

REVIEWS OF ASSESSMENT TOOLS AND DELIVERY

## What are the barriers to the SHAI being completed within a ME/CFS service?

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### Abstract

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a debilitating condition, characterised by unexplained and excessive fatigue, muscle pain and sleep disturbances. Health anxiety is common in ME/CFS and accurate measurement is essential in facilitating therapeutic gains. However, there are clinical concerns over the utility of the Short Health Anxiety Inventory (SHAI) in measuring health anxiety in this population. This study aims to use qualitative responses from two ex-service users and specialist health clinicians to explore the barriers to completing the SHAI within a specialist ME/CFS service. Qualitative responses from a focus group consisting of 15 specialist health professionals including occupational therapists, physiotherapists, dieticians, cognitive behavioural therapists, counsellors, clinical psychologists and assistant psychologists were transcribed and analysed for themes. Patient voices were represented by two former service users through individual semi-structured interviews on the telephone, which were recorded, transcribed and later analysed thematically. Clinicians and service user involvement agreed on core difficulties with the utility of the SHAI in the ME/CFS population. The timing of the SHAI being administered pre-diagnosis, the language of the SHAI and lack of context around the questionnaire were identified as barriers that were likely to contribute to the SHAI not being completed by service users. Sensitive and accurate measurement is required in order to retain patient engagement, which could further facilitate appropriate assessment and treatment of health anxiety and ME/CFS. Findings suggest that adaption of the SHAI is vital for use with ME/CFS.

### Key learning aims

- (1) To understand the different barriers to completing the SHAI in a ME/CFS service.
- (2) To understand the implications of administering the SHAI to ME/CFS service users.
- (3) To learn from multi-disciplinary ME/CFS health professionals about perceived difficulties in administering the SHAI.

**Keywords:** CBT; chronic fatigue; fatigue syndrome; health anxiety; ME/c

### Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, debilitating condition characterised by unexplained, chronic and excessive fatigue which affects an individual's quality of life and capacity to complete daily or routine tasks (NICE, 2007). Other common symptoms include joint pain, sleep disturbances and cognitive difficulties (NICE, 2007). Prevalence rates are estimated at 0.17–2.07% and depression and co-morbid anxiety disorders are common (Cella *et al.*, 2013; Johnston *et al.*, 2013). This is reflected in the great economic impact of ME/CFS on employment and productivity in the UK, which is estimated

to be over £102 million a year (Collin *et al.*, 2011). However, the aetiology of ME/CFS remains poorly understood.

It has been reported that health anxiety is common in those living with ME/CFS (Daniels *et al.*, 2017). Health anxiety is characterised by a pre-occupation with health concerns and misinterpretation of bodily sensations which is not alleviated by medical reassurance (Abramowitz *et al.*, 2007). Daniels *et al.* (2017) suggest that patients with ME/CFS may be more pre-disposed to developing health anxiety due to the complex and heterogeneous nature of the condition; ME/CFS bears a significant physical impact and a range of worrying symptoms. When considering the heterogeneity, uncertain prognosis, lack of understanding and confidence among health professionals (Daniels *et al.*, 2020), it seems logical that patients with this condition worry about their health. Health anxiety in those with ME/CFS has been found to be significantly higher than that of other medical conditions (Tyrer *et al.*, 2011) and is comparable to the levels found in chronic pain (Rode *et al.*, 2006).

Health anxiety is a relatively new concept to be explored within the field of ME/CFS. Yet, pragmatic evidence from case studies suggests that treatment using a CBT-based health anxiety model can benefit those with ME/CFS who are health anxious, both in terms of their physical and mental health (Daniels and Loades, 2017; Daniels *et al.*, 2020). Daniels and Loades (2017) suggest that there is a high degree of overlap between their symptomatic presentation and by targeting overlapping characteristics, there is likely to be benefit to both conditions.

Current NICE guidelines recommend treating associated co-morbid anxiety, depression or mood disorders in individuals with ME/CFS (NICE, 2007). However, only small to moderate improvements in functional impairment, anxiety, depression and fatigue have been found following CBT interventions (Castell *et al.*, 2011). Large effect sizes were reported by Daniels *et al.* (2020), although this was a small uncontrolled sample and specifically targeted health anxiety, despite also reporting treatment effects for anxiety and depression. Based on data from replicated studies, health anxiety is common in ME/CFS and is associated with higher symptom severity and elevated psychological distress (Daniels *et al.*, 2020). It is therefore essential that health anxiety is identified and treated.

The Short Health Anxiety Inventory (SHAI; Salkovskis *et al.*, 2002) is a short form measure designed to screen for clinical levels of health anxiety. It is derived from the clinical cognitive behavioural model of health anxiety and is frequently used in clinical practice and in intervention and epidemiological literature (Alberts *et al.*, 2013). The SHAI has been found to be reliable for use in ME/CFS (Daniels *et al.*, 2017; Daniels *et al.*, 2020); however, there are clinical and practical concerns of its acceptability and accessibility to those with ME/CFS. Earlier research has indicated negative views towards the SHAI on the part of the clinician (Daniels *et al.*, 2020) which has influenced recruitment to a treatment trial for ME/CFS, and also more directly the patient, where it has been suggested that the content and phrasing of the questionnaire is inflammatory, resulting in non-completion (Daniels *et al.*, 2017). Anecdotal information from the service lead suggested that reasons for patient non-participation centred on perceptions that patients' primary concerns were anxiety, rather than chronic fatigue, as a consequence of the SHAI; one patient commented on the questionnaire: 'I'm not a hypochondriac' (P. Gladwell, personal communication, 2014). Such concerns indicate that there may be key barriers to the assessment and treatment of ME/CFS due to characteristics associated with the SHAI. The aim of this study was to explore in more detail the potential barriers to the SHAI being completed within a specialist ME/CFS clinic, using qualitative responses from a range of ME/CFS clinicians and service user involvement, in order make recommendations for future use and development of the SHAI.

## Method

### Design and setting

This study adopted a qualitative design, using a mixed focus group (clinicians) and individual telephone interviews (former service users) approach to generate themes pertaining to the study aims.

### Participants

#### The service

The ME/CFS service from which the sample was taken in the present study consisted of multi-disciplinary specialist health professionals, including occupational therapists, physiotherapists, dieticians, cognitive behavioural therapists, counsellors, clinical psychologists and assistant psychologists. The service delivers a range of evidence-based interventions in individual and group formats.

Following a referral into the service, patients are sent an appointment letter and several questionnaires to complete ahead of their assessment. The Health Anxiety Inventory short-version (SHAI; Salkovskis *et al.*, 2002) formed part of the pre-assessment questionnaires, alongside other questionnaires from the UK ME/CFS National Outcomes Database. These are more fully reported in Daniels *et al.* (2020), a related study.

#### Former service users

Two former service users who had received treatment at the specialist ME/CFS service were recruited to participate in the study. One former service user was already associated with the broader programme of research (see Daniels *et al.*, 2020) in a public and patient involvement (PPI) role; the other was a service user identified by the ME/CFS service who regularly advised in a PPI-related role.

### Measures

#### Short Health Anxiety Inventory (SHAI; Salkovskis *et al.*, 2002)

The SHAI is an 18-item questionnaire that measures cognitive factors associated with health anxiety on a 4-point scale. The 18-item measure is a short form of the original health anxiety inventory (Salkovskis *et al.*, 2002). Items assess awareness of bodily sensations, worries over health and feelings of fear associated with having an illness and are summed to produce a total score, with a cut-off of  $\geq 18$  to indicate clinical levels of distress. The SHAI has demonstrated good reliability and validity across samples with pain, long-term health conditions (Alberts *et al.*, 2013) and ME/CFS (Daniels *et al.*, 2017; Daniels *et al.*, 2020).

### Procedure

#### Focus group discussion with ME/CFS clinicians

Fifteen clinicians (four occupational therapists, three physiotherapists, four clinical psychologists, a dietician, assistant psychologist, a cognitive behavioural therapist and counsellor) from the ME/CFS service participated in an hour-long discussion about their experiences of using the SHAI using semi-structured questions related to (a) how the SHAI was used in the service and (b) what, if any, barriers were perceived to completing the measure. All clinicians who were invited to the focus group participated. The discussion was very inclusive, all members of the focus group contributed on more than one occasion and the conversation was very fluid and cooperative. The discussion was audio recorded and later transcribed.

### *Telephone consultations with former service users*

For this study, two former service users with personal experience were invited to represent the 'patient voice' and both accepted the invitation to participate. They were interviewed individually over the telephone for 30–45 minutes. During this call, the SHAI was discussed line by line and participants were consulted on their views on why the SHAI was not being completed and what could be getting in the way. The telephone call was audio recorded, transcribed and later analysed.

## **Analysis**

### *Focus group with ME/CFS clinicians*

Once transcribed, the data were analysed using Braun and Clarke's (2006) six phases of analysis: data were initially coded, with themes then drawn and reviewed. Initial codes were generated by systematically coding interesting features throughout the transcripts. Codes were then gathered into potential themes and reviewed across the entire data set. Themes were reviewed by the authors, refining the specifics of each theme to generate clear definitions and names. Inter-rater reliability was not calculated. The themes were defined and named and weaved together to offer a narrative of the emerging themes from the focus group.

### *Telephone consultations with former service users*

Themes emerging from the telephone calls with two former service users were further transcribed and analysed using thematic analysis (Braun and Clarke, 2006), as described above. As the clinician focus group was completed first, care was taken to not simply fit the data into pre-existing codes.

## **Results**

Results from the focus group with 15 clinicians from the specialist ME/CFS service are discussed below; results from telephone consultations with former service-users are discussed thereafter.

### *Results from clinician focus group*

Discussion over the use and barriers to completion of the SHAI produced salient themes relating to timing, phrasing and language, demand characteristics and response bias, context and negative past experiences. An item-by-item breakdown of pertinent comments relating the SHAI can be found in Supplementary Table 1.

### *Timing*

The theme of the timing of administration of the SHAI as a barrier to its completion was highlighted by clinicians. In particular, early administration was thought to hamper patient engagement. For example, it was suggested that if the SHAI is given to patients before they have had the opportunity to discuss their ME/CFS symptoms, it may lead to them misinterpreting the purpose of the SHAI. There was a sense of agreement that it would be helpful to screen for health anxiety among patients in the service, but not at the point of assessment. This is reflected in the quote below:

*'People have just not understood how to answer these because people often don't have a diagnosis so they have been going to their GP for all these unexplained symptoms and*

*naturally you're going to be worried about what is wrong with you, you want to find out what is wrong with you. So there's something odd about that, how you apply those questions at that time as well, when a diagnosis isn't known yet.'*

Clinicians expressed concerns that administering the SHAI as part of the assessment may skew patients' interpretations of the questions and consequent responses. One clinician felt the scores on the SHAI were 'skewed by the fact that they are coming into a service', because when patients go to an assessment, 'thoughts are going to be around their health'. In this sense, at first point of access, patients are already pre-disposed to thinking about their health. This may impair the validity and the specificity of the SHAI, as scores may be inflated by the process of being referred to a specialist service. It became apparent through discussion that the completion of the SHAI would possess more meaning to the patient post-diagnosis of ME/CFS.

*I think down the line with people there is value in identifying those people who are constantly symptom-focusing, I think that's kind of important, but not at the point of assessment, perhaps that's not the best stage?'*

Taken together, analyses suggest that early administration of the SHAI may negatively influence patients' perception of and responses to the SHAI.

### Context

The theme of context arose as an important factor to consider when using the SHAI with regard to the context in which the SHAI is administered and also the context of ME/CFS within wider society. One clinician queried the use of the SHAI and its complex placement in the ME/CFS population. Particular concerns were shared in how best to legitimise patients' experiences whilst assessing for health anxiety. Clinicians shared fears that the SHAI may not be fully understood by patients and that this may unintentionally reinforce messages about the credibility of their symptoms associated with ME/CFS.

*I think that there is a particular culture around ME/CFS, more so than other health conditions around whether this is real. That is a real theme in our patient group and outpatient clinics.'*

Clinicians reported that as part of their clinical practice, clearly explaining the rationale behind the SHAI was imperative to ease patients' concerns and maintain engagement. Communicating to patients the purpose of the SHAI as an explorative tool was seen as important in order to engage patients:

*'Often I've done a bit of work about "yes it is separate to the other forms" and putting it in the context of "we are learning a lot about psychological help for people with all sorts of conditions like, cancer, Parkinson's, MS, so, we're exploring", just trying to provide a bit more context within a wider medical background.'*

Clinicians agreed that without this explanation, patients may respond negatively to the SHAI, becoming self-stigmatising or feeling as though they were being perceived by clinicians as a hypochondriac or that they were exaggerating their difficulties somehow. Without giving appropriate context, there were concerns that patients may feel that the SHAI trivialises aspects of their condition or discredits concerns that patients may have about their physical

health. Clinicians shared a sense of responsibility to reassure patients in order to buffer against any potential stigmatisation that may be implicit in the SHAI:

*'Patients could think "it's all in my mind" especially if the question, the individual questions reinforce that.'*

*'Look, all we really need to say to people is "we know you're ill – do you think you worry about it too much?" That's really what we're saying isn't it? People can understand that!'*

Therefore, a desire for a more transparent and simplified way of measuring health anxiety and illness-related worry, without rupturing rapport, was desired by clinical staff:

*'When you finally find a place that you feel trusted and that you can trust and that you can believe and you find you finally feel like you're getting somewhere, to suddenly have this, this questionnaire, it's a little bit like a slap in the face. I feel it is quite . . . strongly worded as to make them think, yeah, their illness it's saying that their illness might be in their mind, and that we actually maybe secretly do think that.'*

Some clinicians also doubted the appropriateness of using the SHAI with those with ME/CFS. Throughout, the uniqueness about the condition was emphasised, with clinicians commenting on the differences between health anxiety in general, and health anxiety in those with ME/CFS. This is reflected in the quote below:

*'I think also there's, whether this is capturing people's anxiety in the way it presents in this cohort of people. I think the construct is different, being anxious about your health in the context of having a health condition compared to not, I think this isn't the best tool to do it.'*

### *Negative past experiences*

Numerous clinicians mentioned the contentious culture surrounding ME/CFS and commented on the need to consider the SHAI in the context of negative past experiences that ME/CFS patients may have endured. Words such as 'confrontation' and 'fight' articulate a sense of understandable opposition, given the context in which the questionnaire completion may occur:

*'It depends on what their experience of having the illness is and the messages that they've been told, that they've been trying to fight against [previous difficulties with accessing help] and if that's not been good, to be suddenly confronted with something like this could be incredibly, well, it could be enough to make someone walk out I'd have thought.'*

Clinicians commented that due to the public treatment of ME/CFS, a measure that appears to lack sensitivity may be viewed as unacceptable or inappropriate to use for those with ME/CFS. Clinicians shared concerns that some of the items and concepts raised in the SHAI were directly incongruent with how patients viewed themselves and their illness; causing them to feel as though their symptoms and feelings were not being validated:

*'Yeah, and I think the legitimacy issue, it just, is actually probably very different to a lot of other conditions.'*

Clinicians shared concerns that the use of the SHAI may lead to patients disengaging with the measure and/or the service, given that some patients may not have previously been believed or faced stigma in their help-seeking journey. With acknowledgement of this, it was evident that psychosocial factors that were beyond the control of the service, could directly affect service use because of the SHAI.

*'I think we really take a lot of stuff about people's journeys totally for granted and the jargon that people are suddenly faced with, as, you know, even with all the other forms, let alone this.'*

Taken together, there was a shared appreciation that the ME/CFS population may have uniquely difficult experiences of gaining help for their medical illness, and associated measures used at assessments may be insensitive to this. Concerns were mostly raised that the SHAI was not suitable for use with those with ME/CFS due to some items being perceived as confrontational, echoing previous negative experiences of delegitimation.

### *Phrasing and language*

The theme of phrasing and language used in the SHAI was identified as a key barrier to completion. Clinicians were in agreement over the inaccessibility of the SHAI, in terms of the medical language used and its lengthy appearance. There were concerns that this could cause difficulties with patients accurately understanding and responding to the questionnaire. There was also agreement that there were elements of repetition within the SHAI. Clinicians shared concerns that the questionnaire was 'pitched too high' as 'each line is very wordy' and not accessible to non-medical audiences:

*'in terms of readability . . . that looks really high on a reading scale for most patients.'*

Given that the SHAI is typically issued amongst a battery of other questionnaires, within a ME/CFS service, clinicians suggested that the poor readability of the questionnaire, nestled amongst other measures may be overwhelming for service users. Considering that fatigue is a common issue in the general population, this may be exacerbated in those with ME/CFS, who may struggle to a greater degree with concentration and energy difficulties. The demands of completing a measure laden with emotive items, in combination with complex language, may lead to a reluctance to complete the SHAI:

*'By the time they've got through the rest of the form, they've probably run out of energy and steam and mental ability and concentration to be able to cope with it and then they look at the words and just think "whoa, I can't do it".'*

The SHAI's focus on physical symptoms was also thought to hinder patient engagement and endorsement of specific items. Clinicians agreed that some of the phrasing of the language in the SHAI was potentially inappropriate and unacceptable to those with ME/CFS: that the principles of the SHAI may not generalise to those experiencing physical health problems. Some items were considered to be subjective and therefore more likely to be endorsed in those experiencing physical complaints. For example, one clinician stated:

*'I wonder with the specific items, the wording of it, how many things you might endorse, just because you've got a health problem with multiple symptoms.'*

Some items in the SHAI were also thought to be at odds with the experience of individuals with ME/CFS. Clinicians stated that those with ME/CFS may feel that they are ill and very unwell, and

perceive that the authenticity of their illness is being questioned through the SHAI. This may lead to feelings of rejection or belittlement, as illustrated in the below quote:

*'They feel ill, their felt experience is that they are very poorly so the idea that their GP telling them there is nothing wrong is never in a million years going to be reassuring.'*

In particular, there were strong opinions about the phrasing of individual items of the SHAI, pertaining to phrases such as 'serious illness', 'bodily sensations', 'lastingly relieved' and 'worry':

*'well "lastingly relieved if my doctor tells me there is nothing wrong", you know, it's like you want them to find the thing that's wrong with you from all these investigations, so that's going to skew that answer as well. . . I'm not going to be relieved if my doctor tells me there is nothing wrong because I'm still ill, that's why I'm here!'*

#### *Demand characteristics and response bias*

The issue of demand characteristics and response bias to the SHAI was highlighted by the group. Clinicians shared concerns that patients may possibly feel the need to emphasise their symptoms to gain a ME/CFS diagnosis and be 'believed'. In this sense, service users may respond with social desirability, utilising the measure as a tool to gain additional help from clinicians. Clinicians also expressed concerns that ME/CFS patients may answer questions with a sense of preserved caution. It was perceived that patients may be fearful of being misunderstood or believed by health professionals, depending on their responses to the SHAI. Specifically, clinicians perceived a sense of fear of being blamed, not believed, or told 'it is all in my head', during the completion of the SHAI. Words such as 'guarded' and 'resistance' were used by clinicians, conveying a sense of defensiveness and unease from patients. One clinician stated:

*'Giving somebody a questionnaire working in ME/CFS, I can imagine, there could be some resistance to it and people being quite guarded around what information they are giving you and if this will go as part of their diagnosis then they might be quite guarded about how they might achieve that. There could be, for some people, well not everybody but, could be some resistance to answering that or disclosing information.'*

This perceived sense of guardedness, reluctance and apprehension for fear of being misunderstood or misdiagnosed was seen as a barrier to completing the SHAI. This led to clinicians contemplating whether further training in delivering the SHAI in a ME/CFS service was required:

*'Maybe we're not couching it enough in terms of actually, like with other conditions you can have like anxiety as well as other conditions, maybe we're not doing enough around that because then it becomes either it's this or it's CFS.'*

There was an agreed sense that the SHAI did not fully capture the multifaceted nature of health anxiety within the ME/CFS population, with the SHAI lacking sensitivity to how features of anxiety is uniquely manifested through living with an illness with no unified cause, whilst also acknowledging features of health anxiety that are in themselves debilitating and common to other medical diagnoses.

#### *Results from telephone consultations with former service users*

The main themes that emerged from discussions with participants were similar to that of the clinician focus group, but were narrower in focus: Timing, Context and Phrasing and



Language. Although participants reported similar views on the timing and context of the administration of the SHAI as barriers to completion, there were differences in opinion on some items of the SHAI.

### Timing

There was agreement amongst participants that it would be helpful to think about the timing of administering the SHAI. Administering the SHAI before diagnosis was seen as confusing and left a sense of ambiguity around the purpose of the SHAI. More specifically, administering the SHAI pre-diagnosis led to some items on the SHAI being difficult to answer, with terms mentioned being perceived as conditional or not applicable at that stage.

*'A lot of questions are tapping into what I as someone living with CFS experience on a daily basis. You're giving the questionnaire at a point when you are trying to assess people who don't have the diagnosis yet and so they could feel confused by the term serious illness.'*

As reflected in the quote below, participants warned that the timing of the SHAI was crucial in facilitating rapport and engagement. There was some acknowledgement that the point of administration of the SHAI interacts with the individual's symptomatic and diagnostic journey. Phrases such as 'in their face' suggests that pre-diagnosis, the use of the SHAI may be perceived as intrusive:

*'Perhaps it is about timing? If people are diagnosed already, they might be more open. If people are really bad with symptoms, it can be in their face.'*

### Context

Participants agreed that setting the context of the SHAI was important to aid its completion. One participant suggested that an introductory statement was needed to 'soften' the use of the SHAI. It was expressed that this would make the SHAI seem more warranted and be greeted with less perceived stigma. This could potentially cushion any negative perceptions of the 'bluntness' of the language used in the SHAI. Without this, participants cautioned that patients may perceive a sense of judgement from clinicians when using the measure.

*'The statements and language are so dry and very direct. I wonder if an introduction would help put people's minds in a different mindset? It's very blunt! So like, "This type of questionnaire is generally used in the medical profession and not just ME/CFS, it applies to other conditions . . ."'*

Both individuals suggested recommendations to overcome the barriers they identified, including providing an introduction to give context and to distinguish the use of the SHAI as being a measurement of health anxiety, and not in relation to ME/CFS symptoms.

*'If they said, "We are not trying to judge. This is a questionnaire used in other services and is part of the whole package to treat you better."'*

Participants emphasised that it would be helpful if the holistic treatment of ME/CFS was communicated when administering the SHAI, as mentioned in treating 'the whole package' in the above quote. It could be inferred that for some patients on their diagnostic journey, there may be a misunderstanding or unawareness of the role of health anxiety in ME/CFS. Through

explaining the use of the SHAI and emphasising holistic benefits of completing the measure, clinicians could enable openness and instil hope in patients completing the SHAI.

### *Phrasing and language*

Both participants felt there were issues with some of the language used in the SHAI. Concerns were raised over language being outdated or too technical (e.g. ‘hypochondriac’).

Participants queried whether other patients would be able to understand a number of the words used in the SHAI such as ‘bodily sensations’, ‘ill’, ‘images’, ‘serious illness’ and ‘lastingly relieved.’ These misgivings over the language were particularly salient in reference to the context of ME/CFS and its surrounding social context.

*‘Lastingly relieved is a strange use of words. If you feel ill and the GP says nothing is wrong, I’m not relieved but angry.’*

Participants also described difficulties answering item 2 (e.g. ‘I notice aches/pains less than most other people my age’) and item 14 (e.g. ‘My friends and family would say I worry too much about my health’) of the SHAI. Both individuals struggled to be sure of ‘what people think’. These responses may reflect isolation from other people their age or a tendency to focus attention on one’s own experience, rather than noticing what others are experiencing in the world around them.

*‘How do I know what other people are experiencing . . . a six to me may be a two to you . . . I have no idea how much pain others may be going through!’*

However, participant views differed on a number of other items (including items 6–10 and item 13), capturing the variety of responses that can be generated after completing the SHAI. Contrasting comments included ‘I didn’t have a problem with that one’, ‘I think it is fine’ and ‘I don’t have a problem with it’ for items 8, 10 and 13. Whilst Participant 2 did not have a problem with item 9 (e.g. ‘If I hear about an illness I never think I have it myself’), they stated:

*‘If people with ME/CFS are not given a diagnosis you do listen to illnesses and wonder if that is what is wrong with you. I tried to make sense of what I was experiencing as no one was making sense of it for me. It is a natural thing to do before receiving a diagnosis. You look at your symptoms and think is that what is happening to me?’*

There was concern that many of the items on the SHAI held negative connotations and both Participant 1 and Participant 2 reported experiencing strong emotions in response to some of the items. The language used in some items of the SHAI held a perceived stigma towards patients’ strength and ability to cope with symptoms. Words used in the SHAI such as ‘resist’ or ‘afraid’ may be seen to locate the responsibility of the distress within the individual with ME/CFS. There was a sense that some of the language used in the SHAI implies a specific weakness within the individual, which contrasts against societal expectations of being ‘strong’:

*‘Resisting thoughts seems a bit clumsy and suggests a battle . . . It insinuates that I am weak in character because I can’t resist them and that a resilient person would be able to.’*

*‘The verb “afraid” insinuates you could be weak or get scared. Strong people don’t get scared.’*

As demonstrated, participants often compared implications of strength and resilience, with weakness and fear. There was a sense that the SHAI dichotomised or categorised respondents’

efforts to manage their symptoms. Overall, participants expressed that the language used in the SHAI was experienced at times as invalidating, stigmatising or disapproving.

## Discussion

This study aimed to understand the barriers to the Short Health Anxiety Inventory (SHAI; Salkovskis *et al.*, 2002) being completed within a specialist ME/CFS service, and explore ways in which this may be overcome, to mitigate impact on assessment and treatment of health anxiety in ME/CFS. This was in response to earlier research indicating that negative views towards the SHAI from clinicians and patients influenced recruitment to a treatment trial for CFS/ME and general non-completion of the questionnaire in practice (Daniels *et al.*, 2017; Daniels *et al.*, 2020). Overall, the themes generated in this study indicate that adaptation of the SHAI is critical for use with ME/CFS. Concerns raised suggest that the SHAI measure is unacceptable to service users due to the wording and language used, and that this (a) impacts clinicians' ability to engage and develop a therapeutic relationship and (b) potentially leads to neglect of a pressing clinical need. Research into socialisation to the model in ME/CFS (Daniels and Wearden, 2011) indicates that holding a shared understanding of the presenting problem is an active component in the therapeutic alliance, supporting clinicians' views. In addition, such research supports the notion that if questions on the SHAI give the impression that health anxiety, rather than ME/CFS, is the problem, or rather that it is a mental health problem rather than a physical health problem, this is likely to undermine a shared understanding and lead to disengagement, risking impacts on treatment of health anxiety and treatment of ME/CFS as well.

Based on the findings of this study, it is recommended that ME/CFS services or those that offer treatment for ME/CFS, should carefully consider the timing of the administration of the SHAI as well as the wider cultural context of ME/CFS. It can be inferred that the administration of the SHAI upon initial consultation may provide a barrier to engagement for service users, potentially altering their perceptions of the role of the service, expected diagnoses and resultant treatment as result. Without acknowledging the broader sociocultural context surrounding ME/CFS, a perceived sense of stigma presents as a barrier to the completion of the SHAI.

Previous studies have shown that those with ME/CFS experienced stigmatisation prior to receiving a formal diagnosis (Åsbring and Närvänen, 2002; Vogel *et al.*, 2006); perceived and self-stigma are known to influence help seeking and engagement (Varni *et al.*, 2012; Vogel *et al.*, 2006). Withdrawing from others and withholding information is a common tactic in reducing stigma (Åsbring and Närvänen, 2002), therefore legitimising patient concerns and achieving a shared understanding of the problem and what might help, remains an important feature of service engagement and therapeutic alliance (Daniels and Wearden, 2011). Previous research has indicated that administration of the SHAI upon initial consultation is likely to be already providing a barrier to engagement for service users (Daniels *et al.*, 2017; Daniels *et al.*, 2020), giving the false impression that ME/CFS is considered a psychological or psychiatric problem, thereby inaccurately representing values and role of the service, diagnoses and resultant treatment. Once these beliefs are established and service users disengage, it is difficult to resolve, correct or overcome.

It is noted that the SHAI originated from a need to sensitively measure health anxiety in medical contexts, without the elevation of scores through compounding concerns relating to the belief that one is physically ill (Salkovskis *et al.*, 2002). Despite the measure possessing proved utility, with good reliability in medical clinics and ME/CFS groups (Alberts *et al.*, 2013; Daniels *et al.*, 2017), it is evident that incompatibilities exist given the unique difficulties facing this population. If it is not acceptable and valid to the clinician, its use is limited.

### Strengths and limitations

A strength of the current study is the clinical relevance and ecological validity for health practitioners and patients with ME/CFS which underpins this study. Clinician's verbatim quotes provided rich qualitative data that can be used as a foundation for the development and adaptation of the SHAI. As a range of ME/CFS health practitioners were consulted, this increases the applicability of findings and reflects experiences from different specialist viewpoints. There was a high degree of cohesion within the group conversation and equal representation of different professionals within the group: it was evident that a shared view was held across the group. Whilst it is noted that clinician views were explored in a group setting and former service users were consulted individually, individual interviews were deemed more appropriate and agreeable to participants: this protected their anonymity and created a safe space to explore freely. We acknowledge that individual staff interviews may have provided more in-depth insights; however, the use of focus groups is known to be useful in the context of understanding the consensus views within a specific group, particularly as through the interactive process more data may emerge than through other methods (Duggleby, 2005; Parker and Tritter, 2006). Focus groups are also well suited to studies such as this which are exploratory and preliminary in nature, and where individual interviews with NHS staff team members are likely to be possible resource wise; however, a focus group uses comparable methods and offers the additional data and insight associated with a 100% participation rate.

This study has identified a range of barriers to completing the SHAI within ME/CFS, an area that has not previously been explored in depth. As there has also been a call for treatments that specifically target anxiety in ME/CFS (Stoll *et al.*, 2017), it is hoped that this study adds to the dearth of literature in this area to promote appropriate assessment and treatment of health anxiety in ME/CFS services, allowing for the clinical needs of patients to be met.

Although former service users were interviewed as part of this study, a limitation of this study is that current patients within the service were not consulted regarding their experiences of completing the SHAI, although this work is underway. We also note that the clinician voice is over-represented in this study as fewer service users were consulted over their views of the SHAI. However, due to service-level limitations, we were unable to consult more patients within the service. Whilst there was a clear consensus within the group interview with clinicians over the barriers of the SHAI in this exploratory study, further investigation is required to establish the generalisability of such viewpoints and comments amongst clinicians.

Future research should be underpinned by a more expansive representation of service user experiences, offering in-depth individual clinician consultations in order to provide richer data that may be more generalisable. Due to the nature of the measure we were unable to differentiate fears relating to ME/CFS or fears relating to contracting an additional medical condition such as cancer, multiple sclerosis and so on. Future development of the SHAI should aim to more closely specify whether illness-related fears are associated with an existing condition or otherwise. This work is currently ongoing.

### Implications

Administering the SHAI at the end of the assessment appointment would allow for additional context to be provided by the assessing clinician for those accessing ME/CFS services; this would provide an opportunity to acknowledge that although it is normal to worry about one's health, particularly during the process of investigation and repeated assessment, for some, this worry can become a pre-occupation which can be distressing. Providing information about the purpose of the questionnaire could also improve its completion.

Given the expanding evidence base in relation to interventions for ME/CFS in recent years, there is a paralleled need for the accurate and acceptable measurement of typical outcomes associated with ME/CFS, such as health anxiety (Alberts *et al.*, 2013), and it is hoped this work would underpin this. Sensitive measurement and treatment of (health) anxiety with ME/CFS may capitalise on therapeutic gains offered by CBT, when accurately measured, identified and treated (Daniels *et al.*, 2020). The report ‘No decisions about me, without me’ (ME Association, 2015) indicated that CBT was found to have a positive effect in aiding some patients to deal with co-morbid issues, highlighting the importance of assessing patients with ME/CFS for such difficulties and ensuring they have access to treatment.

### Conclusion

This study has identified a number of barriers to completing the SHAI within a ME/CFS service. Specialist clinicians and former service users alike shared common concerns relating to core difficulties with the utility of the SHAI in this population. The timing of the SHAI being administered pre-diagnosis, the language of the SHAI and lack of context around the questionnaire were identified as barriers to the SHAI not being completed by service users. Given the high co-morbidity of health anxiety in those with ME/CFS, it is important that health anxiety is appropriately and sensitively measured in order to provide better-informed assessment, effective treatment and symptom relief for those with ME/CFS. Findings from this study suggest that adaptation of the SHAI is vital for use with ME/CFS and that further investigation of the measurement of health anxiety in this population is required.

**Supplementary material.** To view supplementary material for this article, please visit <https://doi.org/10.1017/S1754470X20000525>

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### Key practice points

- (1) The timing of the administration of the SHAI in the patient’s treatment pathway is an important factor to consider, especially when using the instrument at pre-diagnostic ME/CFS assessments.
- (2) Explaining the relationship between health anxiety and ME/CFS to patients at assessment may be important in aiding the completion and understanding of the SHAI and reducing service disengagement.
- (3) Making efforts to explain potentially contentious language used in the SHAI may increase openness and connectivity in those with ME/CFS when assessing for health anxiety.
- (4) Sensitively measuring and addressing health anxiety within ME/CFS may offer greater treatment gains within CBT.

### Further reading

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