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Symptoms in patients with takotsubo syndrome: a qualitative interview study

Sara Wallström^{a,b,*}, Kerstin Ulin^{a,b}, Elmir Omerovic^{c,d}, Inger Ekman^{a,b}

^aInstitute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

^bUniversity of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

^cDepartment of Cardiology, Sahlgrenska University Hospital, Gothenburg, Sweden

^dDepartment of Molecular and Clinical Medicine, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

* Corresponding author: Sara Wallström, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Box 457, 405 30 Gothenburg, Sweden. Telephone: +46(0)31-786 60 79. E-mail: sara.wallstrom@gu.se

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ABSTRACT

Objective: The aim of the study was to investigate the meaning of narrated symptoms in connection to takotsubo syndrome.

Design, method, participants and setting: Qualitative study consisting of 25 interviews, 23 women and 2 men aged 39-84 and living in Region Västra Götaland, Sweden. The transcribed text was analyzed with phenomenological hermeneutics.

Results: The interviewees reported a large number of symptoms before, during and after the acute onset of takotsubo syndrome, including pain, affected breathing, lassitude, malaise and nausea. Several of these have not been reported previously. Prodromal symptoms were, even if they had been prominent, for various reasons ignored by the interviewees. During the acute phase the symptoms could no longer be ignored and the interviewees sought health care. The remaining residual symptom after discharge from hospital caused a great deal of worry because the interviewees feared that they would be permanent and they felt they could not live this way. On the whole, becoming ill and having a large number of symptoms greatly impacted the lives of the interviewees and made them re-evaluate how they had been living. Furthermore, they reported feeling alone and lost regarding their symptom burden, especially in relation to their residual symptoms, which affected their health and ability to return to daily life.

Conclusion: Symptom assessment should be an integrated part of care to promote health. One way of achieving this is through the patients' own narratives of their experiences, which are an important component in person-centered care.

Keywords: takotsubo syndrome, symptoms, illness experience, phenomenological hermeneutics, qualitative method

ARTICLE SUMMARY

Strengths and limitations of this study

- This study explores an under-investigated area: self-rated symptoms in patients with takotsubo syndrome.
- Interviews offered the opportunity to gain knowledge about a wide range of self-reported symptoms that have not traditionally been connected to takotsubo syndrome.
- This study provides insights on ways that symptoms affect the daily lives of patients with takotsubo syndrome.
- Limitations include the relatively small sample size compared with quantitative studies, and the retrospective nature of the interviews.

INTRODUCTION

Patients' descriptions of their symptoms have long been the main tool in medicine for making various diagnoses. With advances in technology and the development of more sophisticated methods to measure signs of disease, symptoms have an increasingly minor diagnostic role.¹ The biomedical approach views disease and illness as arising from pathophysiological changes. In contrast, the biopsychosocial model advocates that psychological and social factors affect the illness experience, and therefore how a patient experiences their symptoms.² Symptoms, unlike signs, are always subjective and are conveyed as complaints that come with a desire to be understood.^{3 4} The correlation between disease severity and pathophysiology and a person's subjective suffering owing to symptoms is slight, and objectively measurable signs therefore are poor indicators of the suffering caused by a disease.^{5 6} A person's response to symptoms is based on their reality³ and includes physiological, psychological, behavioral and socio-cultural components.⁷ Through understanding of the subjective illness experience, health can be promoted.⁴ Symptoms can only be evaluated by measuring their incidence and the degree of individual suffering they cause; this limits deeper knowledge of their meaning and the subjective experiences they create. It is also not uncommon for symptoms occur in clusters, and they can trigger or reinforce each other, further impeding research on this topic.⁸

Takotsubo syndrome (TS) is characterized by acute onset of extensive but transient contractile dysfunction of the left ventricle.^{9 10} Right ventricular involvement has been identified as a complication in 18%–34% of cases.¹⁰ TS is most common in postmenopausal women with studies identifying 84%–91% of cases as female and that they had a mean age between 63 and 76 years.¹¹⁻¹³ The clinical manifestations or signs of TS include ST-T changes on electrocardiogram, elevated cardiac biomarkers and wall motion abnormality affecting segments of the ventricle.⁹ The underlying etiology is not fully understood, but a catecholamine surge, often due to a stress trigger, is thought to be a vital part.^{10 14} It has been suggested that TS is a protective cardio-circulatory response to counteract sudden death in the form of malignant arrhythmias and cellular necrosis owing to excessive metabolic demand due to intensive neuro hormonal stress.^{15 16} Stress triggers have been identified in 67%–80% of cases, of which 45%–72% were psychological stressors and 28%–55% were physical.¹⁷⁻²⁰ During the acute phase of TS, the clinical presentation is often described as indistinguishable from that of a myocardial infarction.²¹ Chest pain followed by dyspnea¹⁷⁻²⁰, lipothymy with or without syncope^{17 19 20} and malaise¹⁷ is the most common clinical presentation for TS. Chest pain was more common in patients with a myocardial infarction than in those with TS, while dyspnea, syncope and malaise were more common in patients with TS.¹⁷

Because these studies were not based on patients' reports, they may reflect what the medical professionals found important rather than the patients' own experience of their symptoms. Knowledge of how the patients with TS perceive their own symptoms is

therefore needed. The aim of the study was to investigate the meaning of narrated symptoms in connection to TS.

METHOD

Design

Phenomenological hermeneutics, which is a qualitative method with an explorative design, was chosen to fulfill the aim. The method was designed for interpreting the meaning of lived experiences and was therefore deemed appropriate.²²

Participants and settings

The inclusion criteria for the study were (1) having a diagnosis of TS at one of the two participating hospitals in Region Västra Götaland, Sweden and (2) speaking Swedish. Strategic sampling was used to include participants of both sexes and of a wide age range. In total, 31 patients were asked to participate; three of these declined, no narrative could be obtained from two, and one was in the end not diagnosed with TS. The remaining 25 interviews were included in the study. Seven of the interviews were conducted during the hospital stay, and the remaining 18 were conducted after discharge. For two of the interviews after discharge, no face-to-face meeting could be arranged, so these interviews were conducted by phone. Characteristics and cardiovascular risk factors of the participants are presented in Table 1.

Ethical considerations

The study conformed to the Declaration of Helsinki²³ and was approved by the Regional Ethical Review Board of the University of Gothenburg (Application No. 275-11 and amendment T693-11). Informed consent was given by all the participants.

Data collection

Data was collected through narrative interviews, which were conducted during 2011, 2012 and 2014. The research question was answered. Data was collected until the interviews lasted 15–120 minutes and were recorded and transcribed verbatim. The opening question was: Can you tell me about how it was when you became ill? Follow-up questions were used for clarification, and whenever the research question was not addressed spontaneously. Throughout the interview the interviewees were encouraged to narrate freely, and interruptions were avoided as much as possible.

Interpretation of data

Phenomenological hermeneutics consists of three interwoven parts: naïve reading, structural analysis and interpretation of the whole. First, the text is read through and an initial impression of what the text is about is formed; this is termed the naïve reading. In the structural analysis, the text related to the aim is divided into meaning units, which are

abstracted and formed into sub-themes. Parts of the text that are not related to the aim are considered but not included in the structural analysis. The sub-themes are combined into themes and possibly a main theme. The focus of analysis continuously shifts between the overall impression of the text and its individual parts.

The naïve reading is validated in the structural analysis but it may also reveal new aspects of the meaning of the text. During structural analysis the division of meaning is repeatedly reevaluated; in fact, it is not unusual for several structural analyses to be performed to explore all aspect of the phenomenon. In the final part of the analysis, interpretation of the whole, the pre-understanding, naïve reading and structural analysis are combined to interpret the overall meaning of the text. Theoretical literature is used to gain a more profound meaning of the text.²² In this study, the concepts of health, illness and disease were reflected upon to enlighten the meaning of the text. In this article the interpretation of the whole is presented with the discussion.

RESULTS

The first impression of the text revealed that the interviewees experienced a large number of symptoms connected to TS, and that these started before the acute onset and continued after discharge from hospital. Both the prodromal and residual symptoms affected the daily lives of the interviewees. The most prominent symptoms, or the ones that prompted the interviewees to seek medical care, were often not the symptoms that they had previously connected with heart disease. Three phases of the text were distinguished: prodromal symptoms, symptoms at onset and residual symptoms. Experiences of these phases were connected but still separated in the interviewees' narratives. The abstracted meanings of the phases represent the themes of the structural analysis, while symptoms within them are the sub-themes. The overall meaning of having symptoms and becoming ill is described in the main theme.

From denial to yearning

The experience of having symptoms and becoming ill made the interviewees evaluate their lives. Being affected by symptoms was existentially threatening and raised questions about how one should and could live. The prodromal symptoms were largely ignored, while the acute onset came as a shocking realization that illness could no longer be denied. The residual symptoms were seen as very troubling and made the interviewees wonder whether they would ever get well again. They felt anxious and alone in this worry. They expressed that they did not want to live the rest of their lives in illness, and yearned to regain their health.

Ignored warnings

Prodromal symptoms were described by 17 of the interviewees. These had been present for days to weeks before the acute symptoms began. These symptoms were seen as something

new but were largely ignored for various reasons. Some interviewees did not want to bother the health care service; some did not think the symptoms indicated anything serious; others simply felt they did not have time to deal with the symptoms at that point.

Nine of the interviewees described pain before the acute onset of TS, but it was ignored or not seen as a sign of something serious: "And I didn't really have time for the pain, either. Instead it was like: 'I'll deal with that later.'" (#1). Chest pain (n=3), and pain in the arms, neck, back or jaw (n=3), were most common, followed by pain in the abdomen or midriff (n=3). Two of the interviewees did not specify a location for their pain, and two said, without prompting, that pain was not the most prominent prodromal symptom: "And I have never had any pain! ... It only tickles sometimes." (#2).

Affected breathing (n=8) was as common a prodromal symptom as pain, but was viewed as more prominent or significant and affected the daily lives of the interviewees. Shortness of breath (n=5) was the most common description of the breathing difficulties, followed by tightening of the throat (n=2). The effect on daily life was that interviewees had to limit their walking and other tasks, or stop to rest: "I felt short of breath when I did anything ... The air kind of ran out." (#3). Two of the interviewees had experienced dry coughing as a prodromal symptom, and another said her voice had been hoarse.

Some form of lassitude was the most common prodromal symptom (n=12). It was a general fatigue not connected to sleep and lasted several days or more before the acute onset of TS. "Really, really fatigued ... just like, oh ... (sighs), like can't cope." (#4). Poor stamina and having to rest when out walking was common (n=8) in the days or week before hospitalization. For some, but not all interviewees, this lack of stamina was intertwined with shortness of breath: "I was very, very tired, incredibly tired, and when I walked the dogs, I couldn't cope." (#5). One had experienced a more general loss of strength in her legs and one had trouble walking because her feet were swollen.

Some kind of malaise or discomfort was experienced by 12 of the interviewees, but the descriptions varied: feeling ill (n=4); anxiety (n=5); mental slowness (n=2); swollen and sweaty (n=1); feeling downhearted (n=1), and amnesia (n=1). For those who experienced it, malaise was very prominent. "That day, and the day before, I felt really bad and very anxious." (#6). The night before the acute symptoms began, five of the interviewees had unusual sleeping difficulties and two others felt restless and had an inner tension. "That night before I slept very poorly ... I couldn't relax and didn't get very good sleep." (#7).

Other symptoms mentioned were palpitations or fast pulse (n=3), lack of appetite without nausea (n=2), and general nausea (n=1).

Shocking realizations

The acute symptoms and illness came as a shock for the interviewees. The possibility that their symptoms would lead to an actual illness was not something they had considered. Even with what the interviewees themselves described as serious symptoms, they chose to wait to seek medical attention until the symptoms became unbearable. The interviewees experienced disbelief and shock that they were affected by this illness. While they had lived with symptoms, they did not feel that they had been ill. Instead they saw themselves as active and not the kind of person who was affected by heart disease.

Pain was the most common symptom (n=21) at onset, but the localization, characteristics and intensity of the pain varied greatly among the interviewees. The most frequently described localization was the chest (n=16), but many interviewees (n=15) described other the pain as being localized in other areas. "It was here in the chest and out in the back. It hurt so much, and it also radiated out in the arms." (#8). Eleven interviewees reported pain in the arms, neck, back or jaw; five had pain in the abdomen or midriff; five experienced pain while breathing; two had headaches; and one had pain in the entire upper body. "I had severe headache, and then the onset came very fast." (#9). The most commonly described characteristic of the pain was heaviness or pressing (n=10), followed by radiating (n=6). Stabbing (n=2), prickling (n=1), burning (n=1), stinging (n=1), and cramping (n=1) were also mentioned. Five of the interviewees characterized the pain as discomfort; for example, "... a very uncomfortable pressure over the chest." (#10). The pain was uniformly described as persistent, but its intensity on a Visual Analog Scale varied among the interviewees from 5 to 10. "Had so much pain in the chest that I thought: 'Now I'm going to break.' " (#11). It lessened with medication but did not disappear. Even though pain was the most frequently reported symptom, several of the interviewees (n=8) did not think it was the most important symptom, or had expected more pain in connection to heart disease. "I haven't had pain at any point." (#2). "It did hurt, but it wasn't like I felt panic or anything." (#9).

Affected breathing was the second most frequently described symptom (n=18). "It became harder and harder to breathe." (#2). Twelve of the interviewees stated that their breathing was cumbersome; nine felt respiratory distress; four experienced shortness of breath; three said their breathing was shallow; and three felt like they were gasping for breath. "It felt like I wasn't getting any air." (#1). Other characteristics related to breathing were throat tightness (n=2); hyperventilation (n=2); long exhalation (n=1); gurgling in the lungs (n=1); coughing (n=1); and difficulty speaking (n=1).

Malaise was experienced by 15 of the interviewees, but the descriptions of it varied: feeling ill (n=12); something is wrong, or this is not okay (n=2); a 'yucky' feeling (n=3); feeling strange (n=2); and feeling it in the entire body (n=2). Eight of the interviewees experienced anxiety or fear, and some were convinced that they would die. Seven stated that the onset

of TS was horrible or very unpleasant. "I felt really bad; I haven't felt that bad at any other time ... This was in the body, the entire body. I thought like: 'I'm going to die' " (#6).

Six of the interviewees experienced severe lassitude or tiredness at onset of TS. It came suddenly, did not lessen with rest, and was a very prominent symptom for those who experienced it: "Was really fatigued, that was what made me go to the hospital." (#7). Loss of strength in the extremities, either legs (n=3) or arms (n=2), was experienced by five interviewees. "And my arm, it was all, all just limp." (#8).

Nausea or connected symptoms were described by eight interviewees. Seven experienced outright nausea, which was described as severe. "I had so much nausea ... and then I vomited." (#6). Symptoms connected with nausea were vomiting (n=3), lack of appetite (n=2), diarrhea (n=1) and salivation (n=1).

Other symptoms experienced by the interviewees were palpitations (n=4), tremor (n=3), diaphoresis (n=4), lipothymy (n=4), syncope (n=1), unconsciousness (n=1), amnesia (n=4), dip in blood pressure or heart rate (n=4), diffuse symptoms (n=2), becoming quiet (n=1) and had a hard time starting tasks (n=1).

Fear of permanent illness

Eighteen people were interviewed after discharge from hospital; of them, 16 reported residual symptoms, which cause a great deal of worry. While they had lived with symptoms before the onset of TS, living with illness was something new, and they feared that their symptoms would become permanent. They were relieved that the disease was reversible but worried that their illness would not be transient, because they felt they could not live this way. This worry was amplified by the fact that there was very little information to be found regarding residual symptoms in connection with TS, and health care professionals could not tell them what was normal or common for their condition.

Nine of the interviewees had experienced pain. The pain was quite diffuse, but four localized it to the chest, one to the chest with radiation out to the arms, and one to the feet and back. "Well it prickles, in the heart area, and partly it prickles, here (in the arms) I don't know, well it's not a prickly feeling; instead it's, yes, well it's some kind of sensation..." (#12). The described characteristics of the pain were: heaviness (n=2), prickling (n=2), stabbing (n=1), and soreness (n=1). "I can still feel that it stabs sometimes" (#1).

Five interviewees reported affected breathing or related symptoms. Shortness of breath was the most frequently (n=4) used description, followed by cough (n=2), respiratory distress (n=1), hoarse voice (n=1), and long expirations (n=1). "Yes, but this shortness of breath, when you have it, it is like worrying." (#5).

Lassitude was the most common (n=14) residual symptom. It was also the most burdensome symptom for the interviewees and the one that had the greatest impact on their lives. "Soo, so it for sure has affected my existence because I'm not able to cope like I have before." (#13) The lassitude included both lack of stamina (n=9) and general fatigue (n=13). "But, yes extremely tired afterwards! ... Haha, yes it is probably mostly fatigue, psychological exhaustion. It is eh... copious." (#14). The lassitude improved with time, but its effects were less exercise (n=3), more sleeping (n=2), and feeling inactive and boring (n=1). "Yes! I have an increased need for sleep! Fresh when I wake up, but tired again fast." (#15).

Malaise and related symptoms (n=11) were the second residual symptom that greatly affected the lives of the interviewees. The most common and prominent description was that the interviewees (n=7) felt they had become slow of mind after they became ill. This included forgetting things and having to write to-do lists when none had previously been needed, being dazed feeling that their thoughts were sluggish and slow and that everything took a long time. "Indolent in everything! It takes a long time! Terrible!" (#4).

After discharge from hospital, nausea and related symptoms were experienced by six of the interviewees. Nausea without vomiting (n=2) and with vomiting (n=1), changes in taste (n=2), lack of appetite (n=2), increased salivation (n=1), and increased hunger (n=1) were the symptoms mentioned. "I didn't want anything at all, if I only smelled food ... I felt nauseated." (#8). Other symptoms experienced after discharge from hospital were lipothymy (n=1), slow heart rate (n=1), and palpitations (n=1).

DISCUSSION

The analysis shows that the interviewees experienced a wide range of symptoms connected to TS before, during, and after the acute phase of the disease. These symptoms greatly affected the daily lives and health of the interviewees and were therefore a cause of suffering. Furthermore, the symptoms were associated with a lot of worry. Some but not all of the symptoms in this study have been described previously, but in less detail. Others have described prodromal symptoms, mainly various forms of pain, but respiratory difficulties and malaise were also mentioned.²⁴ Lassitude was not reported at all, and affected breathing and malaise only mentioned briefly, whereas all of these were among the most commonly reported prodromal symptoms in this study. Most of the acute symptoms have been previously reported,¹⁷⁻²⁰ but the interviewees in this study gave greater emphasis to symptoms that have been less frequently reported, such as malaise, nausea, and particularly lassitude. Residual symptoms have also been mentioned previously but in less detail.²⁴

Recovered health is one of the primary goals for health care. There are several definitions of health ranging from the one-dimensional one by Boorse,²⁵ which focuses on biology and normality, and in which health can only be achieved in the absence of disease, to Nordenfelt's²⁶ construct, wherein a person has health as long as her or his individual goals

are meaningful and realizable. Perhaps the most widely used definition is that of the World Health Organization: *"a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity."*²⁷ Because symptoms are a way to narrate about the suffering caused by illness, it is vital that they are addressed and attended to in order to promote health.⁴ The analysis clearly shows that the symptoms, especially residual ones, have an impact on the health and lives of patients with TS. This finding accords with previous studies.²⁴ While it is possible for people to achieve health despite disease, according to the World Health Organization's²⁷ and Nordenfelt's²⁶ definitions, our interviewees could not do so because their incapacitating symptoms that made it impossible for them to live full lives and to pursue their goals.

Both in this study and a previous one,²⁴ these persistent symptoms and impaired capacities caused worry for the interviewees and were not something that they expected or that had not been communicated by health care professionals. In line with early anthropological research on symptoms,⁴ the interviewees narrated about their illness and its effect on their daily lives through their symptoms. While symptoms give a good indication of how an illness is perceived and the suffering it entails, the direct association of symptoms to a biological disease is often lacking.^{5 28 29} Moreover, the subjective illness experience narrated through symptoms also gives an indication of how health is perceived and how it can be promoted.⁴ This is important, because negative illness experience has been linked to increased risk of complications after an AMI and should therefore be identified and addressed.³⁰ This shows the importance of integrating symptom perception into care as a target for therapy. One way of integrating symptoms and illness experience in clinical care is through person-centered care (PCC). PCC is a systematic form of care that takes the narrated personal illness experience as its point of departure for planning care, the prescribed treatment of course including evidence-based medicine.^{31 32}

Further research is needed to investigate the prevalence of self-reported symptoms in a larger sample of patients with TS. It would also be interesting to compare symptoms in patients with TS to symptoms reported in other forms of heart disease, and how the prevalence of symptoms changes after a longer period from onset.

Methodological considerations

Four concepts should be considered when addressing the trustworthiness of qualitative studies: credibility, dependability, conformability, and transferability.³³ In phenomenological hermeneutics one single truth is not sought; instead a credible and likely answer to the research question is desired. Moreover, the method is designed for investigating lived experiences, which ensures credibility.²² The fact that not all of the interviews were conducted at the same time in relation to disease onset and hospital stay may be seen as a limitation. Recall bias is a concern that should always be taken into account, no less in this study than in any other. The dependability of the study was ensured by validation of the diagnosis by a cardiologist (EO) and the collaboration on the analysis until agreement was

reached by SW, KU and IE. Confirmability refers to the neutrality of the study results. All but one of the interviews were conducted by SW, who has no clinical experience of cardiovascular care, which should minimize the influence of preconceptions. Qualitative studies always struggle with the issue of transferability. The sample size and the small number of men in the study may be considered limitations to the transferability of the findings. Although only two men were included, this number reflects the disease proportions in the population. Regarding sample size, 25 is considered a small sample in some contexts, yet it is relatively large for this kind of study. With these considerations in mind, findings of the study should be transferable to other patients with TS. Further research is also needed on how illness experience and symptoms can be integrated as a natural part of care.

Clinical implications and conclusion

In conclusion, symptoms, not only acute but also prodromal and residual ones, are a major part of the illness experience for patients with TS. They affect the health and wellbeing of patients and should therefore be an integrated part of care. One way of achieving this is to emphasize patients’ narratives of their illness, and this can be performed in a structured way through PCC.

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CONFLICT OF INTEREST DECLARATION

The authors have no competing interests to declare.

AUTHORS’ CONTRIBUTIONS

SW contributed to design and planning of the study, conducting and analyzing the interviews, and writing and reviewing the manuscript. KU contributed to designing and planning the study, analyzing the interviews, and writing and reviewing the manuscript. EO contributed to designing and planning the study and reviewing the manuscript. IE contributed to designing and planning the study, conducting and analyzing the interviews, and writing and reviewing the manuscript.

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DATA SHARING STATEMENT

No additional data are available.

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Table 1. Characteristics and cardiovascular risk factors of the interviewees.

	N=25
Women	22
Age mean, years (range)	64 (39-84)
Married/ co-habitant	15
Children	19
Smoking	3
Previous smoker	7
Previous takotsubo syndrome	3
Previous myocardial infarction	1
Diabetes	2
Hypertension	6
Chronic obstructive lung disease	2
History of depression/ anxiety	5
Ejection fraction mean, % (range)	46 (35-60)
Hemoglobin mean, g/L (range)	134 (79-176)

Research checklist for Symptoms in patients with takotsubo syndrome: a qualitative interview study

Research checklist taken from Standards for Reporting Qualitative Research: A Synthesis of Recommendations

	Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1. The criteria are fulfilled.
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2. The criteria are fulfilled except where the differ from the author instructions from BMJ Open, then the autor instructions have been followed.
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 3-4. The criteria are fulfilled.
S4	Purpuse or research question	Purpose of the study and specific objectives or questions	Page 3-4. The criteria are fulfilled.
	Method		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale	Page 4. The criteria are fulfilled.

S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 10-11. The criteria are fulfilled.
S7	Context	Setting/site and salient contextual factors; rationale	Page 4, 10-11. The criteria are fulfilled.
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Page 4, 10-11. The criteria are fulfilled.
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 4. The criteria are fulfilled.
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	Page 4-5, 10-11. The criteria are fulfilled.
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the	Page 4. The criteria are fulfilled.

		study	
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 4 and Table 1 on page 13. The criteria are fulfilled.
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Page 4-5. The criteria are fulfilled.
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 4-5, 10-11. The criteria are fulfilled.
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Page 10-11. The criteria are fulfilled.
	Results and findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 5-9. The criteria are fulfilled.
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 5-9. The criteria are fulfilled.
	Discussion		
S18	Integration with prior work, implications,	Short summary of main findings; explanation of how findings	Page 9-11. The criteria are fulfilled.

	transferability, and contribution(s) to the field	and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	
S19	Limitations	Trustworthiness and limitations of findings	Page 10-11. The criteria are fulfilled.
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 11. The criteria are fulfilled.
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 11. The criteria are fulfilled.

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Symptoms in patients with takotsubo syndrome: a qualitative interview study

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Symptoms in patients with takotsubo syndrome: a qualitative interview study

Sara Wallström^{a,b,*}, Kerstin Ulin^{a,b}, Elmir Omerovic^{c,d}, Inger Ekman^{a,b}

^aInstitute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

^bUniversity of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

^cDepartment of Cardiology, Sahlgrenska University Hospital, Gothenburg, Sweden

^dDepartment of Molecular and Clinical Medicine, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

* Corresponding author: Sara Wallström, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Box 457, 405 30 Gothenburg, Sweden. Telephone: +46(0)31-786 60 79. E-mail: sara.wallstrom@gu.se

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ABSTRACT

Objective: The aim of the study was to investigate the meaning of narrated symptoms in connection to takotsubo syndrome.

Design, method, participants and setting: Qualitative study consisting of 25 interviews, 23 women and 2 men aged 39-84 and living in Region Västra Götaland, Sweden. The transcribed text was analyzed with phenomenological hermeneutics.

Results: The interviewees reported a large number of symptoms before, during and after the acute onset of takotsubo syndrome, including pain, affected breathing, lassitude, malaise and nausea. Several of these have not been reported previously. Symptoms before the acute onset were, even if they had been prominent, for various reasons ignored by the interviewees. During the acute phase the symptoms could no longer be ignored and the interviewees sought health care. The remaining residual symptom after discharge from hospital caused a great deal of worry because the interviewees feared that they would be permanent and they felt they could not live this way. On the whole, becoming ill and having a large number of symptoms greatly impacted the lives of the interviewees and made them re-evaluate how they had been living. Furthermore, they reported feeling alone and lost regarding their symptom burden, especially in relation to their residual symptoms, which affected their health and ability to return to daily life.

Conclusion: Symptoms, not only acute but also before and after the acute ones, are a major part of the illness experience for patients with takotsubo syndrome and affect their health and wellbeing. Assessment of symptoms should be an integrated part of care to promote health. One way of achieving this is through the patients' own narratives of their experiences, which are an important component in person-centered care.

Keywords: takotsubo syndrome, symptoms, illness experience, phenomenological hermeneutics, qualitative method

ARTICLE SUMMARY

Strengths and limitations of this study

- This study explores an under-investigated area: self-rated symptoms in patients with takotsubo syndrome.
- Interviews offered the opportunity to gain knowledge about a wide range of self-reported symptoms that have not traditionally been connected to takotsubo syndrome.
- This study provides insights on ways that symptoms affect the daily lives of patients with takotsubo syndrome.
- Limitations include the relatively small sample size compared with quantitative studies, and the retrospective nature of the interviews.

INTRODUCTION

Patients' descriptions of their symptoms have long been the main tool in medicine for making various diagnoses. With advances in technology and the development of more sophisticated methods to measure signs of disease, symptoms increasingly share the diagnostic role with measurable signs.¹ The biomedical approach views disease and illness as arising from pathophysiological changes. In contrast, the biopsychosocial model advocates that psychological and social factors affect the illness experience, and therefore how a patient experiences their symptoms.² Symptoms, unlike signs, are always subjective and are conveyed as complaints that come with a desire to be understood.^{3 4} The correlation between disease severity and pathophysiology and a person's subjective suffering owing to symptoms is slight, and objectively measurable signs therefore are poor indicators of the suffering caused by a disease.^{5 6} A person's response to symptoms is based on their reality³ and includes physiological, psychological, behavioral and socio-cultural components.⁷ Through understanding of the subjective illness experience, health can be promoted.⁴ Symptoms can only be evaluated by measuring their incidence and the degree of individual suffering they cause; this limits deeper knowledge of their meaning and the subjective experiences they create. It is also not uncommon for symptoms occur in clusters, and they can trigger or reinforce each other, further impeding research on this topic.⁸

Takotsubo syndrome (TS) is characterized by acute onset of extensive but transient contractile dysfunction of the left ventricle.^{9 10} Right ventricular involvement has been identified as a complication in 18%–34% of cases.⁹ TS is most common in postmenopausal women with studies identifying 86%–90% of cases as female and that they had a mean age between 59 and 76 years.¹⁰⁻¹³ The clinical manifestations or signs of TS include ST-T changes on electrocardiogram, elevated cardiac biomarkers and wall motion abnormality affecting segments of the ventricle. The underlying etiology is not fully understood, but a catecholamine surge, often due to a stress trigger, is thought to be a vital part.^{9 10} It has been suggested that TS is a protective cardio-circulatory response to counteract sudden death in the form of malignant arrhythmias and cellular necrosis owing to excessive metabolic demand due to intensive neuro hormonal stress.^{14 15} Stress triggers have been identified in 67%–80% of cases, of which 45%–72% were psychological stressors and 28%–55% were physical.¹⁶⁻¹⁹ During the acute phase of TS, the clinical presentation is often described as indistinguishable from that of a myocardial infarction.¹⁰ Chest pain followed by dyspnea^{10 11 16-19}, lipothymy with or without syncope^{10 16 18 19} and malaise¹⁶ is the most common clinical presentation for TS. Chest pain was more common in patients with a myocardial infarction than in those with TS, while dyspnea,^{10 16} syncope and malaise were more common in patients with TS.¹⁶

Because these studies were not based on patients' reports, they may reflect what the medical professionals found important rather than the patients' own experience of their symptoms. Knowledge of how the patients with TS perceive their own symptoms is

therefore needed. The aim of the study was to investigate the meaning of narrated symptoms in connection to TS.

METHOD

Design

Phenomenological hermeneutics, which is a qualitative method with an explorative design, was chosen to fulfill the aim. The method was designed for interpreting the meaning of lived experiences and was therefore deemed appropriate.²⁰

Participants and settings

The inclusion criteria for the study were (1) having a diagnosis of TS according to the Heart Failure Association diagnostic criteria⁹ at one of the two participating hospitals in Region Västra Götaland, Sweden and (2) speaking Swedish. Non-stratified strategic sampling was used to include participants of both sexes and of a wide age range. The selection was made collaboratively by the authors. In total, 31 patients were asked to participate; three of these declined, no narrative could be obtained from two, and one was in the end not diagnosed with TS. The remaining 25 interviews were included in the study. Seven of the interviews were conducted during the hospital stay, and the remaining 18 were conducted after discharge. For two of the interviews after discharge, no face-to-face meeting could be arranged, so these interviews were conducted by phone. The median time from arrival at hospital to interview was 30 days. Characteristics and cardiovascular risk factors of the participants are presented in Table 1.

Ethical considerations

The study conformed to the Declaration of Helsinki²¹ and was approved by the Regional Ethical Review Board of the University of Gothenburg (Application No. 275-11 and amendment T693-11). Informed consent was given by all the participants.

Data collection

Data was collected through narrative interviews made by the first author who is an RN but not working at this specific hospital, this was explained to the interviewees who were encouraged to ask about details on the study that were unclear or of interest to them. Data was collected during 2011, 2012 and 2014 until the research question was answered. The interviews lasted 15–120 minutes and were recorded and transcribed verbatim. The opening question was: Can you tell me about how it was when you became ill? Follow-up questions were used for clarification, and whenever the research question was not addressed spontaneously. Throughout the interview the interviewees were encouraged to narrate freely, and interruptions were avoided as much as possible. This kind of data-collection involving narrations about existential issues might lead to reflections and regrets about having told things one would not like to share with strangers. Therefore all interviewees

were informed that they could contact the interviewer (SW) to explain or delete parts of the interview. None of the informants contacted the interviewer concerning this issue.

Interpretation of data

Phenomenological hermeneutics consists of three interwoven parts: naïve reading, structural analysis and interpretation of the whole. First, the text is read through and an initial impression of what the text is about is formed; this is termed the naïve reading. The naïve reading guides the structural analysis; it creates a way of entering into the structural analysis, which is a way of examining the text by identifying and formulating themes. In the structural analysis, the text related to the aim is divided into meaning units, which are abstracted and formed into sub-themes. Parts of the text that are not related to the aim are considered but not included in the structural analysis. During this part of the analysis the frequency of the sub-themes, in this study the different symptoms may be counted in order to show how common or uncommon they are. The sub-themes are combined into themes and possibly a main theme. The focus of analysis continuously shifts between the overall impression of the text and its individual parts.²⁰

The naïve reading is validated in the structural analysis but it may also reveal new aspects of the meaning of the text. During structural analysis the division of meaning units is repeatedly reevaluated; in fact, it is not unusual for several structural analyses to be performed to explore all aspect of the phenomenon. In the final part of the analysis, interpretation of the whole, the pre-understanding, naïve reading and structural analysis are combined to interpret the overall meaning of the text. Theoretical literature is reflected upon with the interpreted overall meaning and used to gain a more profound meaning of the text.²⁰ In this study, the concepts of health, illness and disease were reflected upon to enlighten the meaning of the text. In this article the interpretation of the whole is presented with the discussion.

RESULTS

All reported symptoms are those the interviewees themselves connected to TS, whether or not a pathophysiological connection to TS is possible to find. The first impression of the text revealed that the interviewees experienced a large number of symptoms connected to TS, and that these started before the acute onset and continued after discharge from hospital. Even though many of the interviewees experienced the same symptoms the described characteristics varied greatly. Both the symptoms before the acute onset and the residual ones affected the daily lives of the interviewees. The most prominent symptoms, or the ones that prompted the interviewees to seek medical care, were often not the symptoms that they had previously connected with heart disease. Three phases of the text were distinguished: symptoms before the acute onset, symptoms at onset and residual symptoms. Experiences of these phases were connected but still separated in the interviewees'

narratives. The abstracted meanings of the phases represent the themes of the structural analysis, while symptoms within them are the sub-themes. The overall meaning of having symptoms and becoming ill is described in the main theme.

From denial to yearning

The experience of having symptoms and becoming ill made the interviewees evaluate their lives. Being affected by symptoms was existentially threatening and raised questions about how one should and could live. Symptoms before the acute onset were largely ignored, while the acute onset came as a shocking realization that illness could no longer be denied. The residual symptoms were seen as very troubling and made the interviewees wonder whether they would ever get well again. They felt anxious and alone in this worry. They expressed that they did not want to live the rest of their lives in illness, and yearned to regain their health.

Ignored warnings

Symptoms before the acute onset were described by 17 of the interviewees. These had been present for days to weeks before the acute symptoms began. These symptoms were seen as something new but were largely ignored for various reasons. Some interviewees did not want to bother the health care service; some did not think the symptoms indicated anything serious; others simply felt they did not have time to deal with the symptoms at that point.

Nine of the interviewees described pain before the acute onset of TS, but it was ignored or not seen as a sign of something serious: "And I didn't really have time for the pain, either. Instead it was like: 'I'll deal with that later.'" (#1). Chest pain (n=3), and pain in the arms, neck, back or jaw (n=3), were most common, followed by pain in the abdomen or midriff (n=3). Two of the interviewees did not specify a location for their pain, and two said, without prompting, that pain was not the most prominent symptom before the acute onset: "And I have never had any pain! ... It only tickles sometimes." (#2).

Affected breathing (n=8) was as common a symptom before the acute onset as pain, but was viewed as more prominent or significant and affected the daily lives of the interviewees. Shortness of breath (n=5) was the most common description of the breathing difficulties, followed by tightening of the throat (n=2). The effect on daily life was that interviewees had to limit their walking and other tasks, or stop to rest: "I felt short of breath when I did anything ... The air kind of ran out." (#3). Two of the interviewees had experienced dry coughing as a symptom before the acute onset, and another said her voice had been hoarse.

Some form of lassitude (n=12) was the most common symptom before the acute onset. It was a general fatigue not connected to sleep and lasted several days or more before the acute onset of TS. "Really, really fatigued ... just like, oh ... (sighs), like can't cope." (#4). Poor stamina and having to rest when out walking was common (n=8) in the days or week before

hospitalization. For some, but not all interviewees, this lack of stamina was intertwined with shortness of breath.

Some kind of malaise or discomfort was experienced by 12 of the interviewees, but the descriptions varied: feeling ill (n=4); anxiety (n=5); mental slowness (n=2); swollen and sweaty (n=1); feeling downhearted (n=1), and amnesia (n=1). For those who experienced it, malaise was very prominent.

Other symptoms mentioned were palpitations or fast pulse (n=3), lack of appetite without nausea (n=2), and general nausea (n=1).

Shocking realizations

The acute symptoms and illness came as a shock for the interviewees. The possibility that their symptoms would lead to an actual illness was not something they had considered. Even with what the interviewees themselves described as serious symptoms, they chose to wait to seek medical attention until the symptoms became unbearable. The interviewees experienced disbelief and shock that they were affected by this illness. While they had lived with symptoms, they did not feel that they had been ill. Instead they saw themselves as active and not the kind of person who was affected by heart disease.

Pain was the most common symptom (n=21) at onset, but the localization, characteristics and intensity of the pain varied greatly among the interviewees. The most frequently described localization was the chest (n=16), but many interviewees (n=15) described other areas such as the chest, back or arms. The most commonly described characteristic of the pain was heaviness or pressing (n=10), followed by radiating (n=6). Stabbing (n=2), prickling (n=1), burning (n=1), stinging (n=1), and cramping (n=1) were also mentioned. Five of the interviewees characterized the pain as discomfort; for example, "... a very uncomfortable pressure over the chest." (#10). The pain was uniformly described as persistent, but its intensity on a Visual Analog Scale varied among the interviewees from 5 to 10. "Had so much pain in the chest that I thought: 'Now I'm going to break.' " (#11). It lessened with medication but did not disappear. Even though pain was the most frequently reported symptom, several of the interviewees (n=8) did not think it was the most important symptom, or had expected more pain in connection to heart disease. "I haven't had pain at any point." (#2). "It did hurt, but it wasn't like I felt panic or anything." (#9).

Affected breathing was the second most frequently described symptom (n=18). "It became harder and harder to breathe." (#2). Twelve of the interviewees stated that their breathing was cumbersome; nine felt respiratory distress; four experienced shortness of breath; three said their breathing was shallow; and three felt like they were gasping for breath. "It felt like I wasn't getting any air." (#1). Other characteristics related to breathing were throat

1
2
3 tightness (n=2); hyperventilation (n=2); long exhalation (n=1); gurgling in the lungs (n=1);
4 coughing (n=1); and difficulty speaking (n=1).
5
6

7 Malaise was experienced by 15 of the interviewees, but the descriptions of it varied: feeling
8 ill (n=12); something is wrong, or this is not okay (n=2); a 'yucky' feeling (n=3); feeling
9 strange (n=2); and feeling it in the entire body (n=2). Eight of the interviewees experienced
10 anxiety or fear, and some were convinced that they would die. Seven stated that the onset
11 of TS was horrible or very unpleasant. "I felt really bad; I haven't felt that bad at any other
12 time ... This was in the body, the entire body. I thought like: 'I'm going to die' " (#6).
13
14

15
16 Six of the interviewees experienced severe lassitude or tiredness at onset of TS. It came
17 suddenly, did not lessen with rest, and was a very prominent symptom for those who
18 experienced it: "Was really fatigued, that was what made me go to the hospital." (#7). Loss
19 of strength in the extremities, either legs (n=3) or arms (n=2), was experienced by five
20 interviewees. "And my arm, it was all, all just limp." (#8).
21
22

23
24 Nausea or connected symptoms were described by eight interviewees. Seven experienced
25 outright nausea, which was described as severe. "I had so much nausea ... and then I
26 vomited." (#6). Symptoms connected with nausea were vomiting (n=3), lack of appetite
27 (n=2), diarrhea (n=1) and salivation (n=1).
28
29

30
31 Other symptoms experienced by the interviewees were palpitations (n=4), tremor (n=3),
32 diaphoresis (n=4), lipothymy (n=4), syncope (n=1), unconsciousness (n=1), amnesia (n=4),
33 perceived dip in blood pressure or heart rate (n=4), diffuse symptoms (n=2), becoming quiet
34 (n=1) and had a hard time starting tasks (n=1).
35
36

37 Fear of permanent illness

38
39 Eighteen people were interviewed after discharge from hospital; of them, 16 reported
40 residual symptoms, which cause a great deal of worry. While they had lived with symptoms
41 before the onset of TS, living with illness was something new, and they feared that their
42 symptoms would become permanent. They were relieved that the disease was reversible
43 but worried that their illness would not be transient, because they felt they could not live
44 this way. This worry was amplified by the fact that there was very little information to be
45 found regarding residual symptoms in connection with TS, and health care professionals
46 could not tell them what was normal or common for their condition.
47
48

49
50 Nine of the interviewees had experienced pain. The pain was quite diffuse and five
51 interviewees reported affected breathing or related symptoms. Shortness of breath was the
52 most frequently (n=4) used description, followed by cough (n=2), respiratory distress (n=1),
53 hoarse voice (n=1), and long expirations (n=1). "Yes, but this shortness of breath, when you
54 have it, it is like worrying." (#5).
55
56
57
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59
60

Lassitude was the most common (n=14) residual symptom. It was also the most burdensome symptom for the interviewees and the one that had the greatest impact on their lives. "Soo, so it for sure has affected my existence because I'm not able to cope like I have before." (#13) The lassitude included both lack of stamina (n=9) and general fatigue (n=13). "But, yes extremely tired afterwards! ... Haha, yes it is probably mostly fatigue, psychological exhaustion. It is eh... copious." (#14). The lassitude improved with time, but its effects were less exercise (n=3), more sleeping (n=2), and feeling inactive and boring (n=1). "Yes! I have an increased need for sleep! Fresh when I wake up, but tired again fast." (#15).

Malaise and related symptoms (n=11) were the second residual symptom that greatly affected the lives of the interviewees. The most common and prominent description was that the interviewees (n=7) felt they had become slow of mind after they became ill. This included forgetting things and having to write to-do lists when none had previously been needed, being dazed feeling that their thoughts were sluggish and slow and that everything took a long time. "Indolent in everything! It takes a long time! Terrible!" (#4).

After discharge from hospital, nausea and related symptoms were experienced by six of the interviewees. Nausea without vomiting (n=2) and with vomiting (n=1), changes in taste (n=2), lack of appetite (n=2), increased salivation (n=1), and increased hunger (n=1) were the symptoms mentioned. "I didn't want anything at all, if I only smelled food ... I felt nauseated." (#8). Other symptoms experienced after discharge from hospital were lipothymy (n=1), slow heart rate (n=1), and palpitations (n=1).

DISCUSSION

The analysis shows that the interviewees experienced a wide range of symptoms that they connected to TS before, during, and after the acute phase of the disease. This study does not claim to make a pathophysiological link between the experienced symptoms and TS. Furthermore, previous research has found a higher frequency of anxiety among patients with TS than those with acute coronary syndrome, which may influence the experience of symptoms.²² Nonetheless, knowledge about symptoms are still valuable since they are part of the illness experience. The symptoms greatly affected the daily lives and health of the interviewees and were therefore a cause of suffering. Furthermore, the symptoms were associated with a lot of worry. Some but not all of the symptoms in this study have been described previously, but in less detail. Others have described symptoms before the acute onset, mainly various forms of pain, but respiratory difficulties and malaise were also mentioned.²³ Lassitude was not reported at all, and affected breathing and malaise only mentioned briefly, whereas all of these were among the most commonly reported symptoms before the acute onset in this study. Most of the acute symptoms have been previously reported,^{10 11 16-19} but the interviewees in this study gave greater emphasis to

symptoms that have been less frequently reported, such as malaise, nausea, and particularly lassitude. Residual symptoms have also been mentioned previously but in less detail.²³

Recovered health is one of the primary goals for health care. There are several definitions of health ranging from the one-dimensional one by Boorse,²⁴ which focuses on biology and normality, and in which health can only be achieved in the absence of disease, to Nordenfelt's²⁵ construct, wherein a person has health as long as her or his individual goals are meaningful and realizable. Perhaps the most widely used definition is that of the World Health Organization: *"a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity."*²⁶ Because symptoms are a way to narrate about the suffering caused by illness, it is vital that they are addressed and attended to in order to promote health.⁴ The analysis clearly shows that the symptoms, especially residual ones, have an impact on the health and lives of patients with TS. This finding accords with previous studies.²³ While it is possible for people to achieve health despite disease, according to the World Health Organization's²⁶ and Nordenfelt's²⁵ definitions, our interviewees could not do so because their incapacitating symptoms that made it impossible for them to live full lives and to pursue their goals.

Both in this study and a previous one,²³ these persistent symptoms and impaired capacities caused worry for the interviewees and were not something that they expected or that had not been communicated by health care professionals. In line with early anthropological research on symptoms,⁴ the interviewees narrated about their illness and its effect on their daily lives through their symptoms. While symptoms give a good indication of how an illness is perceived and the suffering it entails, the direct association of symptoms to a biological disease is often lacking.^{5 27 28} Moreover, the subjective illness experience narrated through symptoms also gives an indication of how health is perceived and how it can be promoted.⁴ This is important, because negative illness experience has been linked to increased risk of complications after an AMI and should therefore be identified and addressed.²⁹ This shows the importance of integrating symptom perception into care as a target for therapy. One way of integrating symptoms and illness experience in clinical care is through person-centered care (PCC). PCC is a systematic form of care that takes the narrated personal illness experience as its point of departure for planning care, the prescribed treatment of course including evidence-based medicine.^{30 31}

Further research is needed to investigate the prevalence of self-reported symptoms in a larger sample of patients with TS. It would also be interesting to compare symptoms in patients with TS to symptoms reported in other forms of heart disease, and how the prevalence of symptoms changes after a longer period from onset.

Methodological considerations

Four concepts should be considered when addressing the trustworthiness of qualitative studies: credibility, dependability, conformability, and transferability.³² In phenomenological hermeneutics one single truth is not sought; instead a credible and likely answer to the

research question is desired. Moreover, the method is designed for investigating lived experiences, which ensures credibility.²⁰ The fact that not all of the interviews were conducted at the same time in relation to disease onset and hospital stay may be seen as a limitation. Recall bias is a concern that should always be taken into account, no less in this study than in any other. Neither the length of the interview, if it was done by telephone or not, who the interviewer were, the sex or age of the interviewee nor the timing in relation to the onset of TS was found to impact the content of the interview. The dependability of the study was ensured by validation of the diagnosis by a cardiologist (EO) and the collaboration on the analysis until agreement was reached by SW, KU and IE. Confirmability refers to the neutrality of the study results. All but one of the interviews were conducted by SW, who has no clinical experience of cardiovascular care, which should minimize the influence of preconceptions. Both interviewers are registered nurses. Qualitative studies always struggle with the issue of transferability. The sample size and the small number of men in the study may be considered limitations to the transferability of the findings. Although only two men were included, this number reflects the disease proportions in the population. Regarding sample size, 25 is considered a small sample in some contexts, yet it is relatively large for this kind of study. With these considerations in mind, findings of the study should be transferable to other patients with TS. Further research is also needed on how illness experience and symptoms can be integrated as a natural part of care.

Clinical implications and conclusion

In conclusion, symptoms, not only acute but also symptoms before the acute onset and residual ones, are a major part of the illness experience for patients with TS. They affect the health and wellbeing of patients and should therefore be an integrated part of care. One way of achieving this is to emphasize patients' narratives of their illness, and this can be performed in a structured way through PCC.

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CONFLICT OF INTEREST DECLARATION

The authors have no competing interests to declare.

AUTHORS' CONTRIBUTIONS

SW contributed to design and planning of the study, conducting and analyzing the interviews, and writing and reviewing the manuscript. KU contributed to designing and planning the study, analyzing the interviews, and writing and reviewing the manuscript. EO contributed to designing and planning the study and reviewing the manuscript. IE

contributed to designing and planning the study, conducting and analyzing the interviews, and writing and reviewing the manuscript.

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DATA SHARING STATEMENT

No additional data are available.

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Table 1. Characteristics and cardiovascular risk factors of the interviewees.

	N=25
Women	22
Age mean, years (range)	64 (39-84)
Married/ co-habitant	15
Children	19
Smoking	3
Previous smoker	7
Previous takotsubo syndrome	3
Previous myocardial infarction	1
Diabetes	2
Hypertension	6
Chronic obstructive lung disease	2
History of depression/ anxiety	5
Ejection fraction mean, % (range)	46 (35-60)
Hemoglobin mean, g/L (range)	134 (79-176)

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Research checklist for Symptoms in patients with takotsubo syndrome: a qualitative interview study

Research checklist taken from Standards for Reporting Qualitative Research: A Synthesis of Recomendations

	Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1. The criteria are fulfilled.
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2. The criteria are fulfilled exept where the differ from the author instructions from BMJ Open, then the autor instructions have been followed.
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 3-4. The criteria are fulfilled.
S4	Purpuse or research question	Purpose of the study and specific objectives or questions	Page 3-4. The criteria are fulfilled.
	Method		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	Page 4. The criteria are fulfilled.

S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 10-11. The criteria are fulfilled.
S7	Context	Setting/site and salient contextual factors; rationale	Page 4, 10-11. The criteria are fulfilled.
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Page 4, 10-11. The criteria are fulfilled.
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 4. The criteria are fulfilled.
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	Page 4-5, 10-11. The criteria are fulfilled.
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the	Page 4. The criteria are fulfilled.

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		study	
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 4 and Table 1 on page 13. The criteria are fulfilled.
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Page 4-5. The criteria are fulfilled.
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 4-5, 10-11. The criteria are fulfilled.
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Page 10-11. The criteria are fulfilled.
	Results and findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 5-9. The criteria are fulfilled.
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 5-9. The criteria are fulfilled.
	Discussion		
S18	Integration with prior work, implications,	Short summary of main findings; explanation of how findings	Page 9-11. The criteria are fulfilled.

	transferability, and contribution(s) to the field	and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	
S19	Limitations	Trustworthiness and limitations of findings	Page 10-11. The criteria are fulfilled.
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 11. The criteria are fulfilled.
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 11. The criteria are fulfilled.

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Symptoms in patients with takotsubo syndrome: a qualitative interview study

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Symptoms in patients with takotsubo syndrome: a qualitative interview study

Sara Wallström^{a,b,*}, Kerstin Ulin^{a,b}, Elmir Omerovic^{c,d}, Inger Ekman^{a,b}

^aInstitute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

^bUniversity of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

^cDepartment of Cardiology, Sahlgrenska University Hospital, Gothenburg, Sweden

^dDepartment of Molecular and Clinical Medicine, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

* Corresponding author: Sara Wallström, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Box 457, 405 30 Gothenburg, Sweden. Telephone: +46(0)31-786 60 79. E-mail: sara.wallstrom@gu.se

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ABSTRACT

Objective: The aim of the study was to investigate the meaning of narrated symptoms in connection to takotsubo syndrome.

Design, method, participants and setting: Qualitative study consisting of 25 interviews, 23 women and 2 men aged 39-84 and living in Region Västra Götaland, Sweden. The transcribed text was analyzed with phenomenological hermeneutics.

Results: The interviewees reported a large number of symptoms before, during and after the acute onset of takotsubo syndrome, including pain, affected breathing, lassitude, malaise and nausea. Several of these have not been reported previously. Symptoms before the acute onset were, even if they had been prominent, for various reasons ignored by the interviewees. During the acute phase the symptoms could no longer be ignored and the interviewees sought health care. The remaining residual symptom after discharge from hospital caused a great deal of worry because the interviewees feared that they would be permanent and they felt they could not live this way. On the whole, becoming ill and having a large number of symptoms greatly impacted the lives of the interviewees and made them re-evaluate how they had been living. Furthermore, they reported feeling alone and lost regarding their symptom burden, especially in relation to their residual symptoms, which affected their health and ability to return to daily life.

Conclusion: Symptoms, not only acute but also before and after the acute ones, are a major part of the illness experience for patients with takotsubo syndrome and affect their health and wellbeing. Assessment of symptoms should be an integrated part of care to promote health. One way of achieving this is through the patients' own narratives of their experiences, which are an important component in person-centered care.

Keywords: takotsubo syndrome, symptoms, illness experience, phenomenological hermeneutics, qualitative method

ARTICLE SUMMARY

Strengths and limitations of this study

- This study explores an under-investigated area: self-rated symptoms in patients with takotsubo syndrome.
- Interviews offered the opportunity to gain knowledge about a wide range of self-reported symptoms that have not traditionally been connected to takotsubo syndrome.
- This study provides insights on ways that symptoms affect the daily lives of patients with takotsubo syndrome.
- Limitations include the relatively small sample size compared with quantitative studies, and the retrospective nature of the interviews.

INTRODUCTION

Patients' descriptions of their symptoms have long been the main tool in medicine for making various diagnoses. With advances in technology and the development of more sophisticated methods to measure signs of disease, symptoms increasingly share the diagnostic role with measurable signs.¹ The biomedical approach views disease and illness as arising from pathophysiological changes. In contrast, the biopsychosocial model advocates that psychological and social factors affect the illness experience, and therefore how a patient experiences their symptoms.² Symptoms, unlike signs, are always subjective and are conveyed as complaints that come with a desire to be understood.^{3 4} The correlation between disease severity and pathophysiology and a person's subjective suffering owing to symptoms is slight, and objectively measurable signs therefore are poor indicators of the suffering caused by a disease.^{5 6} A person's response to symptoms is based on their reality³ and includes physiological, psychological, behavioral and socio-cultural components.⁷ Through understanding of the subjective illness experience, health can be promoted.⁴ Symptoms can only be evaluated by measuring their incidence and the degree of individual suffering they cause; this limits deeper knowledge of their meaning and the subjective experiences they create. It is also not uncommon for symptoms occur in clusters, and they can trigger or reinforce each other, further impeding research on this topic.⁸

Takotsubo syndrome (TS) is characterized by acute onset of extensive but transient contractile dysfunction of the left ventricle.^{9 10} Right ventricular involvement has been identified as a complication in 18%–34% of cases.⁹ TS is most common in postmenopausal women with studies identifying 86%–90% of cases as female and that they had a mean age between 59 and 76 years.¹⁰⁻¹³ The clinical manifestations or signs of TS include ST-T changes on electrocardiogram, elevated cardiac biomarkers and wall motion abnormality affecting segments of the ventricle. The underlying etiology is not fully understood, but a catecholamine surge, often due to a stress trigger, is thought to be a vital part.^{9 10} It has been suggested that TS is a protective cardio-circulatory response to counteract sudden death in the form of malignant arrhythmias and cellular necrosis owing to excessive metabolic demand due to intensive neuro hormonal stress.^{14 15} Stress triggers have been identified in 67%–80% of cases, of which 45%–72% were psychological stressors and 28%–55% were physical.¹⁶⁻¹⁹ During the acute phase of TS, the clinical presentation is often described as indistinguishable from that of a myocardial infarction.¹⁰ Chest pain followed by dyspnea^{10 11 16-19}, lipothymy with or without syncope^{10 16 18 19} and malaise¹⁶ is the most common clinical presentation for TS. Chest pain was more common in patients with a myocardial infarction than in those with TS, while dyspnea,^{10 16} syncope and malaise were more common in patients with TS.¹⁶

Because these studies were not based on patients' reports, they may reflect what the medical professionals found important rather than the patients' own experience of their symptoms. Knowledge of how the patients with TS perceive their own symptoms is

therefore needed. The aim of the study was to investigate the meaning of narrated symptoms in connection to TS.

METHOD

Design

Phenomenological hermeneutics, which is a qualitative method with an explorative design, was chosen to fulfill the aim. The method was designed for interpreting the meaning of lived experiences and was therefore deemed appropriate.²⁰

Participants and settings

The inclusion criteria for the study were (1) having a diagnosis of TS according to the Heart Failure Association diagnostic criteria⁹ at one of the two participating hospitals in Region Västra Götaland, Sweden and (2) speaking Swedish. Non-stratified strategic sampling was used to include participants of both sexes and of a wide age range. The selection was made collaboratively by the authors. In total, 31 patients were asked to participate; three of these declined, no narrative could be obtained from two, and one was in the end not diagnosed with TS. The remaining 25 interviews were included in the study. Seven of the interviews were conducted during the hospital stay, and the remaining 18 were conducted after discharge. For two of the interviews after discharge, no face-to-face meeting could be arranged, so these interviews were conducted by phone. The median time from arrival at hospital to interview was 30 days. Characteristics and cardiovascular risk factors of the participants are presented in Table 1.

Ethical considerations

The study conformed to the Declaration of Helsinki²¹ and was approved by the Regional Ethical Review Board of the University of Gothenburg (Application No. 275-11 and amendment T693-11). Informed consent was given by all the participants.

Data collection

Data was collected through narrative interviews made by the first author who is an RN but not working at this specific hospital. This was explained to the interviewees. Furthermore, the interviewees were encouraged to ask about details on the study that were unclear or of interest to them. Data was collected during 2011, 2012 and 2014 until the research question was answered. The interviews lasted 15–120 minutes and were recorded and transcribed verbatim. The opening question was: Can you tell me about how it was when you became ill? Follow-up questions were used for clarification, and whenever the research question was not addressed spontaneously. Throughout the interview the interviewees were encouraged to narrate freely, and interruptions were avoided as much as possible. This kind of data-collection involving narrations about existential issues might lead to reflections and regrets about having told things one would not like to share with strangers. Therefore all interviewees were informed that they could contact the interviewer (SW) to explain or

delete parts of the interview. None of the informants contacted the interviewer concerning this issue.

Interpretation of data

Phenomenological hermeneutics consists of three interwoven parts: naïve reading, structural analysis and interpretation of the whole. First, the text is read through and an initial impression of what the text is about is formed; this is termed the naïve reading. The naïve reading guides the structural analysis; it creates a way of entering into the structural analysis, which is a way of examining the text by identifying and formulating themes. In the structural analysis, the text related to the aim is divided into meaning units, which are abstracted and formed into sub-themes. Parts of the text that are not related to the aim are considered but not included in the structural analysis. During this part of the analysis the frequency of the sub-themes, in this study the different symptoms may be counted in order to show how common or uncommon they are. The sub-themes are combined into themes and possibly a main theme. The focus of analysis continuously shifts between the overall impression of the text and its individual parts.²⁰

The naïve reading is validated in the structural analysis but it may also reveal new aspects of the meaning of the text. During structural analysis the division of meaning units is repeatedly reevaluated; in fact, it is not unusual for several structural analyses to be performed to explore all aspect of the phenomenon. In the final part of the analysis, interpretation of the whole, the pre-understanding, naïve reading and structural analysis are combined to interpret the overall meaning of the text. Theoretical literature is reflected upon with the interpreted overall meaning and used to gain a more profound meaning of the text.²⁰ In this study, the concepts of health, illness and disease were reflected upon to enlighten the meaning of the text. In this article the interpretation of the whole is presented with the discussion.

RESULTS

All reported symptoms are those the interviewees themselves connected to TS, whether or not a pathophysiological connection to TS is possible to find. The first impression of the text revealed that the interviewees experienced a large number of symptoms connected to TS, and that these started before the acute onset and continued after discharge from hospital. Even though many of the interviewees experienced the same symptoms the described characteristics varied greatly. Both the symptoms before the acute onset and the residual ones affected the daily lives of the interviewees. The most prominent symptoms, or the ones that prompted the interviewees to seek medical care, were often not the symptoms that they had previously connected with heart disease. Three phases of the text were distinguished: symptoms before the acute onset, symptoms at onset and residual symptoms. Experiences of these phases were connected but still separated in the interviewees'

narratives. The abstracted meanings of the phases represent the themes of the structural analysis, while symptoms within them are the sub-themes. The overall meaning of having symptoms and becoming ill is described in the main theme.

From denial to yearning

The experience of having symptoms and becoming ill made the interviewees evaluate their lives. Being affected by symptoms was existentially threatening and raised questions about how one should and could live. Symptoms before the acute onset were largely ignored, while the acute onset came as a shocking realization that illness could no longer be denied. The residual symptoms were seen as very troubling and made the interviewees wonder whether they would ever get well again. They felt anxious and alone in this worry. They expressed that they did not want to live the rest of their lives in illness, and yearned to regain their health.

Ignored warnings

Symptoms before the acute onset were described by 17 of the interviewees. These had been present for days to weeks before the acute symptoms began. These symptoms were seen as something new but were largely ignored for various reasons. Some interviewees did not want to bother the health care service; some did not think the symptoms indicated anything serious; others simply felt they did not have time to deal with the symptoms at that point.

Nine of the interviewees described pain before the acute onset of TS, but it was ignored or not seen as a sign of something serious: "And I didn't really have time for the pain, either. Instead it was like: 'I'll deal with that later.'" (#1). Chest pain (n=3), and pain in the arms, neck, back or jaw (n=3), were most common, followed by pain in the abdomen or midriff (n=3). Two of the interviewees did not specify a location for their pain, and two said, without prompting, that pain was not the most prominent symptom before the acute onset: "And I have never had any pain! ... It only tickles sometimes." (#2).

Affected breathing (n=8) was as common a symptom before the acute onset as pain, but was viewed as more prominent or significant and affected the daily lives of the interviewees. Shortness of breath (n=5) was the most common description of the breathing difficulties, followed by tightening of the throat (n=2). The effect on daily life was that interviewees had to limit their walking and other tasks, or stop to rest: "I felt short of breath when I did anything ... The air kind of ran out." (#3). Two of the interviewees had experienced dry coughing as a symptom before the acute onset, and another said her voice had been hoarse.

Some form of lassitude (n=12) was the most common symptom before the acute onset. It was a general fatigue not connected to sleep and lasted several days or more before the acute onset of TS. "Really, really fatigued ... just like, oh ... (sighs), like can't cope." (#4). Poor stamina and having to rest when out walking was common (n=8) in the days or week before

hospitalization. For some, but not all interviewees, this lack of stamina was intertwined with shortness of breath.

Some kind of malaise or discomfort was experienced by 12 of the interviewees, but the descriptions varied: feeling ill (n=4); anxiety (n=5); mental slowness (n=2); swollen and sweaty (n=1); feeling downhearted (n=1), and amnesia (n=1). For those who experienced it, malaise was very prominent.

Other symptoms mentioned were palpitations or fast pulse (n=3), lack of appetite without nausea (n=2), and general nausea (n=1).

Shocking realizations

The acute symptoms and illness came as a shock for the interviewees. The possibility that their symptoms would lead to an actual illness was not something they had considered. Even with what the interviewees themselves described as serious symptoms, they chose to wait to seek medical attention until the symptoms became unbearable. The interviewees experienced disbelief and shock that they were affected by this illness. While they had lived with symptoms, they did not feel that they had been ill. Instead they saw themselves as active and not the kind of person who was affected by heart disease.

Pain was the most common symptom (n=21) at onset, but the localization, characteristics and intensity of the pain varied greatly among the interviewees. The most frequently described localization was the chest (n=16), but many interviewees (n=15) described other areas such as the chest, back or arms. The most commonly described characteristic of the pain was heaviness or pressing (n=10), followed by radiating (n=6). Stabbing (n=2), prickling (n=1), burning (n=1), stinging (n=1), and cramping (n=1) were also mentioned. Five of the interviewees characterized the pain as discomfort; for example, "... a very uncomfortable pressure over the chest." (#10). The pain was uniformly described as persistent, but its intensity on a Visual Analog Scale varied among the interviewees from 5 to 10. "Had so much pain in the chest that I thought: 'Now I'm going to break.' " (#11). It lessened with medication but did not disappear. Even though pain was the most frequently reported symptom, several of the interviewees (n=8) did not think it was the most important symptom, or had expected more pain in connection to heart disease. "I haven't had pain at any point." (#2). "It did hurt, but it wasn't like I felt panic or anything." (#9).

Affected breathing was the second most frequently described symptom (n=18). "It became harder and harder to breathe." (#2). Twelve of the interviewees stated that their breathing was cumbersome; nine felt respiratory distress; four experienced shortness of breath; three said their breathing was shallow; and three felt like they were gasping for breath. "It felt like I wasn't getting any air." (#1). Other characteristics related to breathing were throat

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3 tightness (n=2); hyperventilation (n=2); long exhalation (n=1); gurgling in the lungs (n=1);
4 coughing (n=1); and difficulty speaking (n=1).
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7 Malaise was experienced by 15 of the interviewees, but the descriptions of it varied: feeling
8 ill (n=12); something is wrong, or this is not okay (n=2); a 'yucky' feeling (n=3); feeling
9 strange (n=2); and feeling it in the entire body (n=2). Eight of the interviewees experienced
10 anxiety or fear, and some were convinced that they would die. Seven stated that the onset
11 of TS was horrible or very unpleasant. "I felt really bad; I haven't felt that bad at any other
12 time ... This was in the body, the entire body. I thought like: 'I'm going to die' " (#6).
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16 Six of the interviewees experienced severe lassitude or tiredness at onset of TS. It came
17 suddenly, did not lessen with rest, and was a very prominent symptom for those who
18 experienced it: "Was really fatigued, that was what made me go to the hospital." (#7). Loss
19 of strength in the extremities, either legs (n=3) or arms (n=2), was experienced by five
20 interviewees. "And my arm, it was all, all just limp." (#8).
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24 Nausea or connected symptoms were described by eight interviewees. Seven experienced
25 outright nausea, which was described as severe. "I had so much nausea ... and then I
26 vomited." (#6). Symptoms connected with nausea were vomiting (n=3), lack of appetite
27 (n=2), diarrhea (n=1) and salivation (n=1).
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31 Other symptoms experienced by the interviewees were palpitations (n=4), tremor (n=3),
32 diaphoresis (n=4), lipothymy (n=4), syncope (n=1), unconsciousness (n=1), amnesia (n=4),
33 perceived dip in blood pressure or heart rate (n=4), diffuse symptoms (n=2), becoming quiet
34 (n=1) and had a hard time starting tasks (n=1).
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37 Fear of permanent illness

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39 Eighteen people were interviewed after discharge from hospital; of them, 16 reported
40 residual symptoms, which cause a great deal of worry. While they had lived with symptoms
41 before the onset of TS, living with illness was something new, and they feared that their
42 symptoms would become permanent. They were relieved that the disease was reversible
43 but worried that their illness would not be transient, because they felt they could not live
44 this way. This worry was amplified by the fact that there was very little information to be
45 found regarding residual symptoms in connection with TS, and health care professionals
46 could not tell them what was normal or common for their condition.
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50 Nine of the interviewees had experienced pain. The pain was quite diffuse and five
51 interviewees reported affected breathing or related symptoms. Shortness of breath was the
52 most frequently (n=4) used description, followed by cough (n=2), respiratory distress (n=1),
53 hoarse voice (n=1), and long expirations (n=1). "Yes, but this shortness of breath, when you
54 have it, it is like worrying." (#5).
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Lassitude was the most common (n=14) residual symptom. It was also the most burdensome symptom for the interviewees and the one that had the greatest impact on their lives. "Soo, so it for sure has affected my existence because I'm not able to cope like I have before." (#13) The lassitude included both lack of stamina (n=9) and general fatigue (n=13). "But, yes extremely tired afterwards! ... Haha, yes it is probably mostly fatigue, psychological exhaustion. It is eh... copious." (#14). The lassitude improved with time, but its effects were less exercise (n=3), more sleeping (n=2), and feeling inactive and boring (n=1). "Yes! I have an increased need for sleep! Fresh when I wake up, but tired again fast." (#15).

Malaise and related symptoms (n=11) were the second residual symptom that greatly affected the lives of the interviewees. The most common and prominent description was that the interviewees (n=7) felt they had become slow of mind after they became ill. This included forgetting things and having to write to-do lists when none had previously been needed, being dazed feeling that their thoughts were sluggish and slow and that everything took a long time. "Indolent in everything! It takes a long time! Terrible!" (#4).

After discharge from hospital, nausea and related symptoms were experienced by six of the interviewees. Nausea without vomiting (n=2) and with vomiting (n=1), changes in taste (n=2), lack of appetite (n=2), increased salivation (n=1), and increased hunger (n=1) were the symptoms mentioned. "I didn't want anything at all, if I only smelled food ... I felt nauseated." (#8). Other symptoms experienced after discharge from hospital were lipothymy (n=1), slow heart rate (n=1), and palpitations (n=1).

DISCUSSION

The analysis shows that the interviewees experienced a wide range of symptoms that they connected to TS before, during, and after the acute phase of the disease. This study does not claim to make a pathophysiological link between the experienced symptoms and TS. Furthermore, previous research has found a higher frequency of anxiety among patients with TS than those with acute coronary syndrome, which may influence the experience of symptoms.²² Nonetheless, knowledge about symptoms are still valuable since they are part of the illness experience. The symptoms greatly affected the daily lives and health of the interviewees and were therefore a cause of suffering. Furthermore, the symptoms were associated with a lot of worry. Some but not all of the symptoms in this study have been described previously, but in less detail. Others have described symptoms before the acute onset, mainly various forms of pain, but respiratory difficulties and malaise were also mentioned.²³ Lassitude was not reported at all, and affected breathing and malaise only mentioned briefly, whereas all of these were among the most commonly reported symptoms before the acute onset in this study. Most of the acute symptoms have been previously reported,^{10 11 16-19} but the interviewees in this study gave greater emphasis to

symptoms that have been less frequently reported, such as malaise, nausea, and particularly lassitude. Residual symptoms have also been mentioned previously but in less detail.²³

Recovered health is one of the primary goals for health care. There are several definitions of health ranging from the one-dimensional one by Boorse,²⁴ which focuses on biology and normality, and in which health can only be achieved in the absence of disease, to Nordenfelt's²⁵ construct, wherein a person has health as long as her or his individual goals are meaningful and realizable. Perhaps the most widely used definition is that of the World Health Organization: *"a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity."*²⁶ Because symptoms are a way to narrate about the suffering caused by illness, it is vital that they are addressed and attended to in order to promote health.⁴ The analysis clearly shows that the symptoms, especially residual ones, have an impact on the health and lives of patients with TS. This finding accords with previous studies.²³ While it is possible for people to achieve health despite disease, according to the World Health Organization's²⁶ and Nordenfelt's²⁵ definitions, our interviewees could not do so because their incapacitating symptoms that made it impossible for them to live full lives and to pursue their goals.

Both in this study and a previous one,²³ these persistent symptoms and impaired capacities caused worry for the interviewees and were not something that they expected or that had not been communicated by health care professionals. In line with early anthropological research on symptoms,⁴ the interviewees narrated about their illness and its effect on their daily lives through their symptoms. While symptoms give a good indication of how an illness is perceived and the suffering it entails, the direct association of symptoms to a biological disease is often lacking.^{5 27 28} Moreover, the subjective illness experience narrated through symptoms also gives an indication of how health is perceived and how it can be promoted.⁴ This is important, because negative illness experience has been linked to increased risk of complications after an AMI and should therefore be identified and addressed.²⁹ This shows the importance of integrating symptom perception into care as a target for therapy. One way of integrating symptoms and illness experience in clinical care is through person-centered care (PCC). PCC is a systematic form of care that takes the narrated personal illness experience as its point of departure for planning care, the prescribed treatment of course including evidence-based medicine.^{30 31}

Further research is needed to investigate the prevalence of self-reported symptoms in a larger sample of patients with TS. It would also be interesting to compare symptoms in patients with TS to symptoms reported in other forms of heart disease, and how the prevalence of symptoms changes after a longer period from onset.

Methodological considerations

Four concepts should be considered when addressing the trustworthiness of qualitative studies: credibility, dependability, conformability, and transferability.³² In phenomenological hermeneutics one single truth is not sought; instead a credible and likely answer to the

research question is desired. Moreover, the method is designed for investigating lived experiences, which ensures credibility.²⁰ The fact that not all of the interviews were conducted at the same time in relation to disease onset and hospital stay may be seen as a limitation. Recall bias is a concern that should always be taken into account, no less in this study than in any other. Neither the length of the interview, if it was done by telephone or not, who the interviewer were, the sex or age of the interviewee nor the timing in relation to the onset of TS was found to impact the content of the interview. The dependability of the study was ensured by validation of the diagnosis by a cardiologist (EO) and the collaboration on the analysis until agreement was reached by SW, KU and IE. Confirmability refers to the neutrality of the study results. All but one of the interviews were conducted by SW, who has no clinical experience of cardiovascular care, which should minimize the influence of preconceptions. Both interviewers are registered nurses. Qualitative studies always struggle with the issue of transferability. The sample size and the small number of men in the study may be considered limitations to the transferability of the findings. Although only two men were included, this number reflects the disease proportions in the population. Regarding sample size, 25 is considered a small sample in some contexts, yet it is relatively large for this kind of study. With these considerations in mind, findings of the study should be transferable to other patients with TS. Further research is also needed on how illness experience and symptoms can be integrated as a natural part of care.

Clinical implications and conclusion

In conclusion, symptoms, not only acute but also symptoms before the acute onset and residual ones, are a major part of the illness experience for patients with TS. They affect the health and wellbeing of patients and should therefore be an integrated part of care. One way of achieving this is to emphasize patients' narratives of their illness, and this can be performed in a structured way through PCC.

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CONFLICT OF INTEREST DECLARATION

The authors have no competing interests to declare.

AUTHORS' CONTRIBUTIONS

SW contributed to design and planning of the study, conducting and analyzing the interviews, and writing and reviewing the manuscript. KU contributed to designing and planning the study, analyzing the interviews, and writing and reviewing the manuscript. EO contributed to designing and planning the study and reviewing the manuscript. IE

contributed to designing and planning the study, conducting and analyzing the interviews, and writing and reviewing the manuscript.

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DATA SHARING STATEMENT

No additional data are available.

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Table 1. Characteristics and cardiovascular risk factors of the interviewees.

	N=25
Women	22
Age mean, years (range)	64 (39-84)
Married/ co-habitant	15
Children	19
Smoking	3
Previous smoker	7
Previous takotsubo syndrome	3
Previous myocardial infarction	1
Diabetes	2
Hypertension	6
Chronic obstructive lung disease	2
History of depression/ anxiety	5
Ejection fraction mean, % (range)	46 (35-60)
Hemoglobin mean, g/L (range)	134 (79-176)

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Research checklist for Symptoms in patients with takotsubo syndrome: a qualitative interview study

Research checklist taken from Standards for Reporting Qualitative Research: A Synthesis of Recomendations

	Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1. The criteria are fulfilled.
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2. The criteria are fulfilled except where the differ from the author instructions from BMJ Open, then the autor instructions have been followed.
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 3-4. The criteria are fulfilled.
S4	Purpuse or research question	Purpose of the study and specific objectives or questions	Page 3-4. The criteria are fulfilled.
	Method		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	Page 4. The criteria are fulfilled.

S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 10-11. The criteria are fulfilled.
S7	Context	Setting/site and salient contextual factors; rationale	Page 4, 10-11. The criteria are fulfilled.
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Page 4, 10-11. The criteria are fulfilled.
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 4. The criteria are fulfilled.
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	Page 4-5, 10-11. The criteria are fulfilled.
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the	Page 4. The criteria are fulfilled.

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		study	
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 4 and Table 1 on page 13. The criteria are fulfilled.
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Page 4-5. The criteria are fulfilled.
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 4-5, 10-11. The criteria are fulfilled.
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Page 10-11. The criteria are fulfilled.
	Results and findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 5-9. The criteria are fulfilled.
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 5-9. The criteria are fulfilled.
	Discussion		
S18	Integration with prior work, implications,	Short summary of main findings; explanation of how findings	Page 9-11. The criteria are fulfilled.

	transferability, and contribution(s) to the field	and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	
S19	Limitations	Trustworthiness and limitations of findings	Page 10-11. The criteria are fulfilled.
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 11. The criteria are fulfilled.
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 11. The criteria are fulfilled.