

Bristol CFS/ME Service
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Survey of patients attending NHS specialist CFS/ME Services conducted April-July 2019

Background

This survey was conducted because of a perceived risk of closure of NHS CFS/ME specialist services (BACME 2019) because of limited NHS funding. In addition the Joint commissioning panel for mental health (www.jcpmh.info, February 2-18) classified CFS/ME as a Medically Unexplained Symptom (MUS) and recommended that services are provided by mental health teams including IAPT rather than specialist CFS/ME services which offer a range of therapies and expertise.

What NHS specialist services offer

The assessment and diagnostic process is, for many patients a vital element of attending an NHS specialist service. Patients may have lived with symptoms for years, even decades without diagnostic clarity. The clarity about the diagnosis provided by specialist services can be particularly helpful not only for patients, but also their families, employers and/or educational institutions and also other healthcare professionals involved in the patient's care. Following diagnosis, it can be helpful for patients to be able to identify the range of symptoms which are commonly recognised as part of the syndrome, and also on occasion to have symptoms/problems which are not part of the syndrome identified so they can be addressed separately. Related conditions such as POTS can also be identified, and the patient can be referred on for specialist assessment and management. Patients who present with other conditions which require further evaluation before a diagnosis can be given can be referred on to the relevant service, for example if a primary sleep disorder is suspected on the basis of the assessment.

As part of the treatment plan there will typically be an exploration of the issues related to post-exertional malaise, and self-management strategies to manage this will be introduced. In that regard, it is important to identify the overlaps between CBT, GET and self-management strategies (such as establishing sustainable baselines for activities) which

we know to be important in managing any long-term condition. For example, these principles are also incorporated into therapy plans for rheumatoid arthritis fatigue and cancer-related fatigue. In addition to this activity management approach, sleep management is commonly introduced and can bring benefits for patients who have comorbid insomnia, or hypersomnia.

Advice can be offered regarding symptom management, in line with the British Association for CFS/ME (BACME) guide. This may include guidance to primary care regarding medication, but it may also involve non-medication treatment options.

Guidance can also be offered to employers and/or educational institutions regarding appropriate engagement with employment and education. This often involves advice regarding reasonable adjustments which can be considered. The aim of this is to support the patient in maintaining employment where possible. If a patient is unable to manage paid employment, services are often well placed to offer advice regarding access to benefits such as Employment Support Allowance.

Survey method

We wanted to capture and represent people's experiences of the broader approaches offered by specialist services, but only had a limited timescale. This simple survey was conducted with the intention of gathering feedback from patients who were either current or recent patients of NHS CFS/ME Services, with minimal patient burden. Patients were invited to respond to the short survey by emails sent from NHS service email accounts between late April 2019 and August 2019. The majority of patients were those of the Bristol CFS/ME Service and parents of young people attending the Paediatric CFS/ME Service at Bath were also invited to participate. The individual information supplied by each survey participant protected against multiple completion of the survey by a single individual.

The primary question was: "Do you think that adults and children with Chronic Fatigue Syndrome or ME (CFS/ME) should have access to specialist NHS services for assessment and treatment?" Response options were yes or no. The survey then invited participants to add free text, if they wanted to say anything else. No demographic data was collected, to reduce the burden of survey completion. The main emphasis of the data presented below is a thematic analysis of the qualitative data collected.

The leaking of the survey URL via social media created a natural experiment

A "natural experiment" occurred towards the end of the data collection, when the URL of the online survey was made available to the general public via a number of websites and

Twitter accounts. The survey was closed after 12th August 2019 once we realised that any further data collection no longer represented NHS patients. There were 610 responses before the date of the leak, and 282 responses after that date.

Survey findings

A thematic analysis of the comments made by people who responded up to 23rd July 2019 (when the survey URL was made available to the public via social media), is presented below. The initial data analysis presented shows the responses collected before the survey URL was made public on social media.

Theme 1: The importance of a specialist service

Respondents valued the contact with a specialist, particularly for help with diagnosis and to access reliable information. There was a recognition that early diagnosis and treatment was important. Even if there had been a delay in diagnosis, having an expert diagnosis from a specialist service was seen as important aspect of what services offered.

“I received a timely and expert assessment and diagnosis by the specialist CFS/ME service that my GP reported he would not have felt qualified to give.”

“My diagnosis was critical in securing changes required at work in order for me to be able to carry on working. Without a specialist service I’m not sure I would have got that diagnosis and my life, and that of my family, would be immeasurably worse.”

Theme 2: Impact of the potential withdrawal of a specialist service

There was a recognition that any scaling back or closure of NHS Services would be negative, as it would have a detrimental impact on people living with CFS/ME. There were comments indicating that there would be a sense of loss and helplessness if services were to be removed. Services were seen as a lifeline for patients; some would feel completely alone with the condition without contact with a service. The impact of service removal or reduction on the patient’s family was also acknowledged.

“If it were not for the specialist services, I would have zero support or guidance, leaving me unable to work with no explanation from a medical professional why - the CFS/ME specialist services are absolutely vital.”

“If the NHS service goes I have no idea what the future for sufferers will be, there's so much lack of help with a condition that destroys lives, any advice, backing and help through to manage the condition is a huge asset to the many affected by it, I would personally be devastated if the NHS help would go.”

Theme 3: Benefits of meeting others living with CFS/ME through an NHS service

There was a clear indication that meeting others with the condition had been helpful. The isolating nature of the condition was identified, and meeting others with the condition helped to reduce this isolation. Linked with this, the opportunity to learn from others was valued.

“The support of knowing you are not alone from service user groups should not be underestimated.”

Theme 4: Lack of support and understanding outside of the service

A number of comments recognised that there was a limited understanding of CFS/ME from some GPs and other health professionals. In contrast, the services were seen as a source of understanding which patients could access directly, as well as having a role in promoting understanding of the condition amongst other healthcare professionals and in society. There was a desire for CFS/ME to be understood and accepted like other health conditions, and that people living with different health conditions should have access to specialist services.

“This service is desperately needed. There is no other specialist help out there. Input from GP has been minimal at best.”

Theme 5: Recognition and validation of the condition

The services were seen to recognise the impact that CFS/ME has on a person's whole life. It was clear that respondents have been helped to confirm that CFS/ME is real and not “in their heads”. Services were seen as being holistic, supporting people to deal with both physical and mental aspects of the condition: that services look at both and treat both, including secondary depression due to living with the condition.

“The CFS/ME service has shown me it's not in my head & they have helped me deal with this illness.”

“It helped me loads. There is such a stigma around it and I was so embarrassed that I would never tell anyone which meant I didn’t get any help. And being able to speak to someone and others who are going through the same things really helped.”

Theme 6: Self-Management support

Respondents valued the support from specialist services to learn skills and strategies to self-manage the condition. There were specific mentions of both CBT and Mindfulness meditation as being helpful approaches.

“I have been given strategies to support me and a network of people to share and support each other. The practitioners treat everyone as an individual and they actively care about each of us. This is evident in their manner and in the support provided. My mental health has been nurtured through involvement with this service.”

“I have suffered with CFS for over 10 years. The support I have received has allowed me to manage my condition.”

“It is poorly understood by many health professionals: a specialist service has health care staff with a greater depth of knowledge and experience to be able to offer valuable support and guidance in self-management.”

Theme 7: Improvement attributed to support from specialist services

There were comments related to the avoidance of deterioration, which was a risk without support, and there were also comments reporting improvement in health and function as a result of the support of the services.

“Before being offered help on the NHS for my CFS/M.E, I was really struggling. Their services really made a difference to my physical and mental health and my symptoms have never been so bearable.”

“This service has kept me in full time work.”

A parent commented: “We have found this service essential for the help & advice for my daughter’s recovery & support for our family.”

Theme 8: What else is needed?

There were suggestions that more services were needed, and more local provision, not fewer services especially as access to specialist care is not yet available in all areas. The role which specialist services can have in fostering research was noted, and there were calls for research into cures and accurate tests for diagnosis. There was a hope expressed that research would lead to treatments which could lead to greater improvements, rather than just managing symptoms. There was also a suggestion of incorporation of medication prescription into the service alongside self-management and rehabilitation interventions. There was also a call to increase public awareness of the condition.

“Please more funding to find out why we are ill, so that there can be a test to diagnose, and a drug to cure.”

Theme 9: Criticisms of services

NHS patient responses: Out of 612 responses before the 23rd July 2019 (when the survey URL was made available to the public via social media), only three comments criticised CBT and three criticised GET. One of the comments expressed a concern that CBT and GET were based on poor science, and a second comment suggested that they were harmful and ineffective. One comment expressed concern that some services do not offer medical input. One person was unhappy with the delivery of a group that they attended.

“Specialist treatment should be available but not GET and CBT, actually researched and proven treatments should be available. More money needs to be invested in research so that correct treatment is available. Now that a blood test in America has been discovered, this solidifies the fact that this condition is not neurological and therefore should not be treated as such. A broken leg or cancer would not be treated as neurological so ME/CFS should not be either now that it can be proven by blood tests in America.”

Responses following the leak of the survey URL via Social Media

The tone of the comments immediately changed after the URL was shared on social media, becoming intensely critical of CBT, GET and the PACE trial. It is interesting to note the shift in focus from the positive benefits (with a much small number of criticisms) reported above from patients who have current or recent experience of NHS specialist services, and the highly critical focus once the survey URL was made public. This finding is noteworthy, as it casts doubt on the ability of surveys conducted via social media (such as the once conducted earlier in 2019 by Forward ME which has been submitted to the NICE guideline

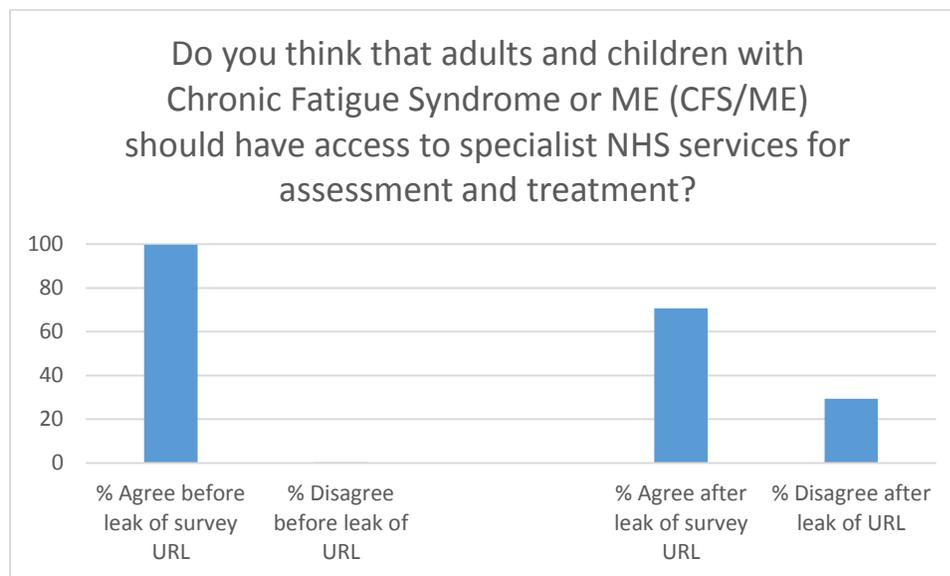
review panel) to accurately represent the experiences of NHS patients accessing specialist services.

As an example of the shift in tone, on a single day (25th July 2019) 47 comments were received which were critical of CBT and GET. A further 16 comments were received which suggested that other approaches should be offered, such as only biomedical treatments. Whilst it is important to recognise the strength of feeling that these comments represent, they clearly do not match the experiences of the vast majority of current or recent NHS patients.

This change in the data generated indicates the importance of this NHS brief survey, and it creates doubt about the meaningfulness of data collected by surveys which are open to social media.

Quantitative data analysis

We wanted to capture something of patients' experiences of specialist services, whilst making the survey easy to complete, so participants were simply asked: "Do you think that adults and children with Chronic Fatigue Syndrome or ME (CFS/ME) should have access to specialist NHS services for assessment and treatment?" From 30th April 2019 until 22nd July 2019, 609 people agreed with this statement (99.8% positive response) and one person disagreed (0.2% negative response). After the survey URL was made public, the response shifted significantly. 199 people agreed (70.6% positive response) and 83 people disagreed (29.4% negative response).



Conclusions

The shift in negative responses from 0.2% to 29.4% provides compelling evidence that the responses of current and recent NHS patients differ greatly from the responses of people responding via social media. We think that this evidence should be taken into account by the NICE Guideline review in considering the scope of the data submitted from surveys which involved recruitment via social media. It is clear that these surveys do not reflect the experiences of all NHS patients who are accessing specialist CFS/ME Services. It is likely that there are a number of sources of bias involved, and certainly the responses to our survey after it became public suggests that the experiences of actual NHS patients is very different from the experiences of those who heard about the survey via social media. We suspect on the basis of this effect that in future a more detailed survey of actual NHS patients would be more useful than a repetition of surveys spread via social media.

The wealth of positive comments received from patients who had recent or current experience of NHS services, and the strength of feeling that specialist services need to be supported to grow as they are providing a service that many patients value highly, are the key findings from this brief survey. There is a clear case to be made to develop this methodology for the future in order to continue to learn from the experiences of NHS patients.

References

BACME 2019. British Association for CFS/ME CFS/ME National Services Survey February 2018. Available from:
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