

BMJ Open Symptoms in patients with takotsubo syndrome: a qualitative interview study

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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 analysed 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, ignored by the interviewees for various reasons. During the acute phase, the symptoms could no longer be ignored and the interviewees sought healthcare. 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.

Conclusions: Acute symptoms, and symptoms before and after the acute ones, are a major part of the illness experience for patients with takotsubo syndrome and affect their health and well-being. 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-centred care.

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

Strengths and limitations of this study

- This study explores an underinvestigated 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.

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 symptoms 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, behavioural and sociocultural 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 occurring in clusters, and they can trigger or reinforce each other, further impeding research on this topic.⁸

Takotsubo syndrome (TS) is characterised 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 aetiology 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 cardiocirculatory response to counteract sudden death in the form of malignant arrhythmias and cellular necrosis owing to excessive metabolic demand due to intensive neurohormonal 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 an acute myocardial infarction (AMI).¹⁰ Chest pain followed by dyspnoea,^{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 dyspnoea,^{10 16} syncope and malaise were more common in patients with TS.¹⁶

As 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 fulfil 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. Out of 25, 7 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.

Table 1 Characteristics and cardiovascular risk factors of the interviewees

| | N=25 |
|-----------------------------------|--------------|
| Women | 22 |
| Age mean, years (range) | 64 (39–84) |
| Married/cohabitant | 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) |
| Haemoglobin mean, g/L (range) | 134 (79–176) |

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 number 275-11 and amendment T693-11). Informed consent was given by all the participants.

Data collection

Data were 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 were collected during 2011, 2012 and 2014 until the research question was answered. The interviews lasted 15–120 min and were recorded and transcribed verbatim. The opening question was as follows: 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 subthemes. 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 subthemes, in this study the different symptoms, may be counted in order to show how common or uncommon they are. The subthemes 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 re-evaluated; 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. 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 subthemes. 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 realisation 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 healthcare 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 hospitalisation. 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 as

follows: 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 realisations

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 localisation, characteristics and intensity of the pain varied greatly among the interviewees. The most frequently described localisation 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 characterised 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 as follows: 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), diarrhoea (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), perceived 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

In total, 18 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 healthcare 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 and 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 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 symptoms 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 is 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 healthcare. 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, where a person has health as long as her or his individual goals are meaningful and realisable. Perhaps the most widely used definition is that of the WHO: 'a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity'.²⁶ As 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 WHO'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.

In this study and in 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 healthcare 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-centred 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 areas should be considered when addressing the trustworthiness of qualitative studies: credibility, dependability, confirmability 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 minimise 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, acute symptoms and 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 well-being of patients and should therefore be an integrated part of care. One way of achieving this is to emphasise patients' narratives of their illness, and this can be performed in a structured way through PCC.

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