Table 5).

Discussion

The result from the present study showed a significant difference in the total number of visits ($n = 2719$) between females and males (67% vs. 33%, $p < 0.001$). In the analysis of unique outpatients ($n = 2373$), significant differences were observed in the numbers of visits to HCCs (70% vs. 30%, $p < 0.001$) and visits to EDs (52% vs. 48%, $p < 0.001$) between females and males. Our hypothesis is that no difference in search patterns exist between sexes at health care facilities. The result showed a significant difference in the health care facility the outpatient tended to visit between sexes ($p = 0.001$); therefore, the hypothesis was rejected. Moreover, 82% of the 2719 visits were at HCCs, and 18% were at EDs. Thus, at an aggregate level, 1.12% (112 of 10,000 inhabitants) had visited an HCC or ED at least once over a period of 24 months. The average number of visits for females of all ages was 1.17; it was 1.11 for males. A clear difference was observed between sexes; of the 10,000 inhabitants, 151 females and 73 males had visited a health care facility at least once because of the condition ($p < 0.01$). The result can be interpreted in relation to earlier research showing that the incidence of SVT is slightly higher in females than in males [11, 12, 21]. Furthermore, health care utilization in HCCs [21, 26] and EDs [27] is more common among females. The total per capita cost for health care is higher for females, with a cost difference of 8% after adjusting for reproduction and sex-specific morbidity [26].

As shown in the present study, more than one visit (range of 2–9) in less than 24 months was recorded for 277 outpatients in 623 visits, which were mainly females visiting HCCs. Furthermore, 35 outpatients made 80 visits in both HCCs and EDs (20 females, 15 males). Previous research has reported the consequences for both patients and society due to repeated visits to a health care facility [8]. Effective management of SVT, such as early identification and response to symptoms, may substantially affect health care utilization for this group of patients [2, 21].

The results showed that 95% of outpatients visiting EDs were hospitalized, and no significant differences were observed for groups stratified according to sex or age, although hospitalization was more common among outpatients aged ≥ 66 years. A recently published study reported that SVT is associated with significant higher annuals rates of ED visits, physician office visits, hospitalization, and diagnostic testing [5]. According to previous studies, the hospitalization rate increased with advancing age, with the highest admissions reported in patients aged 80–84 years and a slightly higher presence in females [12, 13]. As the intention of health care is to provide available and equal access to care [23], this group is an important population on which to focus.

This study estimated the incidence of missed arrhythmias (diagnoses) in relation to assessment in a random sample of 100 outpatients admitted to the ED. The results showed a 5% missed diagnosis involving potential AVNRT or AVRT, which is comparable to the findings reported in the study by Orejarena et al. [11]. Thus, diagnoses for outpatients may be delayed by the clinical assessment [4, 14]. The current study did not consider the individual physician's ability to interpret arrhythmias in an ECG; the ECG may have been read by a junior doctor or a specialist. Furthermore, the result of 5% missed arrhythmias (diagnosis) occurring in four females and one man might be due to random selection. Regardless, the results should be considered based on previous research reporting that females are likelier to receive more accessible, less expensive primary care, while males were more likely to receive specialist inpatient care [26], as well as other data showing a significantly longer history of symptomatic SVT for females before catheter ablation than for men [12]. Recently published studies concluded that SVT imposes a substantial economic burden on health care systems [4, 28] and is consistent with the burden attributed to atrial fibrillation [28, 29].

The results of the current study show a higher incidence of nonspecific ICD codes, especially symptom code R002. Previous research has shown the potential utility of selected diagnostic codes in inpatient and ED settings for identifying symptomatic SVT [10]. For patients visiting health care facilities, despite their own insecurity about the meaning about the symptoms [6, 15], they unfortunately encounter health care providers who attribute their palpitation and related symptoms to underlying causes other than SVT [14, 27]. Previous studies have described the difficulties these patients encounter when

trying to prove their symptoms before their arrhythmia is confirmed on an ECG [4, 6, 14]. Obtaining a diagnosis seems important because of the need to treat these patient's and conceivably refer them to a cardiologist [1, 9, 14].

The present study found a low referral rate; only three outpatients were referred to a cardiologist from the HCC. Of the 292 referrals, 57% were female outpatients, suggesting that the number of referrals is equal; however, given the large percentage of women who presented with the condition, the referral rate should be considered. The low referral rate is consistent with previous studies [14, 15]. The consequences of a low referral were presented as unnecessary investigation and admissions for patients with SVT presenting to the ED [30] compared to the current study, where patients mainly presented to HCCs. Sex-related differences are significant in terms of SVT diagnosis and management [14, 21, 27]. Overall, females had to wait for 60 months for catheter ablation after the onset of initial symptoms compared with 15 months for males [27]. Current knowledge is lacking regarding the delay in referral for an indicated, first-line treatment procedure such as catheter ablation [27]. In previous studies, a previous visit to an electrophysiologist and following catheter ablation significantly reduced health care utilization [21] among patients presenting to the ED with SVT [2].

The results provide a glimpse of the health care resource and group levels burdens, but the personal burden due to repeated visits to healthcare facilities for episodes of tachycardia is not difficult to imagine. Patients' subjective experiences have been described in previous research [4, 6, 15]; however, they require further in-depth consideration, and upcoming studies are planned.

Limitations

Although our study contributes to knowledge about disparities in adult outpatients with episodes of tachycardia stratified by sex and ages, it has several limitations. First, this study was based on retrospective data obtained from medical records and registers to explore health care utilization for a period of 24 months. Clinical presentation of episodes of tachycardia was based on selected ICD code assessed by the physician. The categorical use of ICD code requires further investigation for evaluate their validity. Second, the population consisted of outpatients visiting HCC and ED facilities that did not appear to have been explored at the time, except for a few identified studies [5, 21, 28]. Due to the availability of data, the subgroup analysis was conducted only with ECGs from outpatients admitted to ED, which may be a limitation. The results for the health care utilization of outpatients with episodes of tachycardia to determine the health care burden requires further confirmation by examining patient-centred outcomes and cost-effectiveness data. Another limitation, referrals, may have reached the cardiologists through other routes that are unknown to the authors of present study. Finally, as with all studies, the generalizability of the results to a similar context and to other countries must be valued and assessed by the reader. This study was performed in a Swedish context, which might be a limitation.

Conclusion

As shown in the present study, females had a higher health care utilization rate than males, especially in the ≥ 66-year age group, and mainly in HCCs. The sex- and age-related differences provide an interesting body of evidence for clinical practice and future research. The result of this study is noteworthy due to clinical workup and illuminate the need for development of an early assessment of potential recurrent arrhythmias. Finally, the low referral rate to specialist care from HCCs compared to the high proportion of patients' hospitalization from EDs deserves further investigation.

Abbreviations

ANOVA: Analysis of variance; AVNRT: Atrioventricular nodal re-entry tachycardia; AVRT: Atrioventricular re-entry tachycardia; AV: Atrioventricular; CI: Confidence interval; ECG: Electrocardiogram; ED: Emergency department; ICD-10-SE: International Classification of Diseases and Related Health Problems, the 10th Revision Swedish version; HCC: Health care centre; SVT: Supraventricular tachycardia; RR: Specific part of a heartbeat, the R-wave (measuring R-wave to R-wave).

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Authors' contributions

All authors mentioned contributed to the conception and the design of the study. AKN and AK reviewed the literature, gathered, analysed, and interpreted data, and wrote the first draft of the manuscript. AKN, MB, GNB and AK revised the manuscript critically for important intellectual content. All authors have read and approved the final manuscript.

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Availability of data and materials

The dataset generated and/or analysed during the current study are not publicly available but available from the corresponding author on reasonable request.

Declarations

Competing interests

The authors declare no competing interests.

Ethics approval and consent to participate

Permission was obtained from the Ethical Review Board of Uppsala, Sweden (Dnr: 2019-03295 with additional application 21-01-2020). The investigation conforms with the principles outlined in the Declaration of Helsinki [25].

Content to participate

The need for written consent was waived by the Ethical Review Board of Uppsala, Sweden, due to the retrospective nature of the study. The Ethical Review Board of Uppsala, Sweden have approved the registry protocols in this study.

Consent for publication

Not applicable.

Competing interest

The authors report no competing interest.

Author details

[1]Department of Cardiology, Skaraborg Hospital Skövde, 54185 Skövde, Sweden. [2]Faculty of Caring Sciences, Work Life and Social Welfare, University of Borås, Borås, Sweden. [3]PreHospen - Centre for Prehospital Research, University of Borås, Borås, Sweden. [4]School of Health Sciences, Skövde University, Skövde, Sweden. [5]Research and Development Centre, Skaraborg Hospital Skövde, Skövde, Sweden.

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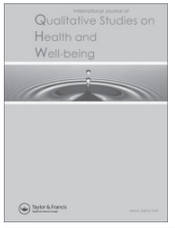

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Foreign movement in one's own body: Patients' experiences of being awake while treated with catheter ablation—a phenomenological study

Ann-Katrin Nordblom, Anna Kjellsdotter, Gabriella Norberg Boysen & Mia Berglund

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Foreign movement in one's own body: Patients' experiences of being awake while treated with catheter ablation—a phenomenological study

Ann-Katrin Nordblom [a,b], Anna Kjellsdotter [c,d], Gabriella Norberg Boysen [b,e] and Mia Berglund [c]

[a]Department of Cardiology, Skaraborgs Hospital Skövde, Skövde, Sweden; [b]Faculty of Caring Sciences, Work Life and Social Welfare, University of Borås, Borås, Sweden; [c]School of Health Sciences, Skövde University, Skövde, Sweden; [d]Research and Development Centre, Skaraborg Hospital Skövde, Skövde, Sweden; [e]Prehospen, Centre for Prehospital Research, University of Borås, Borås, Sweden

ABSTRACT

Purpose: To address the consequences of living with supraventricular tachycardia and to improve the quality of treatment, there is a need to highlight patient experiences of treatment with catheter ablation. Therefore, the aim was to describe the phenomenon of catheter ablation, as it is experienced by patients being treated awake.

Methods: A descriptive design was applied based on a reflective lifeworld research founded on phenomenological epistemology. Interviews were conducted between December 2021 and Mars 2022 with seven women and five men, three to twelve months after they underwent catheter ablation.

Results: Patients undergoing catheter ablation while awake during treatment, which includes experiences of relying on others expertise, being actively passive, and striving to be cured. It entails experiences of having a foreign object moving in one's body and heart and can be endured through strategies of mainly shifted one's mental focus.

Conclusions: The effort of undergoing a catheter ablation procedure is worthwhile as the confirmation of a physical curable condition that opens a future with possibilities instead of the obstacle in daily life that tachycardia entails. For the patients, an informative and caring conversation was needed that would have provided the support they lacked before and during the ablation.

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catheter ablation; lived experience; patient perspective; phenomenology; reflective lifeworld research; supraventricular tachycardia

For patients with episodes of supraventricular tachycardia, an electrophysiological examination is usually necessary to establish the diagnosis (Brugada et al., 2020; Page et al., 2016). Knowledge of patients' perspectives regarding electrophysiological examinations and catheter ablation is lacking. Electrophysiological examination and catheter ablation involve a physical intervention, with the intention to localize abnormal activity, which leads to the determination of a diagnosis and decide the course of further treatment with catheter ablation during the same procedure (Brugada et al., 2020). Catheter ablation has become the first-line option, in most cases as a cure, for the two most common regular supraventricular tachycardias: atrioventricular nodal re-entry tachycardia (AVNRT) and atrioventricular re-entry tachycardia (AVRT), with success rate of 98% and 95–97%, respectively (Brugada et al., 2020). Previous studies on patients with recurring tachycardia have described an inhibited existence that involves having to give up social activities such as driving or performing leisure activities in the case of unpredictable occurrences of tachycardia (Nordblom et al., 2017; Withers et al., 2015; Wood et al., 2007). Further, these studies also described patients' frustration of struggling to obtaining the correct diagnosis (Withers et al., 2015; Wood et al., 2007) with repeated, time-consuming visits to health care facilities and increased utility of health care resources (Carnlöf et al., 2017; Sacks et al., 2020). Overall, the literature reveals that it is problematic for patients to be referred to specialist care for assessment of their tachycardia (Carnlöf et al., 2017; Nordblom et al., 2022; Withers et al., 2015).

There are only few studies on the patient perspective from cardiac catheterization (Beckerman et al., 1995) and electrophysiological examination (Adam & Wicha, 1994), which have revealed that patients have negative experiences in this regard considering that they were performed at the time when catheter ablation was a new procedure. However, medical technology is developing rapidly and has shortened the electrophysiological examination and catheter ablation procedure without the corresponding research regarding the patient perspective. This gap in knowledge makes it important to analyse patients' experiences of being awake during an electrophysiological examination and undergoing catheter ablation for AVNRT and AVRT

CONTACT Ann-Katrin Nordblom ann-katrin.nordblom@vgregion.se Department of Cardiology, Skaraborgs Hospital Skövde, Skövde SE-541 85, Sweden

to continue improving the quality of treatment and to enhance care.

According to Toombs (2001), phenomenology provides a powerful means to illuminate the experience of a body disorder—a bodily dysfunction that arises during an episode of tachycardia. Phenomenology renders explicit the dynamic relationship between the body and the world, provides insights into the disruption of space and time, and discloses the emotional dimensions of this temporary physical dysfunction (Toombs, 2001). Patients' experiences of being awake during electrophysiological examination and treatment with catheter ablations have, to the best of our knowledge, not been described since the 1990s. Research in this context is motivated by enhancing improvements for the individual and the health care system when it comes to utilization of existing resources. The issue in focus in this paper is access to this first-line option for treatment and determining whether updated and nuanced research based on the patient's perspective may increase knowledge and overcome barriers related to treating patients with episodes of tachycardia. Therefore, the aim of the present study was to describe the phenomenon of catheter ablation as experienced by patients who were treated while awake.

Methods

In this study, the phenomenon catheter ablation as experienced by patients who were treated while awake was explored by utilizing the reflective lifeworld research (RLR) approach, which is based on phenomenological epistemology as described by Dahlberg et al. (2008). To establish a greater understanding of a patient's perspective, the phenomenon was studied temporally from the time the letter for catheter ablation reaches the patient and during examination and treatment to the time spent in the ward before the procedure, during aftercare in the ward, and until discharge. According to the routines of the studied clinic, the patient is awake and regional anaesthesia is used during electrophysiological examination and catheter ablation. To access the heart's cavity, catheters are placed in the vein from the groin and brought up to the heart. When catheters are inserted into the heart cavity and the electrophysiological examination begins, the patient is instructed to relax, rest, lie completely still, and only speak if it hurts. After treatment, the patient is required to rest in the hospital bed and is returned to the ward for checks and nursing care during continued bed rest for three hours.

The RLR approach examines the structures of lived experiences, and the phenomenon can be understood as one that is shared with other people who have had the same experience, but one that is also unique in terms of the patient's past through memories, earlier experiences and the future perspective with their hopes and expectations (Dahlberg et al., 2008). The lifeworld, understood as the everyday world of experiences, includes both the subjective and objective worlds. It is the concrete reality that is generally taken for granted and not reflected upon in daily activities. When interviewing patients, their narratives provide the researcher an opportunity to capture their unique experiences of these patients as voices of their lifeworld (Dahlberg et al., 2008). The RLR approach enables an understanding of the phenomenon of catheter ablation as it is experienced by patients who are treated while awake, as it enables their experiences to be illuminated in depth, with an openness and sensitivity with regard to how meanings are created from a patient's perspective.

Open and Reflective Attitude

A descriptive design was applied, with an open and reflective attitude adopted throughout the research project (planning, organizing, and analysing data); interviews were conducted to capture patients' experiences (Dahlberg et al., 2008). According to the RLR approach, openness implies that the researcher needs to have an open attitude and be curious to witness the phenomenon as it presents itself. Openness can be understood as a true willingness to listen to, see, and understand the phenomenon as it is experienced by the participant without any predetermined perspective. One of the RLR methods principle is bridling, which is a conscious approach by the researcher to adopt an attitude of reflection and carefulness, within effort to reduce the pace of the understanding process and stay focused on not determining what is indefinite. This entails the researchers' understanding and pre-understanding of bridling. Bridling implies having a critical and reflective attitude towards the phenomenon of catheter ablation as experienced by patients who are treated while awake, thereby contributing to a movement towards a new understanding of the phenomenon (Dahlberg et al., 2008).

Participants and data collection

Participants living in middle west Sweden were recruited from one specialist clinic between December 2021 and February 2022; pilot interviews were conducted in September 2020. After two pilot interviews were conducted, an initial analysis was performed to see if the questions captured the meaning of the phenomenon. This resulted in the initial question being adjusted and the direction of the phenomenon being clarified. The participants were required to have experienced an electrophysiological

examination and treated with catheter ablation for AVNRT or AVRT, were aged ≥18 years, and could understand the Swedish language. Potential participants ($n = 18$) received a letter of invitation to participate, with a self-addressed stamped envelope. Seven women and five men ($n = 12$) (included in the pilot interviews), between 21 and 89 years, with experiences of episodes of tachycardia (3 months to 41 years) agreed to participate and were interviewed 3–12 months after they had a catheter ablation, with an average of 5 months. The participants selected the interview venue; four participants were conducted in one face-to-face meeting and the remaining eight were interviewed over the telephone or online. The duration of the interviews varied between 29 to 93 minutes, with an average of 63 minutes. The interviews began with the following open question: "Can you tell me about your experiences during the catheter ablation?" Thereafter, follow-up questions were posed for further exploration (e.g., *tell me more, can you give an example, how did you feel when* … , and *what do you mean by* …) and to gain deeper insights into the phenomenon. All interviews were conducted and audiotaped by the first author and transcribed verbatim, with one exception. In one interview there was a technical error with the recorder. However, the participant declined a fresh appointment as the participant has been looking forward to talk about the experiences and had waited for this moment. Therefore, the interview was continued and the first author took notes throughout the interview.

Data analysis

The analysis was iterative and constantly moving between the whole and the parts to a new whole. The process implies going back and forth from the whole, the descriptions of the phenomenon in the transcript interviews, analysing the meanings units, and then reconstructing the whole to understand the essence of the phenomenon (Dahlberg et al., 2008). The reconstruction was characterized by the authors' conscious approach of openness and bridling, which was implemented through reflection. To illuminate the different parts of the data, a structure of meaning units was created that responded to the aim and then these units were divided into clusters, which included meanings units that seemed to belong together and formed a further temporary pattern of meaning. Identification of clusters was an iterative process in the search for the essential meaning of the phenomenon of catheter ablation as experienced by patients who were treated while awake. In this part of the analysis, it was important not to let certain preconceptions prevail or create any notions of the phenomenon in advance. This was done by going back and forth between closeness and distance and between the parts and the whole of the interview text, with the goal of identifying something new. The essence is to understand the most abstract level of the description of the phenomenon and this can be understood as the most invariant structure of meanings associated with the phenomenon in the actual context. After the essence was identified, a description of the nuances and variances of the phenomenon was created at a more concrete level and these were contextualized with quotations from the interviews (Dahlberg et al., 2008). In the subsequent results, the essence is presented first, followed by its constitutes—that is, the meanings that constitute the actual essence.

Ethical considerations

Permission for this study was obtained from the ethical review board (Dnr: 2019–03295). The investigation conformed to the principles outlined in the Declaration of Helsinki (World Medical Association WMA Declaration of Helsinki, 2013). Verbal and written information regarding the aim of the study was provided to all participants with the assurance of confidentiality. The interviews were voluntary, and the participants were permitted to withdraw from the study at any time. Informed consent was obtained from each participant.

Results

Essence of the phenomenon

Catheter ablation, as experienced by patients who are treated while awake, involves relying on another's expertise and entails being safe and confident; on the other hand, it also entails being unprepared and vulnerable. Vulnerability includes putting oneself in the hand of others, being simultaneously objectified and confirmed. Being awake during catheter ablation implies following instructions, being actively passive, trusting and demanding to achieve simultaneously, and striving to regain health. Sensations of foreign movements in the body when the catheters are inserted into and placed in the heart, thereby leading to experiences feelings of curiosity and being terrified, endured by shifting the mental focus away from oneself. Curiosity entails the ability to distance from one's own body in the moment, while a terrifying experience entails existential fear and anxiety. In addition, communication between staff creates both curiosity and uncertainty. It is about creating an individual story of the event, built on ideas and knowledge. The foreign environment and context instil a sense of disorientation that reinforces vulnerability. After the monitors are turned off, there is pride, gratitude, and joy at having endured the treatment and a hope for a future without the obstacles brought on by the tachycardia.

Thus, the phenomenon comprises 1) relying on expertise in a foreign environment, 2) enduring foreign movement and sensations in the body, 3) actively passive cooperation in striving to be cured, and 4) being simultaneously objectified and confirmed.

Relying on expertise in a foreign environment

Catheter ablation, as experienced by patients who are treated while awake, means relying on expertise in a foreign environment and trusting in the knowledge and professionalism of the staff, with the expectation of being well treated well and receiving help to deal with the tachycardia. It includes striving to regain health and look at a future with possibilities instead of obstacles, which living with tachycardia may entail. To accept the offer to do a catheter ablation is experienced as putting oneself in someone else's hands, with confidence in the knowledge of the profession; on the other hand, there is also an attitude of things leaving things up to fate. The foreign environment entails being in a hospital and listening to the technical communication between the staff in the electrophysiological lab and a noise than can be filtered as long as the atmosphere in the room indicates that everything is normal, while also wondering what the communication implies. As one participant reflected:

> And so, someone in the control room said 17, yes good, and then they burned a little on 17 and so they kept on. And then they said 324 and I wondered what it was? 324, what is that? Further in or longer out or what? Up? Down? I do not need to know, but that's what I was thinking. (P4)

To rely on expertise in this foreign environment implies trusting the expertise, despite imagining the worst. Listening to various numbers being spoken raises thoughts regarding the significance of the numbers and the patients create their own rational explanations—perhaps the numbers are coordinates to help the operator find their way inside the heart or that they correspond to the heart rate when there is a fear of cardiac arrest. One participant, with negative life-threating experience in the past, articulated fear and trust:

> Then it was on 300 and then I associate it with death. But then I thought that they are five competent people here, and if that happens, then they will save me. And then I was in good hands I thought. (P8)

The communication and the activity in the room constitute a hope for a cure from the tachycardia and a future with possibilities instead of obstacles, which confirm the decision of rely on expertise.

Enduring foreign movement and sensations in the body

Catheter ablation, as experienced by patients who are treated while awake, consists of experiences of foreign sensations and movements inside the body and the heart and enduring treatment by shifting the mental focus from oneself. Having catheters inserted into the groin results in feelings of pressure and even a sense of harsher invasiveness. As one participant reflected,

> When they inserted the first instrument into my body, I thought that they would be a little careful when they send it in, but no they were not. I felt it all along my back. It became an uncomfortable feeling right there, and it lasted for only two seconds, but it was probably the only thing I thought was unpleasant. (P6)

During the electrophysiological examination, the patients experienced short, repeated palpitations, which were rather familiar but slightly different compared to their own episodes of tachycardia—a sensational, scary, and, simultaneously, exciting experience. Further, the burning sensation during the treatment is experienced differently by participants and could go unnoticed in certain patients or turn into discomfort and border on pain for short periods. The burning sensation is experiences as an itchy, warm feeling in the chest, not purely unpleasant but more like drinking a hot beverage, felt along the oesophagus. One participant described his experience in the following manner:

> Though it did not hurt. What should I say? Well, kind of drinking a hot drink in the winter, stuck in the heart? A very hot drink, that's how I can explain it. Not very nice but not very bad either. (P12)

To endure both the examination and treatment during the time as well as the physical and mental discomfort, the patients described different strategies of shifting mental focus from themselves to something else. These strategies were described as fixing their gaze and attention on a point on the ceiling or distracting themselves by listening to the interaction among the staff. This discomfort of being under treatment could cause a short-term feeling of stress or anxiety. One participant reflected on how she endured this:

> There was one time that I wanted to stop the whole thing; it was very hard in the end, when they would stress my heart, and I felt in my whole body, almost as if my heart were popping out of my mouth, but it was not for a long period, and I felt that I could handle this. (P11)

Most patients related that when they felt that they have reached a limit for what they could endure, the course of treatment was over and discomfort or pain disappears.

Actively passive cooperating in striving to be cured

Catheter ablation, as experienced by patients who are treated while awake, entails cooperation between the patient and the operator with the common goal of curing the condition. Cooperation can be understood as necessary for relieving the symptoms of the tachycardia, but also includes shortcomings. Actively passive cooperation was experienced as trusting; on the other hand, it was demanding and difficult to achieve. Consequently, there is limited opportunity for patients to ask questions, which increases the feeling of vulnerability and being left in the hands of others. One participant articulated how she experienced a (lack of) support and expressed vulnerability:

> I felt completely left out, which meant that I had to concentrate on not thinking it was disgusting and… I knew they were in control; they had all the stuff and there was everything so … They did know how my heart felt, but they did not know how I felt. (P5)

Thus, as evident from the above account, being actively passive was accomplished through self-control by trusting the process and the expertise; on the other hand, it was exhausting because they were instructed to lie completely still. This was done without the support of a sedative, as they were told that sedative could cause difficulties in inducing tachycardia, which the patients saw as an impetus to endure a little bit more. Thus, active passive cooperation becomes motivating and significant when tachycardia is induced, diagnosed, and suitable for ablation. The patients' perceptions of being actively passive included cooperation with the staff; during ablation, this was mostly mutually experienced. In the ward, the patients experienced shortcomings in cooperation if the staff did not fully do their part, by not keeping time for checks for the groin, parameters (blood pressure and pulse), removal of pressure dressings, or delivery of promised medicine.

Being simultaneously objectified and confirmed

Catheter ablation, as experienced by patients who are treated while awake, entails the experience of being simultaneously objectified and confirmed. Being objectified and exposed in a vulnerable situation imply being unprepared. Being unprepared entails accepting an intervention without having sufficient information regarding what it involves, which causes feelings of uncertainty and a lack of support. The information a patient received prior to catheter ablation was described as neutral and fact-filled; on the other hand, it was confusing and frightening, as it was difficult to understand and relate to their own illness. Insufficient information implies unanswered questions about the unknown that is about to occur and the uncertainty of not being prepared leads to a feeling of being left out. When the letter regarding ablation was sent to patients' who did not feel prepared, a few declined until they received the information they needed. One participant expressed his insecurity in the following manner:

> I had to say no because I could not. I could not get over that feeling, and I felt very unprepared. So, I felt that I at least wanted to talk to the cardiologist, someone who explains it a little to me, what we are doing and what is to be done. (P10)

In the context of this study, being objectified implies that the heart, the centre of the body, is being handed out as an object in the hands of others. During electrophysiological examination and catheter ablation, it is possible for patients to see their own bodies on the X-ray machine and on monitors where their own hearts are imaged with the help of advanced technology. The patients express a surrealistic feeling of being objectified when they saw their own hearts visualized on the monitor; they experienced it as exciting and frightening at the same time. Being objectified entails vulnerability and exposure, which are experienced not only during preparation for ablation but also during aftercare when checking inserts in the groin, as these are performed by staff of different sexes. These checks are performed with the blanket pulled away, and patients experienced this as being exposed in a vulnerable situation, without regard to dignity, in a hospital environment where privacy is not self-evident due to dormitory rooms and unlooked doors. From being the focus of and having everyone's attention during the ablation, the transfer to the ward takes the patient to an environment that can be described as spartan. Patients experienced that meeting with staff is good but consistently short, which leads to the perception that considering the patient perspective is lacking; there is no room for small talk and reflection; instead, the participants felt ignored. The opportunity to share the joy of being treated was not given space, and numerous questions remained unanswered. The lack of patient perspective was articulated by one participant in the following manner:

> I experienced the aftercare as very spartan. I felt this patch, I thought it was a big cut at first, but it was very small … But I felt a little … abandoned, a little lonely. I wanted to share the inherent peace I experienced after the procedure to treat something that has bothered me for several years. (P10)

On the other hand, catheter ablation entails experiences of relief and a confirmation that tachycardia can be observed on monitors, that it is real, and cannot be explained by stress or anything else, a confirmation that strengthens self-esteem. After catheter ablation,

joy was experienced over having undergone the treatment with all that it entailed. As one participant put it,

> I felt an ego boost that if I can handle an ablation, then I can do anything. And, I mean, here I was, awake, even though I did not feel any pain. Well, when I got the anaesthesia in the groin, there was some pain, but still it was cool, you know, and when I lay there, I do not think I have ever been so in the present as now and then. (P11)

Thoughts of not experiencing tachycardia in the future are experienced with gratitude and euphoria. Although the electrophysiological examination and the catheter ablation treatment were occasionally stressful, it strengthened patients' self-esteem as it enabled them to avoid future episodes of tachycardia and made the effort worthwhile.

Discussion

Since studies in supraventricular tachycardia mainly focus on developing technology to optimize strategies for electrophysiological examination and catheter ablation in objective endpoints, there are gaps in the literature regarding the patient's perspective during these procedures (Adam & Wicha, 1994; Beckerman et al., 1995; Page et al., 2016). In this study, the phenomenon of catheter ablation, as experienced by patients who were treated while awake, is explored and described to understand the patient's perspective based on how they felt with regard to undergoing treatment that enables them to regain their health (Galvin & Todres, 2013). The main findings are characterized by reliance on expertise and being actively passive in striving to be cured. In this specific context, the expertise is dependent on the patient lying still and breathing normally; otherwise, the position of the catheters inside the heart is affected with increased risk for complications and reduced success of the treatment (Brugada et al., 2020). The result also pinpoints vulnerable situations in which the patient perspective is lacking through the experience of being or feeling unprepared, mainly expressed as need of support before the planned ablation (mostly elective procedures), but also during and after the ablation. Suffering during care is previously described (Berglund et al., 2012) when patients felt distrusted and when their perspective on illness and health was overlooked. However, knowledge is lacking in the context of being treated while awake with catheter ablation and needs to highlight shortcomings in current care to enable development. Based on this finding, it could be suggested that there is potential to improve the quality of treatment and enhance care. The medical and care perspectives make different demands on health care; improvement in care—with a focus on the patient's perspective—is important, mainly in terms of the communication throughout the entire process from time of referral to electrophysiological examination, catheter ablation and after discharge (Bergtun et al., 2018; Liljamo et al., 2020). What is required is more explicit in relevant verbal and written information developed with a lifeworld perspective, with openness and responsiveness to the patient, including providing them the opportunity to have a dialogue with a professional with knowledge in the field—for example, a nurse. The result of this study also illuminates the feelings of relief and confirmation in being believed, pride in having managed the catheter ablation, and gratitude for a potential cure with a view to living a future without hindrance from tachycardia (Carnlöf et al., 2017; Nordblom et al., 2022; Sacks et al., 2020).

First, the identified cooperation between patient and operator highlights an important factor for successful treatment. It entails that the patient must be actively passive by striving for self-control to comply with the instructions, which were experienced with trust and a sense of security; on the other hand, it was demanding and difficult to achieve. To our knowledge, this has not been described in this context before and would likely contribute to an increased awareness of what the treatment requires of the patient and is open for the further development in terms of providing relevant support. It may be possible, in combination with dialogue, to provide some form of relaxing exercises to prepare the patient to be actively passive under the procedure. Previous research during atrial fibrillation ablation has shown promising results with non-medical interventions; that involves stimulating the patient´s own resources parallel to traditional medical treatment (pain relief)—for example, in nurse-guided relaxation and visualization responding to subjective experience (Norgaard et al., 2015). Further, intervention with virtual reality headset has shown to improve pain perception and comfort improvement (Roxburgh et al., 2021). Even though atrial fibrillation ablation differs from an ablation for AVNRT and AVRT in several aspects, these non-medical interventions could provide support for the patients during an ablation regardless of an arrhythmia.

Second, the experience of being awake under electrophysiological examination and catheter ablation was described by the participants, with initial questions and concerns about what was going to happen during the procedure, transitioned into subsequent calmness and belief in the help provided. The participants did not report painful experiences as a big issue, except from short moments. Previous research has provided an illustration of electrophysiological examinations and catheter ablation as something that is difficult for the patient to manage (Adam & Wicha, 1994;

Beckerman et al., 1995). In our view, the result from the present study contributes to updated and nuanced knowledge, which may strengthen the patient's opportunity to receive information regarding catheter ablation as an option to treatment. It is time to let patients participate in the decision to be referred to specialist care and, if suitable, further treatment with catheter ablation.

Third, this study described experiences for patients worth discussing from an existential lifeworld perspective. The focus of care is to reduce suffering, with the goal of well-being. Here, well-being is understood in a phenomenological approach as a means of being in the world as well as a felt sense of what this is like as an experience (Galvin & Todres, 2013). The theory of existential well-being opens what is important to people and, therefore, to what caring could mean, requiring a further direction for care. To experience illness when the body acts differently during episodes of tachycardia brings insecurity to the lifeworld and creates a feeling of existential homelessness, a foreign feeling to one's own body (Gadamer, 1996). In the present study, participants expressed vulnerability, a kind of suffering, when seeking for help and being insufficient informed before and during catheter ablation. This could be considered an instrumental means of working in the care process in the studied clinic and results in a failure from the patients' perspective; information prior to a planned catheter ablation was asked for at an earlier stage of the care process and adapted to the patient. Here, the earlier stage of the care process is understood as the first health care contact (such as primary care) prior to, and including, specialist care. Berglund et al. (2012) founded that suffering was also arise due to health care actions that neglected a holistic and patient-centred approach to care. To avoid suffering caused by health care providers, several actions can be developed and implemented, such as digital care pathway with different kind of information written as well as visible in short information films (Liljamo et al., 2020). Furthermore, the result revealed the need for information from and dialogue with someone knowledgeable in the fields before the procedure as well as after, which could be managed by nurse-managed reception. Bergtun et al. (2018) presented the need of nurse-led structured follow-up for patients who have undergone atrial fibrillation ablation, which strengthens the motive for this kind of implementation in the context of arrhythmia and ablation.

Finally, our findings suggest several developments areas for health care practitioners to improve health care. In the present study, during the hospital stay, participants experienced that the personnel had limited time at each meeting, which hampered the opportunity for them to ask questions and led to unanswered questions throughout the care period; it also limited the opportunity to share positive experiences. The restored health and process of a sort of homecoming in the participants' own bodies was not given attention by the staff, and an increased awareness regarding this process could improve care. In our study, this result indicated that vulnerable situations included feelings of being objectified, and questions arose regarding what objectification entailed. The term has a negative connotation as something reductionist, as if the patient is dehumanized (Todres et al., 2009) in the electrophysiological lab, understood as a highly technological, specialized environment. The focus was on the heart, the object, when the subject, the patient, could watch it simultaneously. It provides focused distancing, which is necessary for certain expertise in the electrophysiological lab, such as the operator and the assistants. However, a caring nurse must protect and support the patient's well-being in such an environment.

This leads to the next finding from this study: experiences of different kinds of strategies to endure the electrophysiological examination and catheter ablation and the associated physical and mental discomfort. The strategies mainly helped shift the patients' mental focus from themselves to something else to help distract them and endure the procedure. According to Galvin and Todres (2013), existential dwelling is to come home to the actual situation, to hear, abide, linger, and be present with what the situations include. This could explain how certain participants described security and confidence as a mood of being peacefully grounded in the present moment, supported by a past—with episodes of tachycardias—and the openness of a future that is arriving without tachycardias. When the participants encountered being treated while awake, the extent of the past had the breadth of being genuinely curious (without previous life-threating experiences); on the other hand, they were afraid of not surviving (based on previous life-threating experiences), but still motivated with trust and hope for a positive change in their daily life. Finally, this study revealed and described the subjective and lived experiences that come to expression, which are holistic experience that entail more than physical and biological aspects.

Methodological considerations

The terms objectivity, validity, and generalizability are assessed by considering aspects of quality and describing the scientific value of a lifeworld research study (Dahlberg et al., 2008; van Wijngaarden et al., 2017). Objectivity brings certain ethical consequences to the research, thereby avoiding skewed results, which imposes special requirements, such as the coherence criterion of validity. To conduct valid

research, it is essential to follow the researcher's reasoning throughout the study. During the entire research project, including conducting interviews and analysing data, it was important for the authors to have an open and bridled attitude (Dahlberg et al., 2008). This was made possible by reflective dialogues in the author group to be aware of one's own pre-understanding and not to let the understanding be predetermined. The first author (AKN), a nurse in the ablation team, did not have a caring role for the participants before, during, or after the catheter ablation. During the entire process, the first author had to critically reflect and bridled her experiences as a nurse in this context and let the patient perspective be the focus in the research process. The other authors (MB, AK and GNB) have been part of the reflection. First author performed and transcribed all the interviews, strengthening the trustworthiness and consistency of the data collection. In addition, the pilot interviews enhanced the credibility of the data collection method. The interviews were conducted face-to-face in locations selected by the participants, online or over the phone. This seemed to suit everyone, considering the pandemic situation. The interview were conducted after the catheter ablation, after a minimum period of 3 months—to provide a healing period—and 12 months as the maximum to avoid any memory lapses. Conducting interviews on phone or online may have contributed to a feeling of security, thereby allowing the participants to express feelings and criticisms that might not have been expressed in a face-to-face meeting. On the other side, certain aspects may have been lost, such as noticing nonverbal signals. However, the participants expressed that the interview gave them insights that this was the missing informative and caring conversation they required before and after the catheter ablation. The interviews took an average of 63 minutes, which provided the opportunity for follow-up questions and in-depth reflection by the participants. A diverse sample of 12 participants was included and the variety among the group of patients' who participated in the study produced rich descriptions, which enabled the authors to describe the phenomenon in its essence and constituents to deepen the overall understanding. The data analysis process was conducted initial by the first author, then by the author team. During the analysis, the authors guarded against potential bias of pre-understanding, and the rigour of the data was continuously safeguarded by constantly engaging in critical reflection discussion. Furthermore, to enhance the trustworthiness of the analysis, an iterative process created an independent structure of meaning units to meet the goal. These units were brought together into clusters that formed into a temporary pattern of meaning. The clusters were discussed by the authors and continued until sufficient reconstruction was consistent and, finally, refined the essence. Representative quotations from the participants were used to reveal connections between the interviews, analysis, and findings. In addition, the manuscript has been peer-reviewed at a seminar with other researchers, thereby contributing to the establishing the strength and validity of the results.

With regard to generalizability, the result is always contextual (Dahlberg et al., 2008). Generalizability comes from presenting the results in a structure of meaning and in quotations from the interviews (van Wijngaarden et al., 2017). The context of being treated while awake can be transferable to similar contexts, such as patients undergoing cardiac electrophysiological examination for all kinds of arrhythmia as well as cardiac catheterization during coronary angiography. Overall, the results provided meaningful information on how to better understand, as well as support and care for patients in the studied context.

Strengths and limitations

We claim that this study is one of the first in over 20 years to examine the patient's perspective during electrophysiological examination and treatment with catheter ablation for AVNRT and AVRT. However, further studies are recommended, as the current study has a few limitations. First, this study was conducted in a Swedish context and participants were recruited from one clinical centre. It would be interesting to include additional electrophysiological centres to address the differences and similarities on a national as well as international level, and more research in this area could provide valuable insight and synergies to existing knowledge. Second, this study has an adult population, and it would be interesting to study the experiences of younger participants', such as teenagers, who could possibly add different perspectives to the findings of the present study. However, the age range in the present study is mainly representative of those who received catheter ablation due to AVNRT or AVRT in an electrophysiological centre.

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Notes on contributors

Ann-Katrin Nordblom, RN, MScN, is a cardiac nurse at the Department of Cardiology, Skaraborg Hospital of Skövde, Sweden, working in the cardiac team at the Electrophysiology Lab., and PhD-student in Caring Science, with two publications.

Anna Kjellsdotter since 2012. Associate professor, Research leader and Manager of Innovation at FoUUI at Skaraborg Hospital of Skövde, Sweden, with about 20 publications.

Gabriella Norberg Boysen, prehospital emergency nurse for more than 20 years. PhD in Caring Science since 2017, and senior lecture at the University of Borås, Sweden, with 11 publications.

Mia Berglund since 2011. Associate Professor at University of Skövde, Sweden, with more than 30 publications. She received Excellence in Teaching Award 2022.

ORCID

Ann-Katrin Nordblom http://orcid.org/0000-0003-1204-0598
Anna Kjellsdotter http://orcid.org/0000-0003-0307-0517
Gabriella Norberg Boysen http://orcid.org/0000-0003-3203-3838
Mia Berglund http://orcid.org/0000-0002-2671-1041

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Paper III

Being taken seriously: a phenomenological study of participation in care for patients with supraventricular tachycardia

Aims and objectives*:* For patients with a recurring and elusive heart disorder participation is challenging because of the need for care across the healthcare system. This paper describes patient participation in healthcare as experienced by patients with supraventricular tachycardia.

Methodological design: A descriptive phenomenological design in line with the reflective lifeworld research approach was used. Interviews were conducted with 17 patients, and the analysis was carried to analyse participation as it evolved from the initial healthcare encounter through various phases of illness and treatment.

Findings*:* Patient participation for those with supraventricular tachycardia, involves a currency of trust that is hampered by lack of continuity, leaving patients in an "existential waiting room"—a state characterized by trust in healthcare and a hope for treatment for an unpredictable condition that significantly impacts daily life. Participation in their own care allows patients to resume their lives. However, it is hampered by inconsistent involvement. This phenomenon fosters a transition towards increased existential safety that begins when the patients is believed. Knowledge and a joint struggle to obtain objective evidence and appropriate treatment are crucial. Participation manifests as a sense of trust in being taken seriously as a whole person, bringing hope for help with their unreliable heart. When participation is not facilitated, it results in powerlessness and broken trust in the healthcare system, even if suitable treatment is offered.

Conclusions: Participation in healthcare for patients with supraventricular tachycardia is challenging. Repeated interactions at various healthcare levels and with multiple healthcare professionals' highlights a complex and unstructured care, making it hard for patients to be taken seriously, especially when tachycardia is undocumented. A diagnosis validates the patient's experiences, serving as a bridge to being believed and providing direction for action and treatment. Increased participation can be achieved through a joint effort to determine the diagnosis, grounded in mutual trust in the patient's competence and narrative.

Keywords: patient participation; primary and secondary healthcare; phenomenology; reflective lifeworld research; supraventricular tachycardia; primary and supplementary analysis; person-centred care

Introduction

Recurrent palpitation is a symptom of supraventricular tachycardia (SVT) and a common reason for seeking primary healthcare (from healthcare centers) and secondary healthcare (from hospitals and specialists), especially when the condition is undiagnosed and untreated [1,2,3]. SVT refers to a subgroup of atrial arrhythmias characterized by episodic tachycardia that begins suddenly and terminates abruptly [4].

The unpredictable episodes and subsequent difficulties in obtaining a diagnosis introduce a temporal context over a longer period, involving repeated interactions with various healthcare professionals (HCPs, mainly physicians). Patients must be enabled to take responsibility for and influence their own health situation through participation, which HCPs must support [5,6]. However, patients face participation challenges primarily due to the temporal context and, second, their lack of information about treatment options.

Treatment options range from none to self-care strategies, such as vagal maneuvres (e.g., bending one´s head, inhaling deeply, coughing, apply cold water to the face, or straining at an early stage), which may interrupt SVT [4]. The next option is pharmacotherapy (the use of rate-reducing or anti-arrhythmic drugs), followed by long-term management with catheter ablation—an invasive medical procedure performed under local anesthesia for diagnostic and treatment, with a high success rate for SVT and a low complication rate. Patients need to be actively involved in discussions about treatment options [4], emphasizing knowledge acquisition and interacting with HCPs, rather than merely participating in decision making [7].

Self-strategies can assist patient but may lose effectiveness over time. In cases where pharmacotherapy is either insufficient or causes unacceptable side effects, catheter ablation is offered to patients experiencing frequent, prolonged, or troublesome symptoms [4]. For these individuals, healthcare must be coordinated across various levels to ensure effective SVT management [4,8]. Despite international guidelines [4] recommending catheter ablation as a first-line option, the average time between effective diagnosis and treatment can be lengthy [9]. Whether this delay is related to the process whereby patients participate in their own care by making an informed choice (i.e. shared decision-making) remains unclear.

Patient participation is an established concept in healthcare, both nationally in anonymized— where it has been strengthened through laws and regulations [10] —and internationally [11]. From a caring science perspective, patient participation encompasses learning, the caring relationship, and reciprocity [12]. Being respected, listened to, and regarded as an individual entails receiving relevant information and engaging in reflective dialogue according to one's needs and circumstances [7].

Existing studies on patient participation in healthcare [5-7] have focused on different healthcare contexts, including those involving atrial fibrillation [13], which is similar to SVT. However, the literature has gaps regarding the participation of patients with SVT in their own care [1,8,9]. In this study, we explored patients' experiences of participation in interactions across various healthcare levels and with multiple HCPs. Patients who do not participate in their healthcare often feel incapable of understanding or making decisions regarding their own care due to the lack of a supportive relationship [7,8]. Such experiences can lead to feelings of powerlessness and exclusion, ultimately resulting in suffering [14]. Nearly half of primary healthcare patients also visit emergency and specialized care facilities, but many patients perceive the chain of care as unstructured and ineffective due to a lack of coordination across healthcare levels [15,16].

To the best of our knowledge, no previous studies have investigated patient participation from the perspective of individuals with SVT who experience repeated and often long-term healthcare interactions. Therefore, this study aimed to describe patient participation in healthcare as experienced by patients with SVT.

Methods

This study explores and illuminate the phenomenon of patient participation in healthcare using the reflective lifeworld research (RLR) approach, which is based on phenomenological epistemology [17]. Phenomenological studies focus on lived experiences, providing a non-dualistic, non-reductionist, and holistic perspective that incorporates existential and social context [18].

As an epistemological basis, lifeworld refers to the study of individuals as embodied subjects—an experiential world that is both common and shared with others but partly unique and personal, encompassing past, present, and future [17]. The interview and analysis focus on the relational aspects, or the "in-between", exploring how the subject experiences the object within the world [19].

The methodological principles of RLR emphasize openness and flexibility towards the lifeworld descriptions, with a central focus on the studied phenomenon, the things themselves, and their meanings. For researchers, having a bridled attitude is key to remaining alert, critically evaluating the studied phenomenon against their own pre-understanding (self-awareness), and sustaining reflective openness (attitude) toward this phenomenon throughout the research process [17,19]. Bridling one's pre-understanding involves slowing down the interpretative process, reflecting, and refraining from prematurely defining what is indefinite, thereby expanding the scope of one's understanding [19].

The significance of exploring patient participation emerged in the authors' previous research [20], which highlighted patients' experiences and the need for their greater engagement in healthcare. As the previous study and the present study employed the same method (RLR), data collection approach (lifeworld interviews) [17,19], and context (patients with SVT in healthcare), the previously unexamined primary data could be integrated with supplementary data [21,22]. To describe and understand the phenomenon of patient participation, the study examines how it develops from initial healthcare interactions through various phases of illness and treatment.

Informants and data collection

Patients living in central-west anonymized were recruited from pilot interviews conducted in September 2020, as well as from a specialist clinic with patient referrals from several regional hospitals between December 2021 and Mars 2022, and between April 2023 and June 2023. The inclusion criteria were as follows: patients who had undergone catheter ablation for SVT, diagnosed with atrioventricular nodal reentry tachycardia (AVNRT) and/or atrioventricular reentry tachycardia (AVRT), aged >18 years, and able to communicate in and understand Swedish. The exclusion criterion was a diagnosis of atrial flutter or atrial fibrillation.

Patients were identified in two steps. First, the clinic's medical secretary scheduled SVT ablations based on the planned elective program. Second, the ward coordinator identified patients who had undergone ablation for AVNRT or AVRT, ensuring that the first author (anonymized) had not participated in their care. Twenty-seven patients met the inclusion criteria and were sent a formal invitation letter to participate in this study. The first author contacted those who expressed interest in learning more about this study, and ultimately, nine women and eight men agreed to participate. The patients in this study comprised a diverse sample of adults of various genders and ages, residing in both rural and urban areas. Their education levels ranged from primary to academic school, and representative of patients treated with catheter ablation for AVNRT and AVRT at a specialist clinic.

Primary healthcare provides accessible services for common care needs, while secondary healthcare addresses more acute and complex conditions trough specialist providers [23]. The patients had prior experience with both healthcare levels, although a significant proportion had engaged only in secondary healthcare. According to the routine, the patient interactions for both primary and secondary care were primarily with a physician and rarely with a nurse or biomedical scientist. None of the patients employed specific self-initiated strategies for controlling palpitations beyond abruptly stopping their activities and resting. Half of the patients received medication before undergoing catheter ablation for AVNRT (14 patients), AVRT (2 patients), or their combination (1 patient). The average patient was a 57-year-old woman (21–89 years) who had experienced palpitations for an average duration of 13 years (3 months to 41 years) before undergoing catheter ablation.

As the interviews were conducted during the COVID-19 pandemic and post-pandemic period, the patient chose the interview locations based on convenience. Seven patients selected face-to-face interviews, and ten patients selected telephone or digital interviews. The audio-recorded interviews lasted between 29 and 93 minutes, with an average duration of 60 minutes. Each interview began with information on ethical considerations, including the patient's right to discontinue participation without providing a reason. In the primary data collection phase [20], the interviews started with an open-ended question: "Tell me about your experiences in interacting with healthcare when seeking care for sudden palpitations." In the supplementary data collection phase, the first question was open-ended: "Can you describe a situation in your contact with healthcare when you felt that you have participated in your care?" Follow-up questions were tailored to deepen the discussion: "What do you mean?" and "Can you tell me more?" After each interview, the interviewer took reflective notes on their own nonverbal experiences, such as their observations of the patients' emotional state. These notes were considered part of the data. In fact, the research situation—the interview itself—was always more contextually rich than the transcript data. To preserve the sense of the research encounter, the first author conducted and transcribed each interview verbatim [17]. However, during one interview, a technical error occurred with the recorder, but the patient refused to reschedule the interview, stating that they had waited for that opportunity to share their experiences. Therefore, the interview was continued, and the first author took notes throughout.

Data analysis

The data were analyzed according with the RLR principles [17]. The analysis followed a descriptive tripartite structure—a movement from the whole to the parts and back to the whole [17]. It began with repeated reading of the full text to develop a sense of the whole, maintaining openness to its meaning. This process included bridling, which involves resisting premature or careless understanding [17,24], allowing the phenomenon to emerge in a new way [17,18] and contributing new knowledge. The analysis then shifted to the parts—to identifying the meanings of the phenomenon of patient participation in healthcare. These meanings were sorted into clusters based on similarities and differences, with flexibility maintained as long as possible [17].

Furthermore, the phenomenon was examined by contrasting participation (figure) with nonparticipation (background) across clusters to reveal new patterns of meanings [25]. Nuances and the richness of meanings were integrated into a new whole. Finally, the findings are presented in a structure format, beginning with the phenomenon's essence (key meanings) [17], followed by its constituents, and supported by contextual descriptions and quotations.

Findings

The phenomenon of patient participation in healthcare, as experienced by patients with SVT, involves a currency of trust that is hampered by a lack of continuity, leaving patients in an "existential waiting room"—a state characterized by trust in healthcare and a hope for treatment of an unpredictable condition that significantly impacts daily life.

Effective participation in their own care allows patients to resume their lives. However, it is hampered by inconsistent involvement. This phenomenon fosters a transition towards a sense of increased existential safety that begins when the patient is believed. Knowledge and a joint struggle to obtain objective evidence and appropriate treatment are crucial. Participation manifests as a sense of trust of in being taken seriously as a whole person, which, for patients with SVT, brings hope of help with their unreliable heart. When patient participation is not facilitated, it results in powerlessness and broken trust in the healthcare system, even if suitable treatment is offered.

Thus, the phenomenon has the following constituents: (1) being taken seriously—a joint struggle; (2) trust in an uncertain situation; (3) lack of continuity; and (4) knowledge—a transition to existential safety.

Being taken seriously—a joint struggle

Patients with SVT participate in healthcare when they are taken seriously, receive professional help, and are treated as a whole person. Their need for objective evidence of their condition sometimes involves a joint struggle with HCPs, and for other patients, an individual effort to have their tachycardia documented on an electrocardiogram (ECG) as proof.

One patient described their interaction with healthcare as uncertain and ambiguous due to the existential impact of an unclear health situation:

> At first, I hesitated to go there, but then, the palpitations increased, and I did not want to die before I could explain my health issues to my kids, so I went in for a check. And so, it went on for several years. (Patient 9)

The existential impact of SVT may concern the transience of life, included uncertainty about the future due to the unexplained and elusive nature of the condition. Conversely, reassurance that the condition is not dangerous was described as a form of relief—though some patients experienced that they were not being taken seriously, especially when the message was not accompanied by information and a dialogue explaining that the condition is treatable. One patient articulated their experience of a lack of support during a sustained episode of tachycardia, describing the feeling of being ignored and not respected as a person with a life:

> When I told them about this, they responded, "It is not dangerous." Well, I can say that this is serious for me. Not dangerous?! Sit here and have this tachycardia for several hours, then you will see it yourself. (Patient 11)

The patients were able to clearly identify the moment when they began participating, describing their experiences of being treated as a capable individual who actively contribute to treatment decisions. This moment was reflected in interactions with HCPs who made a difference in the continuing care process— who demonstrated commitment and listened to the patient. One patient described frustration followed by relief and the experience of finally being taken seriously:

> They told me, "Next time you have the tachycardia, you call 112," but I don't want to have it that way! I'm just over 50 years old; I don't want to deal with it that way. The physician really listened to me and then wrote a referral to the cardiologist. (Patient 5)

Additionally, the phenomenon of participation occurs when patients are aware of their treatment options and involved in the decision-making, understanding the significance of their choices for their wellbeing.

Trust in an uncertain situation

Patients with SVT experience participation in healthcare as a form of trust in the midst of an uncertain situation. It is rooted in confidence in the competence of the HCPs but is hindered when patients feel disbelieved, which erodes their overall trust to the healthcare system. Participation can be understood as trusting HCP's and relinquishing responsibility for one's care, which also requires remaining attentive to the procedure. One patient described this experience during ablation treatment:

> I experienced the ablation as quite effortless—I handed over the responsibility for myself to the experts. I don´t like pain, but if everything seems normal in the operating room, then I keep cool. (Patient 9)

The patients experienced participation as trustworthy when communication with HCPs occurred at a personal level. This means HCP's needs to show genuine interest, first, in the patient's narrative, and to provide knowledge about the condition and how to manage it in daily life.

Trust in an uncertain situation is perceived as particularly difficult because the heart rhythm disturbances are elusive. Patients reported not being taken seriously when the tachycardia episodes suddenly stopped, which led to responses such as "Come back if the symptoms return." Experiences of being neglected when seeking help in healthcare resulted in broken trust during an uncertain situation and frustration due to their lack of participation and support. Some patients experienced this as hindering their ability to seek care; as such, their next of kin or other significance persons supported them in making another attempt due to the substantial impact of the tachycardia episodes on their daily life.

Lack of continuity

Trust, which is central for participation, fluctuates in interactions with different HCPs and is hindered by a lack of continuity. A lack of participation arises from experiences of being ignored and especially from inconsistent care. This discontinuity disrupts the formation of trusting relationships and contributes to a sense of existential insecurity.

Patients describe a feeling of resignation—of quietly giving up—when their efforts to be heard are repeatedly met with unresponsiveness. The need to repeatedly recount one's medical history becomes not only exhausting but also symbolic of a fragmented care that fails to acknowledge the person behind the symptoms. One patient reflected on how they coped with the lack of continuity:

> I did not handle it in the end. Just not being believed in … there were so much other stuff they were good at, but in the end, I did not manage to repeat my story again…. (Patient 2)

The patients' insecurity following their nonparticipating in their examination—or the absence of an examination altogether—resulted in their existential fear of a serious condition, experiences of powerlessness, and diminished trust in healthcare, as they knew that something was wrong with them, but they did not know how to manage their symptoms and condition.

Knowledge—a transition to existential safety

Participation in healthcare interactions, as experienced by patients with SVT, reflects a desire to regain health and transition toward existential safety. Specifically, it is experienced as a transition toward being securely grounded in one's knowledge of one's illness and its treatment, which offers the possibility of reducing one's existential uncertainty. In this context, participation includes informed knowledge of treatment options and the ability to decide to pursue further treatment when it is supported by HCPs. A patient with previous negative experiences of participation described the turning point as the moment when their need for security became central:

> Just to hear what this is about—and they were checking "Do you get what this means?" and "Do you want us to send this referral?" … I think my need for security … emerged just by having knowledge and being involved in the decision. (Patient 2)

Participation occurs when prior existential uncertainty turns into a need for security, having a diagnosis, and knowing how to manage the episodes. This shift increases opportunities for patients to understand their symptoms and learn tachycardia management, healthcare access, and treatment options. Knowing each option's consequences allows patients to process the information and make informed decisions about the proposed treatment. One patient expressed their frustration and sadness for lost years of a quality life:

> Thanks to meeting that physician, it went on well, but having to wait for so many years, I truly think that is a scandal when there is a treatment. I try not to think about it, but it truly bothers me. It has destroyed so much for me these years…. (Patient 1)

Even after successful catheter ablation and the patient's satisfaction with the treatment, the broken trust leads to a lingering sadness over lost years of a quality time in life. Some unanswered questions persist, such as the reason for not being allowed to participate in their care earlier and being involved in the decision-making process for treatment. Through this reflection, the significance of participation in one's own healthcare becomes unmistakably clear.

Discussion

The findings of this study reveal that patient participation in healthcare is fragmented due to lack of continuity and HCPs' passive responses, leading to patients' existential insecurity, on the one hand and, on the other hand, their desire to regain health. When patients have limited opportunities for participation, they experience powerlessness, uncertainty, and a sense of neglect. This existential insecurity has an impact beyond the healthcare process, with some patients expressing lingering distrust and sadness over lost years of quality of life. Furthermore, unanswered and frustrating questions arise, including why their treatment was delayed when a cure was available. These findings underscore the importance of patient participation in increasing patients' knowledge of their condition and their sense of security as a result of their enhanced ability to interact with and trust HCPs [7,12].

Among patients seeking care for recurrent palpitations, distress is common because they are unaware of the cause of their symptoms and whether the condition is dangerous [8]. McCabe et al. [13] reported that individuals living with unpredictable and recurrent episodes of atrial fibrillation experienced severe consequences linked to negative emotions. However, those with a better understanding of atrial fibrillation reported fewer negative emotions related to their arrhythmia [13]. While atrial fibrillation has similarity with AVNRT and AVRT in terms of symptoms, occurrence at the atrial level of the heart, and impact on well-being, their management and treatment differ [4].

For patients, a diagnosis becomes a bridge between their symptoms and their effective treatment, providing HCPs with direction for action and treatment during persistent tachycardia episodes, such as in emergency situations. Our findings suggest two necessary aspects of participation for patient with SVT: being believed, with or without objective evidence, and receiving knowledge of treatment options and actively engaging in the diagnostic process and decision-making regarding the type of treatment. Oliveira et al. [9] explored the independent predictors of nonreferral of patients with SVT for catheter ablation and detected biases that led to the underutilization of catheter ablation as a first-line treatment for SVT. In fact, their findings indicate that catheter ablation has not been discussed with patients with SVT as a first-line treatment option [9], reinforcing the frustration expressed by the patients in the present study about not being informed of the treatment earlier in their care process.

Evidently, when the patient perspective is overlooked and not recognized as a resource, participation and shared decision-making are given no space.

Our findings highlight variations of participation, ranging from absent to fully present. In some cases, patients also initiated informative and reflective dialogue with HCPs, including about a supportive care plan before planned treatment, such as catheter ablation for SVT. This study reinforces the importance of patient participation in the treatment of SVT to achieve quality of life by strengthened health processes. Interactions between HCPs' theoretical knowledge and patients' experiential expertise enhance patients' understanding of their own situation, health condition, and treatment, as well as foster trust, which leads to the best decisions. In practical terms, HCPs can build trust by simply listening to patients' concerns and genuinely acknowledging their experiences [26].

This study's findings are based on patients' primary and secondary healthcare interactions, mainly with physicians. Some patients experienced these interactions as a smooth journey, with good relationship with the physician enabling them to share their health concerns and participate in each step of the care chain. Unfortunately, a predominant pattern of healthcare emerged that lacked the patient perspective and participation, based on frustrated narratives of patients who felt unheard in repeated encounters with HCPs due to a lack of continuity, regardless of the healthcare level. In line with previous research [1,16], the patients in this study experienced an unstructured and uncoordinated chain of care that hindered integrated healthcare. They perceived the healthcare focus as biological measurements, at the expense of their personal experiences. A newly published study [27] revealed that patients with palpitations clinically suggestive of SVT are often managed conservatively until ECG documents tachycardia, highly impacting quality of life and healthcare utilization. The question that remains is whether and how consideration of the patient's perspective and patients' participation in their own healthcare with HCPs can prevent or diminish the patient's existential insecurity.

Methodological considerations

An emergent issue not considered in the primary study [20] prompted an in-depth investigation in this study of the data collection in the previous study using the already collected but still unanalyzed data [22], alongside supplementary data collection. The same research team conducted both studies. Thus, researchers were familiar with the context and used the same data collection method, which potentially minimized bias [22]. However, the use of previously collected data posed risks, including reducing quality in the follow-up and in-depth questions on the primary dataset. While data fit issues can arise, the two datasets had contextual similarities and were collected within comparable timeframes, leading the author group to determine that both the depth and breadth of the topic coverage were adequately maintained [22].

A key strength of this study is its serious consideration and assessment of the patients' narratives. To ensure trustworthiness, the data from the two studies were analyzed transparently. Hence, the findings were presented together with quotes [17]. To retain rigor, all the interviews were conducted by the first author (anonymized), who was thoroughly familiar with all aspects of the data, ensuring the identification of salient themes and, thereby, dependability of the meanings. The data were analyzed several times to capture a nuanced essence of participation beyond a simple binary framework (participation versus lack of participation), which presents only contradictions. Furthermore, credibility was established through repeated discussions of the narratives in the author group to understand their essential meaning, and intersubjective reliability was pursued throughout the analysis process [17]. Additionally, the manuscript was peer-reviewed during a seminar with other researchers, further validating the findings.

Regarding ethical concerns, the first author, a nurse at the specialist clinic where the patients were examined and treated with catheter ablation, ensured that their participation in this study did not overlap with their clinical duties involving the treatment of the patients included in the study.

In qualitative research, the generalizability of the findings arises from their presentation within a structured framework of meaning and in quotations, emphasizing their inherently contextual nature [17,18]. In the context of patients with SVT, where multiple HCPs function at various healthcare levels, achieving patient participation and shared decision-making can be challenging due to healthcare fragmentation. To ensure meaningful patient participation at all healthcare levels [16], cohesive care models should be developed that combine, interprofessional collaboration with person-centered care [28].

Implications for clinical practice

The Patient Act [10] aims to strengthen patient's position and legal status in healthcare, yet compliance remains limited particularly in areas such as participation, accessibility, continuity, and coordination [15]. To improve implementation, person-centred care must be promoted. As a global healthcare movement, it places human experience, compassion, and dignity at the core of healthcare decision with respect for the person as a central value [28]. This study highlights the need to strengthen patient participation in care for individuals with SVT, ensuring that care is not only medically appropriate but also relationally and ethically responsive.

Patients with SVT benefit from access to HCP with expertise in assessment and treatment options. Additionally, strategies for improving communication between HCP's and patients could enhance the possibilities for patients being heard and involved in decision-making regarding their care. This could involve developing protocols that promote continuity, reduce fragmented interactions, and build trust. Additionally, digital tools, such as patient portals, mobile apps, and secure messaging systems can enhance communication provide clinical guidance, contributing to more coordinated and person-centred care.

Furthermore, since, in this study, the patients with SVT primarily encountered physicians, the question arises as to whether nurses, with their specialized competencies, are an overlooked resource in the care of patients with SVT. These patients' repeated interactions across various healthcare levels and with multiple HCPs have been shown to often result in a lack of continuity and unstructured care. From a lifeworld perspective, health encompasses the whole person [17], and this study reinforces the value of patient participation in healthcare.

Conclusions

Participation in healthcare is challenging for patients with SVT due to the need for repeated interactions across various healthcare levels and with multiple HCPs. This study highlights a complex and unstructured care pattern for these patients illuminated by the following insights:

- Patients with SVT struggle to be taken seriously, especially when their tachycardia is undocumented.
- Reveals a fragile currency of trust, undermined by a lack of continuity, leaving patients in an "existential waiting room", where trust in healthcare coexists with uncertainty and a hope for treatment.
- Patient participation can be strengthened through a collaborative effort between HCPs and patients to establish the diagnosis, rooted in HCPs' trust in patients' competence and narratives.

Ethical approval

The study was approved by the Ethical Review Board in anonymized (Dnr: 2019/03295) and complied with the principles outlined in the Declaration of Helsinki [29]. Each patient provided informed consent to participate.

Author contribution

All the authors contributed to the conceptualisation of this study, data acquisition and analysis, and drafting and revision of this manuscript. All the authors approved the final manuscript.

Supplementary data

The consolidated criteria for reporting qualitative research (COREQ) checklist were adhered to throughout this study's development, execution, and reporting [30].

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Paper IV

Improving Care for Patients with Supraventricular Tachycardia Through Experience Based Co-Design: A Reflexive Thematic Analysis

Ann-Katrin Nordblom, Mia Berglund & Anna Kjellsdotter

Abstract

Introduction: Unpredictable and recurrent episodes of supraventricular tachycardia (SVT) present a significant challenge for both patients and healthcare system, particularly when the condition remains undiagnosed. Current evidence on effective strategies to enhance care delivery, improve accessibility, and reduce unmet needs within this patient population remains limited. The aim is to describe how areas for improvement in the care of patients with SVT can be identified and prioritized using the experience-based co-design (EBCD) approach.

Design and method: This qualitative study, based on an inductive design, utilized a structured two-phase EBCD methodology. The process includes participatory workshops with patients and iterative development in close collaboration with healthcare providers, to identify areas for improvement in the care of patients with SVT. Data were analyzed using reflexive thematic analysis, focusing on the lived experiences of patients with recurrent tachycardia/SVT and their encounters in healthcare, particularly during specialist care involving catheter ablation procedures.

Findings: Patients' reflections in workshop 1 and 2 led to the identification of three key areas for improvement: confidence-building support, tailored information, and substantial communication. Healthcare providers' reflection during their process-oriented workshop was in line with the identification of key areas: information and communication.

Conclusion: The EBCD approach was successfully applied in this study to identify areas for improvement in the care of patients with SVT. Reflexive thematic analysis highlighted a key insight from participants: the importance of recognizing the person behind the patient. While standardized information and general instructions were helpful for certain steps in the care pathway, participants clearly preferred personal contact, underscoring the value of human interaction in healthcare.

Keywords: experience-based co-design; patient perspective; reflexive thematic analysis: supraventricular tachycardia

Introduction

Unpredictable recurrent episodes of palpitation are a common reason for patients seeking care in both primary care (e.g., healthcare centers) and secondary healthcare settings (e.g., hospitals, specialists) (Nordblom et al., 2022; Sacks et al., 2020). These symptoms might indicate supraventricular tachycardia (SVT), an elusive condition that presents challenges for both patients and healthcare providers when undiagnosed (Brugada et al., 2019; Carnlöf et al., 2017). SVT affects approximately 0.17-0.20% of the Western population (excluding atrial fibrillation) (Go et al., 2018; Rosengren et al. 2019). In Sweden, the current outpatient management of patients with recurrent SVT lacks a standardized approach, leading to disparities in care, unmet patient needs, and unequal access to specialist care when required. Consequently, patients may experience not being taken seriously or even believed (Wood et al. 2007). Many patients, especially women, may face delays in diagnosis and treatment due to gender bias and the underestimation of their symptoms (Carnlöf et al. 2017; Nordblom et al., 2022). This highlights a need for equitable care that validates patients' experiences and ensures timely access to appropriate interventions.

Along the care pathway of seeking help for recurrent palpitations/SVT and eventually receiving a diagnosis confirming a physiologically treatable condition, many questions may arise. Not knowing or understanding what is happening in one's own body lead to a sense of existential homelessness (Carel, 2021; Toombs, 2001). The previously reliable body becomes unfamiliar, triggering insecurity about the future and even one´s existence. Previous research has demonstrated the impact of living with recurrent episodes of SVT, highlighting patients' difficulties in accessing appropriate care for this condition (Nordblom et al., 2017; Withers et al., 2015; Wood et al., 2007). Building on these findings, a follow-up study by Nordblom et al. (submitted 2025) explored patients' experiences of participation as they navigated healthcare services and interacted with healthcare providers. Patients reported lack of participation that includes lack of information due to self-care management and further treatment options as well as lack of accessibility to specialist care.

According to the World Health Organization (WHO) self-care is "the ability of individuals, families and communities to promote health, prevent disease, maintain health and cope with illness and disability with or without the support of a health worker" (WHO, 2022, p. 8). This definition encompasses health promotion, disease prevention and control, self-medication, caregiving for dependents and timely engagement with healthcare services, when necessary (WHO, 2022). Self-care for patients with SVT includes practicing the Valsalva maneuver and other strategies that can interrupt the SVT at an early stage, such as bending one's head down, inhaling deeply, clearing one's throat, cold water on the face, or coughing (Brugada et al., 2019). When self-care is ineffective, patients turn to healthcare for help and support. To reduce hospitalizations and emergency visits, nurse-led care was introduced in both secondary and primary healthcare nearly a decade ago (Dahlberg & Jakobsson, 2025). While patients with atrial fibrillation often have access to structured nurse-led clinics in

secondary care (Hendriks et al., 2013; Holmlund, 2024), there is limited research on such models in primary care (Dahlberg & Jakobsson, 2025). To the best of our knowledge, no structured nurse-led care is currently not available in Sweden for patients with recurrent tachycardia, such as SVT, in either primary or specialist care.

There is limited evidence on how best to improve the management of patients with SVT to meet their need and increase access to appropriate healthcare and treatment. Evidence suggests that incorporating patient experience into healthcare service design and delivery can positively influence a range of outcomes for both patients and organizations (Doyle et al., 2013). Healthcare systems are continually working to ensure the care they provide is person-centered and delivered in a way that fulfils patients' needs and expectations (Coulter, et al., 2014). Experience-based co-design (EBCD) is a participatory method that engages patients, healthcare providers, and stakeholders in collaboratively improving healthcare services. Originating from chronic care implementation research (Bate & Robert, 2006), EBCD uses qualitative data, interviews, observations, and diaries to identify emotionally significant care experiences. "Trigger" materials such as films or quotes facilitate dialogue, helping to prioritize issues and co-create solutions (Craig et al., 2023; Koirala et al., 2025). Beyond service design, EBCD also supports the development of person-centered research interventions.

Aim

To describe how areas for improvement in the care of patients with supraventricular tachycardia can be identified and prioritized using the experience-based co-design approach.

Methodology

Study design

This study is based on the principles and methods of EBCD. This process leads to the identification of areas of care provision that need to be changed and provides a framework through which improvement activities can be undertaken (Bate & Robert, 2006; Robert, 2013). The EBCD approach is flexible, but the most fundamental elements must be retained: the service user experience data and a joint service user-provider event (Green et al., 2020).

Setting, participants, and study procedure

This study was conducted at a central hospital in the south-west region of Sweden, with an approximate population of about 216 000 inhabitants aged > 18 years (Statistics Sweden, 2024). At the central hospital, advanced cardiac care is provided with a focus on both acute and elective treatment of cardiovascular diseases, and the hospital receives patient referrals from other hospitals across the VGR due to its specialized services. Catheter ablation is offered as a highly curative treatment option for selected patients with SVT, in accordance with international guidelines (Brugada et al., 2019).

"Living books VGR" refers to patients who take part in an initiative by the Västra Götaland Region (VGR) to improve healthcare services. These patient representatives, referred to as patients, share their personal experiences to support development and improvements efforts, such as by participating in working groups or workshops. Four adult individuals with experience of recurrent tachycardia, were recruited following individual interviews. All participants confirmed their willingness to take part in two workshops and provided informed consent to participate in the study.

Healthcare providers (HCPs) on an ablation team were included in the study. The team was selected to cover all aspects of the ablation process in order to identify all relevant aspects of the process improvement. To support this work, a management developer was involved to facilitate the application of suppliers, inputs, process. outputs and customers (SIPOC), a tool used to define the specific stages of the process. Seven individuals were purposefully selected to ensure representation across all aspects of the ablation process, thereby enabling a comprehensive identification of relevant areas for improvement. The team consisted of one medical secretary, two cardiologists, two biomedical scientists, and two nurses, all with extensive experience in cardiology.

This study included two main phases, inspired by Twamley (2023). Phases 1 and 2 constituted the foundation for Phase 3, which will be conducted in a separate study.

Phase 1 involved capturing the experience. Patients experiences were collected through individual interviews. Previous research was summarized through quotes illustrating patients' experiences of interactions with healthcare before and during treatment in specialist care.

Phase 2 involved understanding the experience. First, interview data were analyzed to capture the patients' touchpoints. Next, workshops 1 and 2 were organized, and the same patients were invited to participate. This phase included an analysis of the data derived from HCPs' process-oriented work using SIPOC. All data were analyzed using reflexive thematic analysis.

Phase 3 involved improving the experience. The primary outcome of Phase 3 was to identify the key areas requiring improvement. The study flow chart is shown in Fig. 1.

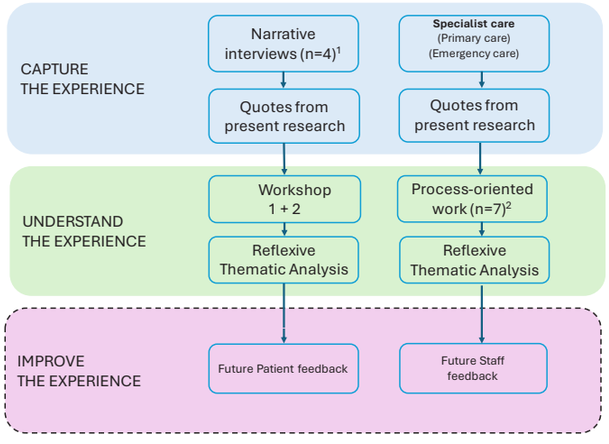
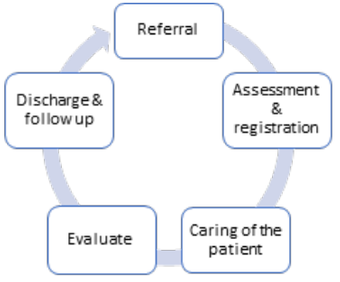


Fig. 1. Study flow chart, [1]patientrepresentative, [2]healthcare professionals. Figure inspired by original by Twamley, Monks and Beaver 2023.

Data collection

In Phase 1, individual interviews (30–45 minutes) were conducted with the patients, giving them the opportunity to describe their personal experiences of sudden palpitations/tachycardia and their motivation to contribute to improving care. These interviews provided a foundation for the upcoming workshop, enabling patients to reflect on their experiences and later focus on identifying and capturing key issues opportunities for improvement in healthcare. All interviews were conducted and transcribed verbatim by the first author (AKN).

Seven HCPs and one process work facilitator were gathered for a 5-day collaborative improvement process-oriented workshop. To understand the ablation process for specialist care, a mapping was carried out using a cause-and-effect (fishbone) diagram (Kumah et al., 2024), for a timeline before, during, and after intervention with catheter ablation. It is presented in a simplified form in a circular flow in Fig.2.



1. Referral of a patient with documented or suspected arrhythmia in need of further assessment for decisions on intervention
2. Assessment and registration of the patient
3. Caring of the patient, ablation treatment
4. Evaluate of intervention
5. Discharge and follow-up

Fig.2. Timeline for the ablation-process

Next, to identify the ablation process for specialist care, a timeline was described in the specific stage of a SIPOC. The SIPOC is a tool for visual overview over a process to map key elements, identify inefficiencies and reflect potential areas for improvement (Daly et al. 2021; Nikita & Singh 2025).

In Phase 2, the findings from the individual patient interviews were summarized, including experiences related to non-acute and acute situations, but mainly regarding being well received and participation. Cultural aspects, digital communications as an alternative for interactions (not the solution), and the need of alternative support were considered as new findings, and notes were taken to preserve the subject to be reflected in the workshops. The findings from the interviews confirmed findings from earlier research (Nordblom et al., 2023, 2025), reinforcing the relevance of these topics for further discussion, as shown in Fig.3.

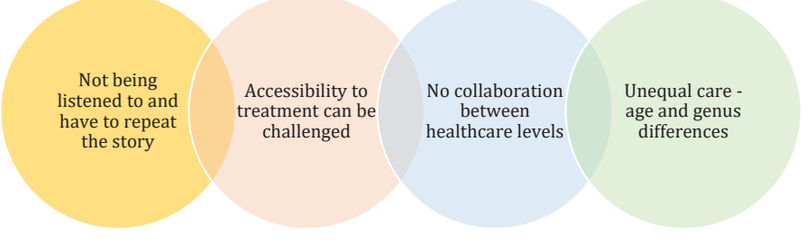


Fig. 3. Presents quotes used as reflections triggers in the co-design workshop with patients' representatives

Workshops 1 and 2 were conducted in April and in September 2025. They were held as digital meetings due to the patients' health status, geographic distance, and preferences. Workshop 1 lasted for 2 hours and 39 minutes, and workshop 2 went for 3 hours and 7 minutes. The data from the workshops were collected through a combination of written notes from the facilitators and an audio recording of the full group discussion around the experience map. Emotions and keywords related to each touchpoint were captured on notes, which were compiled and are presented in Table 1.

The *process-oriented workshop* with HCPs took place over five intensive days in a hospital conference room. A management developer facilitator guided the initial phase, beginning with a cause-and-effect (fishbone) diagram on the first day. Following this, the group continued working more independently using the SIPOC method for the remainder of the week. Reflections during the SIPOC sessions led to the identification of two key areas for improvement: information and communication, including medical responsibility (Table 1).

Facilitating the workshop

The first author and a management developer facilitated the process. During workshop 1, the first author was active in the conversation, mainly leading the discussion and asking follow-up-questions when needed. During this workshop 2, the role as facilitator differed somewhat; to listen actively, ask follow-up questions when needed, ensure everyone had space to speak, and occasionally guide the conversation back to the workshop's purpose. The first author aimed to take part in the discussion with openness and sensitivity, aiming to minimize their influence on the data (Sundler et al., 2019).

Workshop

In workshop 1, triggers served as starting point for the group reflections, prompting deep and meaningful reflections, and were described as persistent issues, regardless of the level of healthcare received (Fig. 3.). Workshop 2 was based on preparatory materials the patients had reviewed in advance. These included informational documents used in clinical practice and suggestions to improve accessibility and care delivery. The documents were distributed in May 2025 to provide participants with sufficient time for reflection. Although a PowerPoint presentation had been prepared to initiate the dialogue, it was ultimately unnecessary, as participants immediately engaged in a lively and sustained reflection. The reflections were rich and nuanced, with suggestions for improvement, and included experiences from previous healthcare encounters.

Data analysis

Data were generated from the group reflections in workshops 1 and 2 (four patients in each) and the documentation of a process-oriented workshop (SIPOC) in specialist care settings (seven HCPs, five workdays). The analysis of data involved a reflexive thematic analysis (Sundler et al., 2019) with a lifeworld approach and a motivation to follow the phenomenon: areas for improvement identified in care. The analytical approach in this study is inductive, based on data reflecting the lived experiences of patients with recurrent tachycardia/SVT and their encounters in healthcare, with focus on the time of treatment in specialist care setting and catheter ablations.

The analysis is reflective and seeks to illuminate meaning through a systematic and thoughtful approach (Sundler et al., 2019). The themes derived from the analysis are data driven and grounded in both the participants' experience and the empirical material. The process began with a reading to become familiar with the data and to explore how meanings could be understood. The focus was on discovering unique and novel aspects of experiences rather than confirming what was already known. The next step involved identifying nuanced meanings—those that differed from one another but remained interrelated. These meanings were marked and described briefly with notes in the margins. Rather than emphasizing interpretation or frequency, the aim was to describe and deepen the understanding of the complexity of meaning within the data. Throughout the process, the first author engaged openly with the material, identifying patterns of meaning and exploring how these could be organized into coherent themes. Finally, the generated findings were rewritten as themes and structured into a meaningful whole (Sundler et al., 2019).

Ethical Considerations

This research was approved by The Swedish Ethical Review Authority [DNR: 2019/03295] and conforms to the Declaration of Helsinki. All participants, both patients and HCPs, were given verbal and written information about the study, and written informed consent was obtained before participation. All participants were made aware of their right to withdraw at any time without consequences.

Findings

The findings are based on the analysis of derived data from workshops 1 and 2, and from HCPs' process-oriented workshop using SIPOC. Patients' reflections in workshop 1 and 2 led to the identification of three key areas for improvement: *confidence-building support, tailored information*, and *substantial communication*. HCPs' reflection during the development process was in line with the identification of key areas, *information* and *communication* (Table 1.).

Table 1. Overview of Main Themes and Sub-themes.

Themes	**Sub-themes**	**Patients**	**Healthcare providers**
Confidence-building support	Support based on trust	We should be given the opportunity to decide what kind of support they need during important conversations to aid memory such as recording the interaction	Suppurative informative films, to listen to music during catheter ablation, VR-glasses to support calming and relaxation during procedure, reduce pain perception
		Even though we appreciated the support and opportunity to talk to the physician, there is often short of time.	A nurse-led pre-ablation clinic was prioritized, to check on need of support, asking and answering questions, having reflective dialogues Follow-up based on the patient's situation.
Tailored information	Clear and reassuring information enables understanding	Foremost to get adequate information, such as the severity, that I don't die of the tachycardia, but it needs to be investigated.	Verbal information is important for patients when offering treatment.
		The information text should be easy to understand, no special terms.	There is a need for updated information, written to the patient, easy to understand, with no images.
	Detailed information	In dialogues, the information must be personalized in relation to our preferences, with the amount of detail we request.	
		It is a balancing act to avoid scaring us but at the same time not neglect the risks.	There should be an effort to be honest and transparent in the dialogue.
		It is relevant to know that the procedure is done during local anesthesia, and estimated time required	General information: -Procedural steps -Appointment details -Pre-procedure preparation -Medication guidelines
	Standardized information	SHD1177[1] should be standardized; now, there are variations in the information between the regions.	
Substantial communication	Complex communication needs clarity	We are living in a multicultural society, with language and generational barriers, where we may	Cultural or language considerations must be understood, such as when an interpreter is needed on site during
			have conceptual confusion.	intervention, and to obtain valuable information in referrals.
			Healthcare visits could be avoided if there was direct contact in the case of palpitations, the waiting time for SHD1177[1] is often to long.	
		Internal communication	The intern dialogue in healthcare is crucial; we as patients may not be aware of it, but this communication has an impact on the actual time of investigation.	There is a need of improved intern communication, such as what information is needed from the referrer to specialist care (referral execution).
			Questionnaires and checklists must be seen as a complement to a good quality dialogue, they do not replace the dialogue.	
			Answering questionnaires due to statistical data is just a waste of time.	Today, questionnaires are used to collect data for the national quality registry (Ablacure) on an aggregating level.
			Digital competence varies, so an alternative is needed for information, such as films, text, and digital meetings	
			Digital portals may be suitable for different types of information but do not replace the important dialogue.	Digital portals with focused information (and films) could convey information about different stage in the care pathway.

[1]SHD1177 = Swedish healthcare direct 1177

Identified areas for improvement in the care of patients with SVT will be presented in following sections, divided into patients' reflection and HCPs' reflection.

Confidence-building support

The patients reflected on the importance of supportive care and alternative forms of support that promoted their confidence. They emphasized the need to acknowledge the patient as an expert in their own life and as an active partner in care, able to express and determine what kind of support they needed during important interactions. This might include having a trusted person present or being allowed to record the conversation to memory aid, since stress and anxiety significantly impair memory, making such support essential for informed decision-making. The experiences in among the patients vary from being able to choose based on their preferences to not receiving any assistance and being neglected, with the conversation instead directed at their next of kin. It was suggested that healthcare providers should be better prepared to ask about and respond to patients' needs of support, which is important in corresponding with patients' legal rights.

The patients also discussed the importance of dialogue in which the interaction between the patient and the healthcare provider is trust-building and responsive to the individual's needs. It was considered important that the information given reflected their needs at the time; otherwise, it could be a burden and more frightening than supportive. Person-centered care was highlighted by the patients as a relevant approach to achieving this, provided it was implemented genuinely and not merely symbolically. Their reflections emphasized the purpose of the dialogue: to determine the patient's need for support. The conversation should be guided by the patient's own questions, enabling healthcare providers to meet the individual where they are, rather than "bombarding them with information". It was acknowledged that some individuals may not wish to receive all available information:

> *I do not want to know, do not give me information I do not want to hear because it is going to give me big concern; I cannot sleep. (P4)*

The patients reflected on trust-building dialogue, characterized by the HCP beginning the conversation with an open question and the patient indicating how deeply they wanted to go into it. Some patients wanted to have the full picture clear, so it was considered important to find a balance. The patients underlined that they believe on the dialogue, and that it was about trust to healthcare, and one patient continues:

> *I have never had a groin procedure, I do not know how I can move. How shall I continue to live my life? (P4)*

The group reflected on the importance of using time well during interactions with specialist care. Further, they emphasized that this was the patient's opportunity to ask someone knowledgeable about the subject. However, the patients also reflected on the benefits of talking to someone ordinary, a person who had shared the same experience and could answer questions to support them, and as one pointed out:

> *I feel I can be myself with someone who shares my experiences-unlike with healthcare professionals, who may not fully understand. (P1)*

HCPs' reflection

The HCP discussed and reflected on the proposal of a nurse-led pre-ablation clinic as an improvement for both patients and the clinic. This would respond to patients' needs of trust and availability and enable them to ask questions of someone educated in the area. The nurse should have a close collaboration with the cardiologists responsible for the ablation department. The competence was there, but the proposal could be hard to implement because it required new resources, mainly time. As one HCP reflected:

> *The patients need opportunity to ask about practical things and other concerns, and we must check on their motivation for the intervention and support the patient to be prepared for the ablation procedure. (P5)*

The proposal was submitted to the clinic management for decision. The HCPs considered peer support as beneficial, something that had requested repeatedly from patients. However, it was quite difficult to provide any kind of support from patient to patient because "confidentiality and data protection regulations pose challenges". The group discussed and reflected on various opportunities to provide support before and during ablation procedure, such as informative films or virtual reality (VR) glasses to support relaxation and even reduce pain perception.

The HCPs' primarily focused and reflected on the referral process, emphasizing the importance of establishing a solid foundation. As the referral often represents the first point of contact between specialist care and the patient, they play a crucial role in building relationships based on trust. A key factor in ensuring the success of the intervention is referring the right patient—those who are motivated and understands the reason for the referral. It is essential that patients are informed not only about the benefits of the treatment but also about potential disadvantages, and that they have a realistic expectation of the treatment outcome. When this part of the process is handled correctly, the likelihood of utilizing available operating times increases, which in turn has a positive impact on accessibility.

Tailored information

The patients' reflections were united regarding the content of the information: It should be tailored. Verbal or written information should be clear and reassuring, and the group agreed that avoiding medical terms was essential, as patients commonly do not understand medical terminology. Adequate information was deemed important; the patients needed to know about the severity, followed by the possibility being investigated to assess the symptoms. It was common for patients to describe being neglected:

> *They say, "You don't need to be worried", and that I just must take it easy. How on earth is it possible to respond that way? Do they even know? (P3)*

The patients reflected on the type of information that should be provided at various levels of healthcare. They emphasized the value of clear, simple language and practical guidance before and after the intervention, such as, "What should I do beforehand? What happens afterward? What should I consider? How shall I live?" They noted that it was helpful to know, for example, whether driving and heavy lifting should be avoided for a few days. At the same time, one participant emphasized the following:

> *You don't need to be zealous with the details on the intervention, because how interesting is it? (P4)*

The group reflected on the challenge of balancing the amount of information at the time of referral. However, opinions varied regarding how much details were needed. Some patients expressed a desire to be fully informed in order to have a complete understanding of what was going to happen, while others wanted limited information:

It is relevant to know that it going to be done under local anesthesia, and that catheters will be inserted into the heart to investigate, and how long it is estimated to take. Concerning risks, it is a balancing act; it may scare some, but the risk should not be neglected either. (P3)

The patients continued how the information should be handed over, and all agreed that it should be a topic in the dialogue with someone at the unit responsibility for the intervention planned; otherwise, the information risked being incorrect and not tailored. The patients emphasized the value of having information that could be easily shared with their loved ones:

When I came home from the hospital, I did not have the energy to support and calm them, but they needed me to explain everything that I was informed about. (P4)

Standardized information was considered valuable, but in a limited way, to ensure equal content and meaning. The information on SHD1177 is a general focused text, for patients searching for information on a specific condition; it is not a comprehensive source. The patients suggested that the information on SHD1177 should be standardized between regions because there were variations in the content.

The HCPs emphasized the importance of health literacy in enabling patients to understand and engage with health information. A key challenge identified was the timing and content of information provided prior to referral. In some cases, specialist care providers had to spend valuable time correcting or clarifying information given by other healthcare professionals. During consultations in specialist care, it was considered essential to offer patients a clear overview of what to expect, including who held the medical responsibility and whom to contact before the intervention. The HCPs also noted the limited ability of specialist care to influence the quality of information provided at other levels of healthcare, underscoring the need for improved coordination and communication across healthcare providers to support patient understanding and continuity.

Substantial communication

The patients reflected on substantial communication and described situations in which language difficulties were evident: “I did not understand what was said, but of course, it is equally important both ways.” They continued reflecting on how communication gaps, unclear messaging, and a lack of transparency in the flow of information contributed to uncertainty in an already vulnerable situation. The patients reflected on the challenges of being cared for in a multicultural society, where language and generational barriers can lead to conceptual misunderstandings. One patient emphasized this point with the significance observation:

I have experienced many situations where someone believes they have been clear, convinced that what they said could not possibly be misinterpreted. You have not achieved anything in a dialogue when the message is not received. I used to think it was silly to repeat what already been said, but it is so essential. (P3)

Patients’ reflections of being believed in communication concerned the management of both acute and non-acute situations. This was reflected as a shared interest for both patients and healthcare system regarding the effective use of existing resources and sustainability in healthcare:

It must be a common interest to identify those with recurrent tachycardia and have a proper care plan - to prevent repeated visits to primary care or emergency services. (P1)

In cases of persistent palpitations or tachycardia, the patients suggested that there should be services offering direct contact with a healthcare professional, aimed to avoiding unnecessary healthcare visits or, in urgent situations, ensuring timely referral to emergency care. They expressed that while they did not require an emergency call (such as 112), the waiting time when calling SHD1177 was often too long. What they needed was someone to talk to quite quickly, without it being an emergency. There are some good examples in the private sector of digital medical clinics with a maximum of 10 minutes waiting before contact with a professional for those experiencing tachycardia. The patients wanted to be taken seriously in healthcare and felt it would be more cost effective if they were treated correctly from the first visit, instead of returning several times for the same reason.

Furthermore, the patients felt that referral confirmation should be mandatory, as current practices varied between ablation departments within VGR. Such confirmation would not only demonstrate patients’ interest in the intervention but also serves as an indication to HCPs that the patient was motivated—or may require further dialogue and information. It could also represent the first verbal contact between the patient and the specialist care responsible for the planned intervention. And as one patient reflected:

I think that the impose referral-confirmation is a part of a stage-created routine. For me as a patient it means that I can process given information and can collect questions for the next conversation. (P2)

The patients emphasized the importance of internal communication within healthcare, noting that while patients may not be aware of it, such dialogue can significantly impact the timing of investigations. They agreed that it was not the patient’s responsibility to understand or manage the resources required for their care; this fell to HCPs.

Patients’ reflected on a checklist for medical history, which raises questions of whether the healthcare provider was informed about and could read their medical record. They felt that HCPs should be prepared before meeting patients. Questions about existing information, such as current medications, were considered unnecessary and risk leading to uncertainty:

But wait, am I really the one who is going to tell you about my medical history? You should have read it before planning an operation, then you should have full control. (P4)

Regarding questionnaires, the patients felt that data must be seen as a complement to a good-quality dialogue—not as replacing the dialogue. The data provide a view of the moment and may be valuable to answer in different situations, in a normal day or during an episode of tachycardia, or in relation the impact in everyday life. However, the questionnaires presented to the patients were anonymous and primarily used to provide data to the national registry. From the patients' perspectives, this process felt like a waste of time, as it did not contribute to their individual care. They suggested avoiding these questionnaires unless they clearly benefited their care and management. Another key area of discussion was communication through digital portals, which included various types of standardized information, instructional self-care videos, and other valuable resources (such as current research knowledge). The patients reflected on the varying levels of digital competence among patients, noting that while these resources could be useful as an alternative, they should complement, not replace, personal contact. They agreed on the importance of recognizing the person behind the patient, emphasizing this as a key factor in the development of meaningful and person-centered care.

HCPs reflected on cultural or language considerations as important information to include in the referrals. During the procedure, they considered it essential that an interpreter be present when required, as attempts to use a telephone interpreter had not worked very well. They discussed the need for improved internal communication, particularly regarding the information required from the provider making a referral to specialist care. Referrals needed to provide a substantial medical history, as these were identified as a key factor in assessing whether an intervention should take place. Important aspects included referral confirmation and clear information about medical responsibility during the waiting period. Another key reflection was the necessity for patients to be given contact details in case any changes, updates, or issues arose. This was considered important for planning and rescheduling, especially when an ablation appointment was canceled and another patient needed to be scheduled. The HCP group reflected on digital portals as a possible way to present information but noted that maintaining and updating these platforms might require more effort than the benefit they provide.

General Discussion

This study achieved its aim of describing how areas for improvement in the care of patients with SVT can be identified and prioritized using the EBCD approach. Patients and HCPs from a specialist care setting, openly reflected and discussed their experiences and suggested several important recommendations for change. Individual interviews with patients provided a foundation for understanding their experiences of interactions in healthcare. The findings from the patients' interviews highlighted *cultural aspects, digital communications as alternative for interactions (not the solution)*, and *the need of alternative support*. These findings were further reflected on during the patients' workshops and also correspond with previous studies describing patients experiences of participation when seeking care in various healthcare settings, including primary care, emergency departments, and specialist care (Nordblom et al., 2025; Withers et al., 2015; Wood et al., 2007), as well as experiences of being treated for recurrent SVT (Carnlöf et al., 2017; Nordblom et al., 2023).

The HCPs contributed through discussions in a 5-day collaborative improvement process-oriented workshop, focusing on the time before, during and after catheter ablation for patients with recurrent arrhythmias. The findings highlighted the complexity of the process, identified the responsibilities of the different professions, and indicated the need for various resources along this pathway. Although the focus of this study was on experiences before, during and after catheter ablation, the patients' reflections on their interactions with various healthcare facilities helped broaden the understanding of the care pathway prior to referral to specialist care. Collaborating to improve the care pathway for patients with recurrent SVT was clearly a priority for the patients and HCPs, with nuanced, engaged reflections and discussions. The patients reflected on the care pathway before and during interactions with specialist care, while HCPs focused on the timeline from initial assessment to referral for specialist care. While some areas remain to be explored, particularly regarding primary care and emergency care, this collaboration represents an important step forward.

The findings revealed three key themes from the patients' reflective discussion: confidence-building support, tailored information, and substantial communication. Illustrative quotations for each of the three themes are presented in Table 1 along with reflective descriptions from the HCPs' process-oriented workshops, which largely matched patients' key themes.

Trust was highly valued and mentioned in relation to all themes. Confidence-building support was deemed essential, with the starting point of being an individual in an existentially vulnerable situation seeking help from healthcare, relying on being met with empathy, understanding, and attentive listening. Being in a vulnerable situation means that the patient is in a disadvantage position in relation to healthcare providers (Ekman et al., 2011). This further underscores the importance of a person-centered approach that actively recognizes and seeks to balance this asymmetry. Supportive dialogue is central to care but must be responsive to the individual need's (Dahlberg et al., 2009; Ekebergh & Lindberg, 2020). The findings identified different stages of the care pathway where dialogue should address the specific information needed at that time. Too much information can be overwhelming and more frightening than helpful. Patients should be able to indicate how deeply they wish to engage, which helps determine the right balance. Another finding was the aspect to use the limited time well during dialogues; it was the patient's opportunity to ask questions of those educated in specialist areas. In response to this finding, patients' needs and request, and the HCPs' process-oriented workshops, a nurse-led pre-ablation clinic was initiated following a decision by hospital management. Patients are now offered a 30-minute session with an arrhythmia nurse—by phone, digitally, or on site, prior to their planned ablation. The aims to mentally prepare patients, identify support needs, clarify

information gaps, and support shared decision-making. The implementation of this type of consultation addresses several key areas identified by the patients in this study, particularly within the specialist care phase of the care pathway. To our knowledge, there is currently no equivalent nurse-led pre-ablation consultation service available in Sweden, though it draws inspiration from similar nurse-led atrial fibrillation clinics (Dahlberg & Jakobsson, 2025; Hendriks et al., 2013; Holmlund, 2024).

The findings suggest that healthcare providers should be better equipped to ask about and respond to patients' choices of supportive solutions, allowing patients to feel more in control of the meeting. Recording consultations—with mutual consent—can aid memory aid, enabling the patient to revisit the information provided and gain a better understanding in hindsight, during a calmer moment. Patients may also benefit from having a next of kin present or using preparatory tools like films before assessment or treatment (Grynne et al., 2023). VR glasses have been used for patients during ablation of atrial fibrillation, in procedures where they are mildly sedated (not fully anesthetized). They have been reported to reduce the experience of pain, increase levels of treatment satisfaction, and provide other non-pain-related benefits (Nørgaard et al., 2015).

Referral in this process is central from several perspectives. First, it represents a possibility for the patient to receive effective treatment, as catheter ablation for SVT is largely curative. Second, patients who have received information and are motivated to have the procedure are more likely to undergo the planned ablation, which in turn results in a high utilization of available healthcare resources.

Tailored information was a central theme in the patients' reflections. They emphasized the need for clear reassuring information that supports understanding, highlighting the importance of avoiding medical terms. They also wanted to be actively involved in discussions about diagnosis and care planning, with information adapted to the specific stage of the care pathway the patient is in, as the pathway can vary significantly depending on their current situation and what lies ahead. These findings align with a study using participatory design (Smith et al., 2017), in which patients and other stakeholder in the healthcare system collaborated to develop written patient education materials. Although such processes are time consuming, they result in clearer and more accessible content.

Patients valued standardized information before catheter ablation for consistency, but noted it often lacked personalization, which led to uncertainty. The patients highlighted the importance of receiving clear instructions on how to prepare, what to expect after discharge, and what actions to take if complications arose before or after the procedure. They stressed the need for clear, detailed instructions on preparation, post-discharge expectations, and handling complications—ideally provided by the unit performing the procedure. HCPs shared similar reflections, emphasizing the importance of giving patients a comprehensive overview of the entire process. A previous study showed that when patients were involved in creating written information, comprehension doubled compared to materials developed without patient input (Chumbley et al., 2002).

The third theme, substantial communication, highlights communication gaps, unclear messaging and a lack of transparency in the flow of information. For patients already in vulnerable situations, these challenges often involve difficulties in achieving mutual understanding. Barriers such as limited language comprehension and generational barriers could lead to conceptual misunderstandings and hinder effective communication. Grynne et al. (2023) developed a digital portal with information in which it was possible to select a language, which increased the accessibility to standardized information. In the present study's findings, the patients suggested that scheduled procedures should always be confirmed by the patient on the phone, which confirms that everything is ok to both parties. For complex communication, such as that involving language and generational barriers, the patients suggested to check on the received message and clarity if needed. The patients reflected on the use of questionnaires and checklists, and their position was clear: If these tools did not provide a direct benefit to the individual patient, they were not considered worth the time. Patient-driven innovations have the possibility of responding to patients' needs appropriately, which increases participation, engagement, and satisfaction with the care given (Berglund et al., 2025). Such innovations can improve the likelihood of adapting care measures to the patients' needs and treatment goals.

Patients noted the poor internal communication within healthcare—such as delayed referrals for examinations—negatively impacted their care. They felt this was a responsibility of the healthcare system to address. The HCPs acknowledged the complexity of internal dialogue and emphasized the need for cross-level collaboration. Inefficient communication, in which referral is highlighted, burdens both patient outcomes and the healthcare system administratively (Ekanayake et al., 2023).

Both groups expressed a shared goal of improving supportive care across the SVT timeline. This discussion led to suggestions for improving accessibility for communication to services, including the option for direct contact with a healthcare professional in cases of persistent tachycardia. Despite the existence of nurse-led atrial fibrillation clinics, structured digital support for patients with SVT remains lacking in Sweden. International evidence supports the effectiveness of nurse-led telehealth interventions in improving outcomes and reducing healthcare burdens (Rockler Meurling et al. 2023). The present study addresses patients' calls for improved care and management of SVT, highlighting a knowledge gap in the research in support both before and after diagnosis has been established. Currently, access to appropriate care often depends on encountering the 'right' healthcare provider, which delay assessment and treatment. This study focuses on patients' experiences around referral decisions and specialist care—one part of the overall care process. Other aspects of the care pathway remain unexplored and will be addressed in future studies.

The absence of patient participation in the development of care for individuals with SVT is concerning, at risks maintaining a system that fails to address the lived realities of those affected. Without integrating patients' experiences, values, and preferences, care can become fragmented,

inequitable, and unsustainable. Furthermore, the lack of standardized management pathways contributes to inconsistencies in care delivery, potentially undermining both patient trust and healthcare efficiency. This study aims to examine the current state of SVT care by emphasizing the need for a more responsive and sustainable approach, one that incorporates the patient perspective into the design of future care strategies. By adopting a lifeworld-oriented perspective, this research contributes to the development of care that is both ethically grounded and practically viable.

Method discussion

The dynamic processes of EBCD enabled the identification of key areas for improvement in care and generated valuable insights into patient participation within the organization. An advantage of the EBCD method used in the study was its ability to identify patient-derived priorities, enabling the design of patient-centered services that address the needs patients themselves report as important (Bate & Robert, 2006; Robert, 2013).

The role of the researcher in the EBCD process differs significantly from that of other research methods. In quantitative methods, the researcher typically maintains an objective distanced stance, focusing on testing hypotheses and measuring outcomes statistically. In contrast, qualitative methods often involve deeper engagement, with an aim to interpret or describe phenomena. In EBCD, the researcher takes on an active role as both facilitator and co-creator, guiding participants through a collaborative process to identify issues and areas for improvement. The first author's role as a facilitator in this process was both challenging and stimulating. It was a creative task to find ways to stimulate dialogue among participants who have never met or collaborated before. Gustavsson & Andersson (2019) reported that a role as a co-designer embraces new perspectives for healthcare professionals that force them to step out of their comfort zones.

One potential limitation of this study is that the workshops for patients were conducted digitally rather than on-site, which may have influenced the outcome. For example, participants were unable to engage inside conversations while another discussion was taking place, something that often happens naturally in physical settings and can contribute to a deeper dialogue. On the other hand, the digital format ensured that all participants were equally involved in the reflections, with a more structured and focused interaction.

While thematic analysis shares similarities with descriptive phenomenological in its focus on meaning-oriented themes, key differences exist. Reflexive thematic analysis, used in this study, organizes patterns of meaning into themes (Sundler et al., 2019), whereas phenomenological approaches often aim to identifying an essential, general structure of experience (van Wijngaarden et al., 2017). These methodological distinctions enhance the depth and rigor of qualitative research (Sundler et al., 2019).

Scientific rigor and phenomenological validity in qualitative research are closely linked to reflexivity, credibility and transferability (Sundler et al., 2019). Reflexivity involves maintaining a reflective attitude throughout the research process and questioning one´s pre-understanding to let the phenomenon emerge. During the EBCD workshops, many reflections focused on the interaction between general healthcare and specialist care. These discussions challenged the first authors understanding of the distinctions between different level of healthcare. Gradually, it became evident that the core of healthcare is the patients, and regardless of the setting, the patient's needs remain central. As Gustavsson and Andersson(2019) discussed, patients have the entire picture of the process, while healthcare providers see only occasional part, which means they are not aware of the patient's whole situation. This realization helped the first author move beyond rigid boundaries and embrace a more integrated, patient-centered approach, where the patient's need guide the care, regardless of the setting.

To understand their experience, individual interviews were conducted, including reflections on their involvement in healthcare improvement. These insights were summarized as strengths and used to initiate discussions in workshop 1, helping balance power dynamics between the participants and the facilitator. The patients indicated that they appreciated this inclusive approach, which differed from previous, more formal work in healthcare. The workshops fostered rich, nuanced dialogue—covered both criticism and positive aspects of healthcare interactions. This provided a rich data collection where, in this context, leading to deeper understanding and revealing new aspects of their experiences. The methodological principle of bridling was a good way to achieve this, which means slowing down the process of understanding, to allow the phenomenon to reveal itself as it is, rather than being shaped by the researchers' values or beliefs. Credibility requires the transparent presentation of findings, supported by participants quotes, along with clear documentation of methodological decisions.

In this study, objectivity was redefined, through the first author's active, reflexive engagement with the data—viewing evidence as constructed rather than discovered. As both facilitator of the workshops and data collector, the first author approached the process with openness and sensitivity, aiming to minimize bias in questions selection, interpretation of responses, and decisions about what was presented. To support credibility, the methodology and decisions were clearly described throughout the study. The themes were illustrated with quotes to ensure consistency between the described meanings and the data.

Transferability refers to the relevance of findings beyond the study context, achieved by presenting both general and individual aspects of meaning to support applicability in other settings (Sundler et al., 2019). Information about the research setting were presented to help readers understand the context in which the findings were generated. The findings in this study should not be regarded as final (Dahlberg et al., 2008); rather, they should be considered an initiated and ongoing conversation that is

created based on the context. The participants in this study represent two different perspectives on care for patients with recurrent tachycardia. The patients (representatives) were recruited with the criteria of having experiences of recurrent tachycardia, and the HCPs were selected based on their experiences of providing care to patients with recurrent tachycardia, chosen to represent all aspects of the ablations process.

While the strategy to recruit mainly from one clinic can be criticized for limiting transferability, the patients' narratives reflect experiences across the VGR. The focus was on patients' experiences and interactions during the period surrounding the referral decision and subsequent specialist care. This phase represents a crucial part of the overall care process for individuals with recurrent tachycardia/SVT. The findings may offer guidance for improving care for these patients, particularly in relation to communication, coordination, and expectations during transitions in care. Although the study context is specific to patients with SVT, several identified issues, such as unclear referral processes, fragmented communication, and lack of continuity, are relevant on a broader level and not limited to this patient population. These insights may therefore be transferable to other areas of healthcare in which similar challenges exist and can inform the development of more integrated and person-centered care models.

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Competing interest statement

The authors declare that they have no known competing financial interest or personal relationships that could have appeared to influence the work reported on this paper.

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