

RESEARCH ARTICLE

Use of an online survey to explore positive and negative outcomes of rehabilitation for people with CFS/ME

Peter William Gladwell¹, Derek Pheby², Tristana Rodriguez³, and Fiona Poland⁴

¹North Bristol NHS Trust, Bristol, UK, ²Buckinghamshire New University, Society and Health, Uxbridge, UK, ³Action for ME, Bristol, UK, and ⁴Health and Society, University of East Anglia, Norwich, UK

Abstract

Purpose: First, to explore the experiences of people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) of rehabilitation therapies so as to build an understanding of reasons for the discrepancy between the notably mixed experiences regarding effectiveness reported in patient surveys and the RCT evidence about the efficacy of Graded Exercise Therapy (GET). GET is a form of structured and supervised activity management that aims for gradual but progressive increases in physical activity. Second, to review patient experiences of two related rehabilitation approaches, Exercise on Prescription (EoP) and Graded Activity Therapy (GAT). **Method:** An online survey conducted by the charity Action for ME generated qualitative data about 76 patient experiences of rehabilitation undertaken during or after 2008, examined using thematic analysis. **Results:** Both positive and negative experiences of rehabilitation were reported. Positive themes included supportive communication, the benefits of a routine linked with baseline setting and pacing, the value of goal setting, and increasing confidence associated with exercise. Negative themes included poor communication, feeling pushed to exercise beyond a sustainable level, having no setback plan, and patients feeling blamed for rehabilitation not working. **Conclusions:** The negative themes may help explain the negative outcomes from rehabilitation reported by previous patient surveys. The negative themes indicate rehabilitation processes which contradict the NICE (National Institute for Health and Clinical Excellence) Guideline advice regarding GET, indicating that some clinical encounters were not implementing these. These findings suggest areas for improving therapist training, and for developing quality criteria for rehabilitation in CFS/ME.

Keywords

CFS/ME, chronic fatigue syndrome, graded activity therapy, graded exercise therapy, internet survey, rehabilitation

History

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► Implications for Rehabilitation

- The insensitive delivery of rehabilitation support for people with CFS/ME can explain negative outcomes reported in patient surveys.
- Therapist–patient collaboration, establishing a sustainable baseline and agreeing a setback plan are all examples of higher quality rehabilitation indicated by this research.
- Greater awareness of the positive and negative experiences of rehabilitation therapies should enable avoidance of the potential pitfalls identified in this research. Positive experiences of rehabilitation therapies include supportive communication with a therapist, treatment which included routines and goals, and value attached to baselines and controlled pacing. By contrast, factors leading to negative experiences include poor communication and support, conflict in beliefs about CFS/ME and rehabilitation, pressure to comply with treatment, worsening of symptoms, baselines experienced as unsustainable, and feeling blamed for rehabilitation not working.

Introduction

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is an increasingly understood medical condition defined by a range of associated symptoms which include mental and physical fatigue, post-exertional malaise, sleep

disturbance, impaired concentration and memory, widespread muscle and/or joint pain, headache, sore throat and tender lymph glands [1,2]. Symptoms cause significant disability, fluctuate in intensity and severity, and can be worsened by physical or mental activity and stress [3]. The term Chronic Fatigue Syndrome (CFS) was proposed as an improved case definition for Epstein-Barr Virus Syndrome in 1988 [4], and the condition is also known as Myalgic Encephalomyelitis (ME) [5]. The composite term CFS/ME is used in this article, as it is used by the National Health Service (NHS) [1], which since its foundation in 1947 has

Address for correspondence: Peter Gladwell, PhD, North Bristol NHS Trust, Ward 22, Frenchay Hospital, Beckswood Road, Bristol, BS16 1LE, United Kingdom. E-mail: Peter.Gladwell@nbt.nhs.uk

Table 1. Patient surveys of the impact of graded exercise therapy.

Date	Survey organised by:	No. respondents	% Respondents reporting:		
			Improvement	No change	Deterioration
2000	ME Association/Action for ME	347	39	22	39
2001	Action for ME	2338	34	16	50
2008	Action for ME	2763	45	21	34
2010	ME Association	4217	22	21	57

been by far the biggest health care provider in the UK, being funded out of general taxation and with most of its services being free at the point of delivery. The term CFS/ME appears widely in the literature, being used for example in the 2002 report of the UK Chief Medical Officer's Working Group [6].

Graded Exercise Therapy (GET) is a commonly-used, evidence-based rehabilitation intervention for which results of randomised controlled trials (RCTs) [7–12] suggest its effectiveness.

GET was defined in the Chief Medical Officer's Working Group report [6] as "... a form of structured and supervised activity management that aims for gradual but progressive increases in aerobic activities such as walking or swimming. It is based on a principle... that a principal factor maintaining the illness is inactivity, subsequent physical deconditioning, and its physiological consequences, which graded and supervised increases in exercise can help to reverse. In addition, it may act as a rehabilitative behavioural therapy by gradually exposing the patient to an activity (exercise) that has been avoided" [13]. According to the PACE trial, GET "... is about gradually increasing physical activity to improve fitness and get the body used to activity again. A therapist helps participants in this treatment group to work out a basic activity routine and slowly build up the amount of exercise as fitness increases" [14]. Graded Activity Therapy (GAT) and Exercise on Prescription (EoP) are both described on the Action for ME website [15]. GAT is stated to be "... a person-centred approach to managing a person's symptoms by using activity. Activities are selected, adapted and graded for therapeutic purposes to promote health and well-being. Therapy is goal-directed and uses activity analysis and graded activity to enable people to improve, evaluate, restore and/or maintain their function and well-being in self-care, work and leisure" EoP, by contrast, "... is where a GP or practice nurse refers patients to leisure centres or gyms for supervised exercise programmes". It will be noted that all these definitions are essentially concerned with the principles underlying the therapeutic approach, and therefore allow for considerable latitude in the ways in which they are interpreted and practised. The positive indications in RCTs for the effectiveness of GET consistently contradict the negative findings from surveys of patient views and experiences of treatment. This contradiction merits detailed examination, as a clear understanding of the processes which may lead to different perspectives on this treatment has the potential to improve patient care.

There is a history of controversy regarding the aetiology, diagnosis and treatment of CFS/ME, debated widely on the Internet, and reflected by recent articles in the *Physiotherapy Frontline* magazine [16], and in the *British Medical Journal* [17]. Differences in beliefs about the condition between clinicians and patients can influence the "micro-politics of the clinic" [18]. Such controversies were exacerbated by too-distinct ("dualist") conceptualisations of mind and body, and beliefs that CFS/ME was a primarily psychiatric condition [19], not yet completely replaced by more complex understandings of either the illness or of biopsychosocial health mechanisms. The absence of clinical signs and biomarkers slowed medical recognition of CFS/ME,

officially recognised by the NHS only 10 years ago [6]. Physical therapy models incorporating disorders of the oxidative stress system [20], the immune system [21] or the consequences of deconditioning [12] have been developed. The controversies outlined above create a challenging context within which to address the consistent contradiction between positive findings of RCTs of GET and negative experiences reported by patient surveys, summarised in Table 1.

All six published RCTs testing the efficacy of GET for outpatients with mild or moderate CFS/ME have found GET to be of some benefit, though the comparability of these results is complicated by differences in the diagnostic criteria used. These studies include the large multicentre PACE ("Pacing, graded Activity, and Cognitive behaviour therapy: a randomised Evaluation") trial [12], a large-scale trial of the effectiveness of four of the main therapies for CFS/ME, viz. adaptive pacing therapy, cognitive behaviour therapy, GET, and standardised specialist medical care.

The evidence-based medicine hierarchy of evidence [22] clearly indicates that the evidence regarding efficacy from RCTs should, in principle, be seen as more powerful than the results of a survey. As a result, the NICE Guideline recommends:

Cognitive behavioural therapy and/or graded exercise therapy should be offered to people with mild or moderate CFS/ME and provided to those who choose these approaches, because currently these are the interventions for which there is the clearest research evidence of benefit. [23]

However, the repeated discrepancy between the RCT results regarding efficacy and survey reports concerning the effectiveness of these therapies remains unexplained, generating ongoing controversy. The many posited theoretical explanations for the discrepancy indicate that a complete explanation may be multifactorial. An RCT should be recognised as a hypothetico-deductive strategy, intended to test a hypothesis about the effectiveness of a treatment. In contrast, the patient surveys employ an inductive strategy [24] to explore their respondents' experience of a phenomenon by descriptively summarising the experiences of people with CFS/ME who have attempted rehabilitation.

Various methodological factors may account, at least in part, for the less satisfactory outcomes reported in member surveys, compared with the results reported for randomised controlled trials. First, where the source of participants in a survey is the membership of a patient organisation, there could well have been survivor bias, where people experiencing good outcomes may have less incentive to remain members of the organisation. Secondly, there may have been variations in both the content and standard of supervision of the various interventions, in particular GET. An Action for ME 2003 survey offers evidence to support this, reporting 40% of those trying GET having been unsupervised, and the Action for ME 2008 survey respondents whose GET was supervised by their General Practitioners (GPs) rather than by hospital-based therapists more often reported worse outcomes. GPs have limited time to explain what is needed for

successful rehabilitation, and have reported a lack of confidence in managing patients with CFS/ME [25]. Inexperienced therapists may insist on inappropriately high starting levels of exercise, having mistakenly equated GET with maximum exertion, a misunderstanding also seen in the literature [26]. Randomised controlled trials tend to be undertaken in centres of excellence, but when treatments studied are translated into routine clinical practice the results may be less satisfactory. Patient surveys, by contrast, report on a wide range of different clinical practice settings, in which there may also have been, given the rather vague extant definitions of these interventions, differences in the ways in which they were implemented. Further, the presence of comorbidities, which would be exclusion criteria in randomised controlled trials, may be associated with worse outcomes. All these explanations are somewhat speculative, hence our aim of generating explanations based upon patient experiences, as reported in a detailed online survey.

In 2010, Action for ME conducted an online survey of rehabilitation therapies, which collected demographic information and detailed reports of the experiences of 273 patients who had tried one of three rehabilitation therapies: GET, the functionally-oriented Graded Activity Therapy (GAT), or Exercise on Prescription (EoP). While the sample of respondents was self-selected a purposive sampling approach, used in qualitative research [27] was deployed to confirm that conceptually-relevant and diverse data was collected. Conducting the survey online drew on existing accessible contact channels between Action for ME and its wider networks. The descriptive statistics of survey respondent characteristics and structured responses have been published in the Action for ME membership magazine *InterAction*, and reported online [28]. Results showed that 60% of those citing GET as their most recent form of rehabilitation reported that they felt worse following GET. Of those trying EoP, 52% reported feeling worse after therapy. Only 26% of those trying GAT reported feeling worse, with 39% reporting an improvement. The range of experiences of rehabilitation, and the demographic data (presented in Table 2), confirm that the diversity of characteristics and responses provided by the data sample was adequate for the intended analysis of types of experience. There were numerous free text comments appended to the survey responses, and these have been analysed to shed light on the discrepancy between RCT and patient survey results.

Research aims and objectives

This research aims to build understanding of the reasons for the discrepancy between reports of the effectiveness of GET as reported in surveys and in randomised controlled trials. Explaining these problems should help indicate what factors may have influenced these poor perceptions of therapy and what may be needed to manage these so as to improve patient care.

Method

This report analyses the qualitative data submitted as ‘‘free text’’ in the responses to the 2010 survey of rehabilitation therapies carried out by Action for ME. These sections encouraged the respondents to write about their experiences of the rehabilitation therapies, to build a picture of what was helpful and unhelpful about the therapies. While the principal focus of our enquiry was GET, the opportunity was also taken to review the outcomes of GAT and EoP, since the Action for ME survey had also enquired about these therapeutic approaches.

The data were analysed using thematic analysis [29] by the first author and a volunteer living with CFS/ME. This entailed reading and re-reading the data to develop a sense of emerging topics, starting with simple flexible themes and

Table 2. Treatment type by sex, age group, diagnostic label, decade of onset and outcome.

	Treatment type			
	Exercise on prescription, n(%)	Graded activity therapy, n(%)	Graded exercise therapy, n(%)	All treatments, n(%)
<i>Sex</i>				
Male	0 (0)	2 (14)	12 (25)	14 (18)
Female	13 (100)	12 (86)	37 (76)	62 (82)
<i>Age group</i>				
<30	2 (15)	3 (21)	14 (31)	19 (25)
30 < 40	2 (15)	6 (43)	11 (24)	20 (27)
40 < 50	7 (54)	1 (7)	13 (29)	23 (31)
50+	2 (15)	4 (29)	7 (16)	13 (17)
<i>Diagnostic label^a</i>				
CFS	4 (31)	7 (50)	23 (47)	34 (45)
CFS/ME	0 (0)	1 (7)	7 (14)	8 (11)
ME	9 (69)	6 (43)	18 (37)	33 (43)
PVFS	0 (0)	0 (0)	1 (2)	1 (1)
<i>Decade of onset</i>				
1980s	2 (15)	1 (7)	4 (8)	7 (9)
1990s	3 (23)	2 (14)	9 (18)	14 (18)
2000+	8 (62)	11 (79)	36 (74)	55 (72)
<i>Outcomes (clinical global impression score)</i>				
Very much better	0 (0)	0 (0)	3 (6)	3 (4)
Much better	2 (15)	2 (14)	6 (12)	10 (13)
A little better	2 (15)	1 (7)	5 (10)	8 (11)
No change	2 (15)	8 (57)	7 (14)	17 (22)
A little worse	3 (23)	0 (0)	9 (18)	12 (16)
Much worse	3 (23)	2 (14)	10 (20)	15 (20)
Very much worse	1 (8)	1 (7)	9 (18)	1 (15)

^aCFS, chronic fatigue syndrome; CFS/ME, chronic fatigue syndrome/myalgic encephalomyelitis; ME, myalgic encephalomyelitis; PVFS, post-viral fatigue syndrome.

working definitions. A paper-based method was used to facilitate shared decision-making, with meaning segments of data printed onto squares of paper which could be sorted and re-sorted until a consensus was reached. Themes were then reviewed to ensure the contextual relevance and comprehensiveness of the developed categories. The data extracts were then linked back to each case and organised within these themes in a matrix then reviewed by all authors.

This report focuses on those 76 respondents who started rehabilitation during or after 2008. This date was chosen so that their therapist should have had time to learn about the 2007 NICE Guideline, which provides clear guidance about implementing GET. Respondents had been treated in a range of clinical settings in which there should have been awareness of the NICE Guidelines. The most frequently mentioned location for therapy was the patient’s home, but quite often this was in combination with therapy supervision and/or exercise at other locations including GP surgeries, hospital outpatient departments, physiotherapy departments, hydrotherapy pools, specialist units, gyms and recreation centres.

Results

Respondents’ demographic characteristics, diagnoses, treatment types and outcomes are summarised in Table 2, which indicates the adequacy of the survey approach to purposive data sampling. Though respondents were self-selected, they nonetheless offered a diverse range of characteristics and experiences of treatment to offer insights into relevant reasons for diverse experiences of treatment.

Thirty-five participants reported other medical conditions, while 36 indicated that they did not have any other illnesses.

5 participants did not answer this question. In some cases, the other medical conditions reported could be seen as part of the CFS/ME syndrome or a related or overlapping condition (e.g. mitochondrial dysfunction, migraine, irritable bowel syndrome, chronic rhinitis or sinusitis, orthostatic hypotension, fibromyalgia). However, 12 participants (16%) reported comorbidities that might have been exclusionary factors in randomised controlled trials, including thyroid disease, polycystic ovary syndrome, Raynaud's syndrome, cardiac conditions including atrial septal defect, asthma, dysmenorrhoea, fibroids, cancer, orthopaedic problems including osteoarthritis and torn knee ligaments, and psychiatric conditions which may be consequences or concomitants of CFS/ME, i.e. anxiety and depression.

The qualitative results are presented in two sections, the first reporting on the positive themes in experiences of rehabilitation, and the second on negative themes. Themes are presented and illustrated with extracts from the data set, each linked to descriptors to indicate the respondent's case number, gender, treatment type and age as well as their view of the impact of the therapy as rated using Clinical Global Impression (CGI) scores: very much better (VMB), much better (MB), no change (NC), a little worse (ALW), much worse (MW) and very much worse (VMW).

Positive experiences of rehabilitation therapies

Positive themes here underlined the specific importance of good, supportive communication with a therapist, meeting a specialist, treatment which included routines and goals, experienced benefits of exercise and value attached to controlled activity pacing.

Supportive communication with a therapist

Many comments on assessment and ongoing therapist support affirmed the importance of good communication and a supportive approach, as when one person reported their experience of a:

Very good verbal assessment with useful information provided (Case 30, female GET recipient, age 49, CGI score ALB).

Others highlighted the importance of a therapist who: "Listened and asked me what I wanted to do" (Case 206, female GET recipient, age 47, CGI score MB) and others of "Having someone who understood the illness and believed in it" (Case 25, female GET recipient, age 24, CGI score MB).

Seeing a specialist could therefore be an especially positive experience, as for one woman, "...only person I have seen in 20 years who has a real understanding of this condition" (Case 30, female GET recipient, age 49, CGI score ALB) and for others appreciating staff who were:

...well-informed, supportive and experienced in treating patients with severe ME (Case 253, male GET recipient, age 49, CGI score MB).

An individualised approach was highlighted by some, so that attention could be paid to individual problems such as balance, and so to enable working together to be experienced as having specific meaning for the persons themselves. As one commented "We were able to work together on specific problems" (detected on physical assessment) (Case 30, female GET recipient, age 49, CGI score ALB).

Treatment which included routines and goals

Being encouraged to develop a routine was helpful for some and one person commented on how this gave "Structure to

the day" (Case 242, female GET recipient, age 49, CGI score ALB).

Several related comments suggested the desirability of having a goal to work towards:

Like to have a goal - like to have a challenge (Case 29, female GET recipient, age 50, CGI score ALB).

This was seen by some people as helping define the process as clearly directed at improvement, as one said she "Liked to see progress" (Case 29, female GET recipient, age 50, CGI score ALB) and another commenting on feeling "much happier to be doing something toward better health" (Case 198, female GET recipient, age 73, CGI score MB).

Other exercise-related benefits were seen as additional to any improvements in health which might include social:

Enjoy the company in the ladies gym (Case 198, female GET recipient, age 73, CGI score MB).

Others valued being outdoors in the fresh air and getting away:

Given a regular daily breath of fresh air (Case 242, female GET recipient, age 49, CGI score ALB).

Walking was a great way to get away from it all for a short time (Case 248, male GET recipient, age 45, CGI score VMB).

Being able to move about more was linked to increasing confidence:

More stable around house and confident outside home (Case 242, female GET recipient, age 49, CGI score ALB).

Value attached to baselines and controlled pacing

Some found the baseline setting and pacing involved in rehabilitation to be helpful in setting realistic and manageable targets for activity. As one participant found, it was:

Better to do a little and often (Case 11, female EoP recipient, age 49, CGI score MB).

Others conveyed how this worked for developing a process of rehabilitation:

Told to keep a daily diary with hourly updates of what I was doing (including sleeping/resting) - this was to help measure my mental and physical activities however little. This then gave me a baseline to work from and build on (Case 59, female GET recipient, age 41, CGI score ALB).

Some identified the new skills that they gained in identifying aspects of their activity:

Learning how energy is used, that each task can be split into mental, physical and emotional energy/exertion, and trying to pace it (Case 14, female GAT recipient, age 33, CGI score NC).

Several participants described the sense of specific control of activities that could then be gained:

I was able to see what activities I was doing, and what affected me the most (Case 61, female GET recipient, age 17, CGI score MB).

Negative experiences of rehabilitation therapies

Negative themes in experiences were also identified. Some comments confirmed corresponding effects from an absence of the positive characteristics described above; as with poor communication and support, and feeling pressure to comply with therapy in ways respondents did not feel able to control. Other negative themes highlighted areas of conflict: between patient and therapist beliefs; a sense of being pushed by the therapist; baselines experienced as unsustainable; worsening of symptoms after treatment, leading to short and long term setbacks; and being blamed for treatments not working.

Poor communication and support

Negative comments on the assessment, or ongoing therapist support, were often indicative of poor communication and feelings of being unsupported. Some emphasised how their opinions were not taken into account:

My opinions did not seem to be listened to (Case 66, male GET recipient, age 44, CGI score ALW).

Many described this as not being responded to in context:

The therapist wasn't listening. Just patted out the same old lines (Case 154, female GET recipient, age 50, CGI score MW).

Some experienced miscommunication:

I felt misunderstood and patronised (Case 241, female GET recipient, age 45, CGI Score NC).

Many of these reported trying in vain to convey to therapists their sense that GET was not successful:

Therapist refused to accept my comments that GET was not working for me (Case 66, male GET recipient, age 44, CGI score ALW).

Conflict in beliefs about ME and rehabilitation

A particular difficulty reported by several respondents, centred on therapist-patient differences in beliefs about the nature of their condition and the role of rehabilitation. Some of these conflicts were about a diagnosis of ME versus that of CFS or Post-Viral Fatigue Syndrome, with consequences for the appropriateness of treatment and expertise of therapists needed to provide this. As one respondent reported:

I thought the CFS expert was trained to deal with people with mild fatigue not ME (Case 241, female GET recipient, age 45, CGI score NC).

Others focused on the likely harmful effects of exercise in ME compared with other fatigue-related illnesses:

Any form of exercise is proven to be harmful to patients with true ME (not CFS or PVFS (post-viral fatigue syndrome)) (Case 256, female GET recipient, age 26, CGI score VMW).

Some emphasised their view that ME was largely misunderstood by health professionals:

Negative attitudes from therapists and doctors; they still don't understand ME and I think never will (Case 218, female GET recipient, age 36, CGI score VMW).

One saw this as a lack of therapist interest in gaining the necessary accurate and specific knowledge about ME:

I pointed my therapist to several websites regarding ME research but she showed no interest and dismissed them and continually quoted NICE guidelines (Case 66, male GET recipient, age 44, CGI score ALW).

Pressure to comply with treatment

Several reported feeling unreasonably pressured to comply with the rehabilitation therapy:

I felt bullied into things - even when I was too tired to do things I had to do them (Case 50, female GET recipient, age 36, CGI score NC).

Such pressure might include recording patients' reluctance to comply as a formal refusal of treatment:

If I didn't wish to participate it would be noted on my medical file that I was refusing treatment (Case 259, female GET recipient, age 36, CGI score MW).

A key pressure experienced as problematic was where patients were asked to ignore their symptoms and to continue trying to do more activity than they felt was sensible. This was found especially problematic when people experienced setbacks in treatment, but were given advice to "push through":

Push through it. . . . ignoring how I felt and do more than I could every day (Case 150, female GET recipient, age 30, CGI score VMW).

Others felt that where they had built an understanding of how to successfully self-manage their exercise in relation to their condition, they were still pushed:

They push you to do more without listening to what you are telling them. I have had ME for years; I know where my body is tired! (Case 28, female EoP recipient, age 28, CGI score MB).

Worsening of symptoms

Some people reported how worsening symptoms after each session put them off continuing with the therapy. As one person wrote:

I was increasingly discouraged by the adverse reaction I experienced to the exercise after each session (Case 45, female EoP recipient, age 51, CGI score ALW).

For some, these effects of worsening their symptoms meant they were prevented from doing anything for a long time:

It caused me to be unable to do anything over the days/week following (Case 138, female GET recipient, age 37, CGI score MW).

In some cases feeling worse meant discontinuing therapy:

I felt worse for several days following a session so stopped attending (Case 145, female EoP recipient, age 22, CGI score NC).

For others, the worsening of symptoms meant specifically increased pain which made continuing therapy too difficult, as in stating a reason for stopping therapy as simply:

Too painful (Case 132, female, GET recipient, age 41, CGI score ALW).

Several reported that their trying to persist with rehabilitation led to a worsening of their symptoms in the longer term, perhaps a year or more. One woman described how: “I suffered a major relapse and am now more poorly than I ever was” explaining “Pushing an already worn out body made me relapse” (Case 48, female GET recipient, age 30, CGI score MW).

Such lengthy adverse effects were reported by others as:

“18 months and still not back to pre-GET levels” observing that “I deteriorated progressively while doing the therapy but attempted to continue” (Case 105, female GET recipient, age 32, CGI score VMW).

One person described their deterioration as preventing their doing anything, while actually being expected to increase their exercise levels without their having any control in setting these:

“My condition worsened so much that I couldn’t physically carry out the exercises any more” nonetheless “. . . I had to increase all this every week and was supposed to see therapist every 6 weeks to be monitored and given more exercises to do” and yet “I was told to continue with the session no matter what” (Case 117, female GET recipient, age 25, CGI score VMW).

Baselines experienced as unsustainable

Some respondents clearly did not experience even the baseline levels they had been set as sustainable:

I was advised to push through any difficulties I was having as I had to find my “base line” . . . I was treated like an army cadet on an assault course (Case 165, female GET recipient, age 29, CGI score VMW).

This linked with reports of problems following initial exercise testing:

In order to establish my “baseline” the physio said it would be hard at the start, as we needed to find out how much I could do (Case 164, female GET recipient, age 42, CGI score MW).

Yet, such initial exercise is not required for setting baselines. A recurring theme across reports was the level of exercise being selected by the therapist, and experienced by patients as too difficult.

Feeling blamed for rehabilitation not working

Some found that difficulties arose or were exacerbated in their relationship with the therapist when they reported finding the therapy unhelpful, and the blame was shifted onto them. One person reported that the therapist:

Made me feel like they didn’t believe how unwell it was making me and that it was my fault I wasn’t improving (Case 31, female GET recipient, age 21, CGI score ALW).

Sometimes grounds offered for blaming the patient when they could not comply, were their assumed lack of effort:

I couldn’t do what was asked of me, the therapist said I wasn’t trying (Case 107, male GET recipient, age 56, CGI score ALW).

Another respondent described then even feeling guilty for being physically ill:

it also made me feel guilty about being physically ill, as if it was my fault and that if only I tried harder I could get better (Case 113, male GET recipient, age 46, CGI score MW).

Discussion

This survey is the first to examine factors contributing to reports of negative patient experiences with rehabilitation therapies used to treat CFS/ME. This research has documented and categorised a range of specific positive and negative aspects of rehabilitation, as evidenced by these survey respondents in their own words. The research had several limitations, including its reliance on self-selected volunteering in the first instance, and on retrospective accounts. Nonetheless, the diversity of its respondents’ experiences of types of rehabilitation, identifying positive and negative components and experienced outcomes, offers credibility and contextualised insights into what patients living with the conditions specifically value in their experience of rehabilitation. The data collection directly interrogated experiences of three forms of rehabilitation, conducted in diverse settings, so as to draw out relevant themes. Considered together, the negative themes offer an explanation with face validity for the negative outcomes from rehabilitation reported by previous surveys.

We suggested a number of systematic reasons why respondents to patient surveys may not be entirely comparable to the participants in randomised controlled trials, which may account at least in part for differences in outcomes. Of these suggestions, this study could not determine the extent of survivor bias. There were undoubtedly variations in the content and standard of supervision of therapy, as reflected by the thematic analysis. In addition, the proportion of respondents reporting comorbidities in patient surveys could well have modified outcomes in comparison with RCTs. However, at worst these comorbidities would have made it difficult to make progress with rehabilitation, and a sensitively implemented rehabilitation plan should not result in patients with these comorbidities feeling persistently worse. Of note, no respondents reported that a comorbidity affected their rehabilitation experience.

The thematic analysis of experiences of all three types of rehabilitation highlighted the common ground of both positive and negative experiences. There are no clear guidelines for the implementation of EoP for people with CFS/ME, and the NICE Guideline advice regarding the implementation of GAT is limited. The details of these experiences can however be compared with the more detailed guidance regarding GET in the NICE Guideline [1] which describes GET as:

An evidence-based approach to CFS/ME that involves physical assessment, mutually negotiated goal-setting and education. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person. This is followed by an increase in intensity, when the person is able, taking into account their preferences/objectives, current activity and sleep patterns, setbacks/relapses and emotional factors.

The reported negative experiences of rehabilitation clearly contradict all of these aspects of the NICE description. The survey data indicate two categories of rehabilitation treatment available to respondents: a higher quality, flexible and supportive approach and a lower quality, prescriptive approach.

The Guideline section relating to GET [1] emphasises the healthcare professional's role in establishing the baseline level of the person's daily activities, then agreeing with them:

A level of additional low-intensity exercise that is sustainable, independent of daily fluctuations in symptoms, and does not lead to 'boom and bust' cycles. This may range from sitting up in bed for people with severe CFS/ME, or gentle stretches or a slow walk for those with less severe symptoms.

A number of participants indicated that their lower-quality rehabilitation failed at this important initial stage. The Guideline indicates that the professional's role should move them on to 'encourage them to undertake this exercise for at least 5 days out of 7, or build up to this level if and when possible'. This should include advice that 'this level of exercise may mildly increase symptoms for a few days (for example, a mild to moderate increase in stiffness and fatigue)'. Again, some respondents gave clear indications that they attempted unsuccessfully to communicate their experiencing more than a mild increase in symptoms. The Guideline goes on to suggest that information should be offered on managing setbacks/relapses, including that it may be necessary 'to reduce, or even stop, some activities and increase the frequency and/or duration of rest periods to stabilise symptoms and re-establish a baseline activity level. This should be discussed and agreed with the person with CFS/ME'. In contrast, some participants clearly indicated that they heard advice to continue at an increased level of activity, regardless of their experience of symptoms, which continued to increase.

The negative experiences reported indicate specific ways in which the NICE Guideline recommendations were not being implemented in these clinical encounters. It is important at this stage to recognise the limitations of this form of retrospective research. Each respondent drew upon their memory of their experience of therapy. This means that the data collected in this research will differ from the types of data collected in recording clinical encounters, or by interviewing therapists about what they were intending to communicate. Despite this limitation, the survey findings do provide important and detailed information about what appears to be working well for patients who have tried the therapies, and what may be going wrong, from their perspective. This data collection method provides valuable insight into the 'take-home messages' of patients, which are perhaps especially important products of the clinical encounter for their further self-management. In this context, negative experiences indicate the nature of problems with the implementation of rehabilitation efforts. Taking these experienced problems seriously as knowledge may enhance the care of patients with CFS/ME.

The information collected in this survey may be used to improve clinical care in the future in a number of ways. First, it can inform the training of therapists by highlighting the relevance of NICE guidelines to underpin patient experience of positive treatment. The negative experiences reported within this survey may be contrasted with the general satisfaction reported by patients taking part in the PACE Trial [12]. It is probable that the training and supervision provided to the therapists involved in that trial, together with the manual provided for therapists and patients, helped to minimise the risk of miscommunication about key elements of GET. Enhanced training of clinicians is likely to minimise the risk of future misunderstandings about how to undertake safe rehabilitation. However, it is still also possible

for patients to access rehabilitation advice from settings where clinicians may not have had training in the sensitive approach indicated by the NICE Guideline. It should be noted that a recent NHS specialist service evaluation indicated good levels of satisfaction with overall care [30], and a recent Action for ME survey [31] indicated that levels of satisfaction with overall care within the NHS appear to be higher than those reported specifically for GET.

If the PACE Trial patient manual does provide transparency about the aims and processes of rehabilitation, then the availability of PACE manuals via the Internet [32], accessible to both patients and therapists, should increase the likelihood that exercise-related rehabilitation can be more consistently effective. However, since the NICE Guideline and summary has been available via the Internet since 2007, accessibility alone does not seem sufficient to have greatly reduced the possibility of the kinds of negative clinical encounters described in this survey. Further actions may therefore be required to effectively prevent the negative experiences clearly identified here as associated with poor quality rehabilitation. One example might be to provide a publicly available and internet-signposted list of criteria by which patients undertaking rehabilitation could identify whether they are receiving good quality rehabilitation support.

Undertaking a thematic analysis of a diverse range of patient reports of their experiences of exercise-based rehabilitation for CFS/ME can therefore provide reasons for apparently contradictory negative experiences and outcomes of such treatment for some patients. These highlight the relevance of adherence to the NICE guidelines and the particular importance of clear communication and development of shared treatment goals in the clinical encounter with this group of patients.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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