

Takotsubo Syndrome: Voices to be heard

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Abstract

This paper is written from the perspective of patients who have been diagnosed with Takotsubo syndrome (TTS). It seeks to understand why these patients may feel dissatisfied with the care they receive. We consider four factors: 1) TTS is a relatively new condition and the knowledge base about treatment is limited and not widely disseminated among clinicians; 2) The age and gender profile of the patient group; 3) The implications of the categorisation of TTS as 'Broken Heart Syndrome' and the over-emphasis of it as a 'psychosomatic' condition; 4) Concern that patients with TTS might be labelled as over-emotional, especially if they do not recover quickly. We argue that these factors contribute to patients with TTS feeling poorly served.

Main paper

Takotsubo syndrome (TTS) is 'an acute and usually reversible heart failure syndrome' which was first described in 1990 in Japan [1]. It is generally 'characterized by a temporary wall motion abnormality of the LV [left ventricle]' [2], with the classic takotsubo of apical ballooning being prevalent. However other associated variants as well as right-ventricular involvement are acknowledged in the current literature [3]. There is growing awareness that it is not the benign condition it was previously considered to be and taking figures from a number of studies from 2004 to 2012, Lyon *et al*, suggest that there is a 5–22% 5-year recurrence rate, 'with the second episode occurring 3 months to 10 years after the first'[1]. A significant number of patients continue to have symptoms post-diagnosis [4,5,6] and according to Dawson it may have 'long-lasting clinical consequences including demonstrable symptomatic

and functional impairment associated with persistent subclinical cardiac dysfunction' [5].

TTS 'is estimated to constitute approximately 1–3% of all patients and 5–6% of female patients presenting with suspected STEMI' [ST-elevation myocardial infarction] [2]. The condition mainly affects post-menopausal women [7], with similar demographics reported across a number of studies [1]. The triggers for TTS identified in Templin *et al*'s study are physical stress (36.0%), unknown causes (28.5%), emotional stress (27.7%), and both physical and emotional causes (7.8%) [7]. Those with the condition may present at emergency services with a number of symptoms including acute chest pain, dyspnea or syncope thereby making it hard to distinguish from acute myocardial infarction [7]. Many patients are fundamentally dissatisfied with the care that they receive. This article seeks to review why this might be.

The concerns and dissatisfaction evidenced and discussed in the remainder of this paper arise from an international online support group founded in 2016 by one of the authors. The author, also a TTS patient, after discharge from hospital following her TTS event, felt isolated and unsupported. Still being symptomatic, after finding a cardiologist who specialised in TTS, she was determined to ensure that other patients did not have similar experiences and she set up the Support Group to provide a safe place for patients diagnosed with TTS to gain knowledge, feel supported and share experiences. The group also contains up-to-date research papers with some members actively involved in developing research. At the time of writing, the group consists of over 1,700 members principally from the USA/Canada (850), the UK (580) and Australia (160).

Consistent concerns within the group fall into four main areas:

- i. An absence of clear clinical pathways;
- ii. Limited or no advice in hospital and at the point of discharge;

- iii. An apparent lack of knowledge about TTS and its treatment in the wider medical community; and
- iv. Little on-going support or follow up for those with the condition.

The anecdotal evidence arising from the support group is supported by the scientific literature. Wallström *et al's.*, phenomenological study, based on interviews with twenty-two women and three men diagnosed with TTS at two hospitals in Sweden, showed that all but two interviewees after discharge reported residual symptoms that caused a great deal of concern. The most common concerns, which participants worried 'would not be transient', were pain, breathlessness, lassitude, fatigue, malaise and nausea. These concerns were amplified by a lack of information regarding residual TTS-related symptoms and a lack of knowledge on the part of health-care professionals who 'could not tell them what was normal or common for their condition' [8].

The lack of knowledge was also illustrated in Schubert *et al's* study in which 23 women recovering from TTS were compared with 23 age-matched women with acute coronary syndrome. The study concluded that women with TTS were 'less likely to receive educational support about their condition, particularly stress...management' and less likely to be offered cardiac rehabilitation, despite perceiving that this would have been 'helpful in aiding their recovery' [9].

We put forward four factors that may contribute to people with TTS reporting sub-optimal support following discharge:

- 1) This is a relatively new condition and the knowledge base about treatment is limited and not well-disseminated among clinicians.**

Whilst research is constantly adding to the evidence base, there have been no randomised trials to guide optimal diagnosis and treatment of patients with TTS either during the acute phase or for long term follow-up. Little is known about health care resource use [10] and there are poor rates of long-term follow-up post diagnosis [11].

Nevertheless, there are excellent summaries on the current state of knowledge of TTS [2] [12], including structured approaches to diagnosis, risk stratification, and management, with algorithms to assist decision-making by practicing clinicians [1]. The transfer of this knowledge to clinicians in Accident & Emergency departments, cardiology departments and primary care, however, would appear to be inconsistent as reported by many in the TTS Support Group.

2) **Gendered concerns of treatment for heart conditions.**

Ninety percent of people with TTS are women with a mean age of 67-70 [2] and there is evidence that women receive poorer treatment than men following heart attacks. Analysis of the treatment and outcomes of 691,290 people who were hospitalised for heart attacks in England and Wales between 2003 and 2013 found that women in the UK were more than twice as likely to die in the 30 days following a heart attack than men (5.2% compared to 2.3%) [13]. The researchers suggest that this may, in part, be explained by women being less likely to receive guideline recommended care. As a 2017 academic study stated: cardiovascular disease 'remains the leading cause of morbidity and mortality in women worldwide. To reduce the burden and improve outcomes in women, the sex differences in diagnosis, treatment and outcomes must be explored and understood. The social and psychosocial (gendered) reasons for the undertreatment of women require urgent attention' [14].

Western societies predominantly have negative social representations of old age, associated with loss, impairment and dependency [15]. There is social prejudice attached to the 'older woman' label and this plays a role in discriminatory mechanisms and institutional exclusion such as limited access to health care and services [16]. Thus, gender and age bias may contribute to sub-optimal treatment in TTS.

3) There is a danger that TTS is becoming wrongly categorised as 'psychosomatic'

It was initially thought that TTS was only triggered by emotionally stressful events and thus it was given the name 'Broken Heart Syndrome'. Most recent research shows, however, that physical stress and underlying health conditions are more prevalent triggers than emotional stress. Despite this, some medical professionals and researchers continue to respond to the condition as if it is predominantly 'psychological' or emotional and their frequent use of the term Broken Heart Syndrome, and additionally by health charities and the press, potentially trivialises a very serious condition thereby undermining the treatment that patients, especially women, receive.

TTS has been described as a 'psychosomatic' disorder [17] and in one paper [5] the term psychosomatic has been connected to the trigger of physical stress, which by its very nature is incorrect. The over-reference to, and potential misunderstanding or misuse of, the term 'psychosomatic' may lead to inadequate care. While research into the psychological associations and implications of TTS is important [[18,19], categorising it as mainly psychological is unhelpful.

4) Patients with TTS who do not recover quickly may be labelled as over-emotional

The lack of understanding of the clinically proven legacies of TTS, along with the mis-categorisation of TTS as entirely psychosomatic and the fact that some people make a full recovery means that those who continue to be symptomatic may be labelled as over-emotional. Furthermore, the fact that TTS affects mainly older women perhaps encourages the condition to be associated with an 'over-excited' and 'over-anxious' older woman who will recover once she 'calms down'. Dusenbery illustrates through discussion of relevant research that women with heart conditions are more likely to be diagnosed with a mental health condition than their male counterparts [20].

Whilst for some TTS patients emotional experiences or stress may be an underlying cause of their TTS, the emphasis in the literature to maintain this factor as the *main* source of TTS is harmful for patients who become fearful of being labelled and dismissed as a 'hypochondriac' or 'time wasters' when they present to services post-diagnosis.

To conclude, despite many patients with TTS continuing to be symptomatic after the event, many report having limited, or no, offer of follow up consultation or further testing post event, and report feeling dismissed and unsupported by the medical profession, thus making them reluctant to return to hospital. Complete 'recovery' is too often declared following an echo-cardiogram display of the heart having returned to its 'normal shape' without further investigation into on-going symptoms. We suggest that this is not only related to TTS being a relatively new condition about which many clinicians may have limited understanding or awareness, but also due to the mis-categorisation of TTS as psychosomatic and TTS patients being labelled as 'over-emotional'. As a result, this group of patients quite understandably feel poorly served.

Based on our experience and the above analysis we would recommend:

1. Provision of more information to patients and their families on discharge would be helpful as well as research into how this information is provided.
2. Dissemination of both current scientific knowledge and guidelines regarding practice to A&E departments and primary care practitioners.
3. Research into the practices and attitudes of medical professionals towards their TTS patients, especially *vis-à-vis* the often negative or 'disappointed' experiences and reports of a number of female patients.
4. A concerted effort by both healthcare organisations, including charities, and cardiac professionals to consider the terminology used when writing about and/or discussing TTS, in order to avoid 'pathologizing' patients.
5. A study into how often cardiac rehabilitation, including psychological support, is offered to TTS patients and the benefits that this could provide.

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