

1 Acceptance and identity change: an 2 interpretative phenomenological analysis 3 of carers' experiences in 4 ME/chronic fatigue syndrome

5 Abstract

6 Myalgic encephalopathy (ME)/chronic fatigue syndrome (CFS) is a debilitating condition
7 and many people rely heavily on family carers. This study explored the caring
8 experiences of 7 family carers. Four themes were established: relations with others; role
9 and identity changes; coping with change and uncertainty; and information and support
10 seeking. Caring disrupted multiple areas of carers' lives, including their identities and
11 relationships. Skepticism from others about ME/CFS was particularly distressing.
12 Acceptance was important for coping and helped some carers achieve positive growth
13 within spousal relationships. Improving support and advice for carers and acknowledging
14 their caring burden could improve their wellbeing.

15 Introduction

16 Myalgic encephalopathy/chronic fatigue syndrome (ME/CFS) is a chronic condition
17 which can cause profound disability and a high level of functional dependence on family
18 members (National Institute of Health and Care Excellence [NICE], 2007; Williams,
19 Christopher and Jenkinson, 2016). ME/CFS has an unknown aetiology and variable,
20 fluctuating symptoms including fatigue, joint and muscle pain, headaches, sleep
21 disturbances, gastric problems and cognitive problems (NICE, 2007). Uncertainty about
22 its origins, prognosis and duration can cause emotional distress, and people with ME/CFS
23 have lower scores on wellbeing and functional status than people with other chronic
24 diseases, including stroke and cancer (Ax et al., 2002; Dickson et al., 2007; Larun and
25 Malterud, 2007; Nacul et al., 2011).

26
27 People with ME/CFS are usually supported at home by family members who assume the
28 role of carer (Nacul et al., 2011). A 'carer' is someone who looks after a person who, due
29 to illness, disability, a mental health problem or an addiction, cannot cope without their
30 support. 'Informal' is used to differentiate those who provide voluntary care from paid
31 care professionals (Carer's Trust, 2017; Department of Health, 2014). In this study
32 'carer' is used to mean informal family carers as described above.

33
34 Qualitative studies report scepticism from healthcare professionals about the legitimacy
35 of ME/CFS leaving many people feeling stigmatised and unsupported by doctors and
36 others around them (Anderson et al., 2012; Dickson et al., 2007; Drachler et al., 2009).
37 This creates a burden for people greater than their physical symptoms alone (Larun and
38 Malterud, 2007) and increases the importance of support from family carers (Dickson et

1 al., 2007). Carers' understanding and acceptance is an important factor in facilitating
2 coping in people with ME/CFS (Dickson et al., 2007). It has also been suggested that
3 carers' beliefs and levels of distress influence their interactions with the patient, affecting
4 how well patients manage their symptoms (Band et al., 2014).

5 It is important to build on research looking at how ME/CFS affects carers' wellbeing.
6 Chronic illness is known to have negative effects on carers' physical and psychological
7 health (Goldberg and Rickler, 2011). A cross-sectional questionnaire study showed that
8 ME/CFS carers have lower scores in mental and physical health than the general
9 population (Nacul et al., 2011). There is little qualitative research focusing on carers'
10 experiences of ME/CFS. Some studies suggest they may feel isolated and find the lack of
11 understanding from others and uncertainty surrounding diagnosis, illness course and
12 management difficult to cope with (Brooks et al., 2014; Donalek, 2009; Hannon et al.,
13 2012; Harris et al., 2016; Mihelicova et al., 2015). However, one qualitative study
14 involving semi-structured interviews with 17 informal carers reported that carers
15 accepted ME/CFS relatively easily (Ax et al., 2002). This study aims to improve
16 understanding about caring in ME/CFS by looking in depth at the lived experiences of
17 family carers.

18 There is no clear consensus on the most appropriate term to describe this illness or
19 whether ME and CFS are the same or related conditions (NICE, 2018; Sharpe 2002). This
20 study used 'ME/CFS', a compromise term adopted by the English Chief Medical
21 Officer's Working Parties' report that has been used widely in healthcare services in the
22 UK (NICE 2018; Sharpe, 2002).

23 Methods

24 Design

25 This study used a qualitative design with semi-structured interviews. Data were analysed
26 using interpretative phenomenological analysis (IPA; Smith, 2004). IPA has been used
27 successfully to explore attitudes and experiences of ME/CFS patients (Arroll and
28 Howard, 2013; Arroll and Senior, 2008; Dickson et al., 2007). IPA has been described as
29 particularly useful to provide insight into complex, ambiguous and emotionally laden
30 subjects (Osborn and Smith, 1998), making it an appropriate method to explore caring
31 experiences in this stigmatised chronic condition. In IPA, the researcher draws out
32 themes showing the meaning of the phenomenon from participants' perspective, but also
33 reflecting the researcher's own interpretation (Smith, 2004). The approach is
34 phenomenological in the sense that it involves getting as close possible to the
35 participant's personal experience, but it also has a strong theoretical basis in
36 hermeneutics (interpretation) because it acknowledges two levels of interpretation: that
37 is, from both the participant and from the researcher (Smith, Flowers & Larkin, 2009).

38 Procedure

39 The study received ethical approval from the University of Derby Psychology Research
40 Ethics Committee. Participants were recruited by advertising on the UK-based ME

1 Association's and Action for ME's websites. Participants responded to the
2 advertisements by emailing the first author to express their interest. Those who met the
3 inclusion criteria were sent an information sheet, consent form and demographic data
4 sheet. Inclusion criteria were: aged 18 or over; and living with and providing unpaid care
5 and support (for example, emotional and/or practical support) to an adult aged between
6 18 and 65 with a diagnosis of ME/CFS made by a GP or specialist.

7
8 After signed consent forms were received, the first author contacted participants to
9 arrange a one-to-one interview. Interviews were carried out by the first author by phone
10 (n=6) and Skype (n=1), and recorded using a digital voice recorder. An interview
11 schedule was constructed (see Appendix 1), using open-ended questions such as "Could
12 you please tell me about your experience as a caregiver for someone with ME/CFS?"
13 Interviews ranged from 42 to 76 minutes (x = 55.43 minutes) and were transcribed
14 verbatim. Participants were given a pseudonym.

15 Participants and sampling

16 Seven participants (three women and four men) were recruited, all of whom lived in
17 England. Their ages ranged from 34 to 62 (x = 51.9; SD = 9.95). Mean length of caring
18 was 8.5 years (SD = 8.46). Participant characteristics are shown in Table 1. All carers had
19 known the care-recipient since before diagnosis and were a spouse (n=5) or parent (n=2).
20 Carers described care-recipients as being diagnosed with CFS (n=2), CFS/ME (n=2) or
21 ME (n=1) with two carers not specifying. Carers were also asked to state the severity of
22 ME/CFS; this can vary widely so could lead to variations in caring demands. Severity can
23 be classified as mild, moderate or severe depending on the impact on daily life and
24 functioning (NICE, 2007). Where illness severity was not provided, NICE criteria were
25 applied using descriptions of the care-recipient's condition (see Table 1).

26
27 Recruitment stopped after 7 interviews. A sample size of six to eight participants has
28 been suggested as an optimal number in IPA to allow examination of similarities and
29 differences between individuals (Pietkiewicz and Smith, 2014). Data were analysed
30 following the four-stage IPA process described by Smith and colleagues (2009). The first
31 author began by reading through each transcript several times to become familiar with the
32 data. During this process, notes were made on potential themes in each transcript. As
33 each transcript was analysed, the researcher returned to previous transcripts to refine
34 themes in light of new information. Individual themes from all transcripts were recorded
35 in a single table along with illustrative quotes, colour-coded by participant and given line
36 and page number references. When all 7 transcripts had been analysed, the first author
37 sorted and categorised recurrent themes, exploring and defining them in more detail and
38 grouping them into clusters under overall 'superordinate' themes. As well as providing
39 advice and feedback on methodology throughout the project, the second author provided
40 validity by reviewing transcripts against the first and final iterations of the coding table to
41 ensure that themes were representative of the transcripts and, thus the analysis was
42 supported by the data (Osborn and Smith, 1998).

43

1 Reflexivity

2 This paper presents the IPA researcher's lens through which participants' experiences can
3 be viewed. It is therefore important to recognise the researcher's own starting point
4 (Ahern, 1999; Brocki & Wearden, 2006; Smith et al., 2009). The first author has personal
5 experience as a spousal carer in ME/CFS and this undoubtedly affected the research
6 process and coloured her interpretations. She adopted a reflexive approach by taking
7 personal notes during the interview period. For example, in a note after interview 1:

8
9 "I was expecting her to be more angry about how the disease has stolen her normal life.
10 She seemed sad but accepting, although they have not lost hope, but she is prepared for
11 what may happen if he continues to decline."
12

13 This enabled her to shine a light on where participants' reality departed from her own
14 preconceptions, and to see what was there and not what she expected to see. This
15 approach is recommended by Ahern who suggests that it is more productive to try to
16 understand the effects of one's own experiences, than to 'bracket them off' (1999).
17

18 INSERT TABLE 1 HERE

19 Findings

20 Four superordinate themes were established: relations with others; role and identity
21 changes; coping with change and uncertainty; and information and support seeking. Each
22 superordinate theme is described briefly below, followed by more detailed explanation of
23 the specific sub-themes within each superordinate theme. Themes are summarised in
24 Table 2. Quotes were chosen from each transcript that were considered to best illustrate
25 each sub-theme.

26 Relations with others

27 A significant theme among carers was changes in their relations with those around them,
28 particularly friends and family. Social relationships and networks changed over time as
29 social contact became more limited, but also as a result of the social stigma associated
30 with ME/CFS. Two sub-themes were discerned: negative reactions from others and
31 reduced social networks.
32

33 Negative reactions

34 Carers found it difficult to explain the symptoms of ME/CFS to others and were often
35 met with incomprehension or scepticism, which was upsetting:
36

37 I would have to explain it to people and they would say 'Yeah, but you
38 know, if she just got up and did something surely you know, oh you know,
39 her muscles might be bad, but they would be if she sat in bed all day, do

1 you know what I mean? That sort of thing. And that's hurtful to her and
2 me really. (Marcus)

3 People talk about fatigue and I think sometimes there've been occasions in
4 the past where I've had to say to myself, just, just leave it alone because
5 people say, it's just a little bit like 'Oh yeah, I get tired', and it's kind of
6 you kind of go, "Ah okay. Yeah okay". (Liz)

7 It's really horrible, even me, and [I've] got knowledge of it, it's really hard
8 to explain to somebody else what somebody's going through, yeah. So she
9 finds it frustrating and I find it difficult to explain to somebody... (Helen)

10

11 Some carers acknowledged that they could see how people found ME/CFS hard to
12 comprehend, especially because people with ME/CFS do not "look ill". Despite this, they
13 felt upset when this invisibility led to negative reactions and they were upset about
14 having to defend the legitimacy of the illness:

15

16 I'm surprised by the lack of support by my family as well. For a long time
17 my sister thought it was psychological and you know, just... And I
18 thought well you're not living with it. Anybody who thinks that it is
19 should come and live with it, because it's like living with somebody with
20 late-stage terminal cancer. (Christina)

21

22 Christina highlights her surprise that even close family members are sceptical of her
23 daughter's illness. The strong retort she issues to her sister ("well you're not living with
24 it") shows how hurt she is by this. Not only is her daughter's condition in doubt but also
25 therefore Christina's own caring burden is being dismissed and she feels disbelieved and
26 unsupported. Her forthright challenge that people should come and experience it for
27 themselves, and her strong comparison with late-stage cancer emphasise her distress
28 about the gulf between her family members' ignorance and the immense impact of
29 ME/CFS on her life.

30

31 **Reduced social networks**

32 Carers reported receiving some helpful support from friends or family but most found
33 that caring reduced opportunities for social contact. Over time some carers began to
34 withdraw from others. In part this occurred because of restrictions on social activities.
35 For some it was also to protect themselves against dismissal by others:

36

37 In the end sometimes you think I'm not going to tell any more people, I'm
38 going to keep it inside, because what's the point, nobody has got a clue
39 about what this means to our lives. (Christina)

40 We've, I suppose we went into our own little shell as a family unit, the
41 two of us and it's meant that we've not done a lot of stuff socially.
42 (Marcus)

1 So I just let them kind of get on with it, cos there's no point really. Um
2 yeah but I think people don't quite, I think that's the problem it's, people
3 don't quite understand, um, what a difficult disease it is. (Liz)

4
5 Both Liz and Christina describe how "pointless" it feels to try and make people
6 understand. There is a strong sense of how isolating this has been, and it makes them
7 withdraw rather than risk further negative experiences. Christina is not fully resigned to
8 this however; later in the interview she says she has changed tack and has started trying
9 to educate people ("I try and tell 2 people a week who've got no idea about it"). So,
10 despite her anger and sense of betrayal at being doubted in the past she is compelled to
11 keep fighting for understanding.

12
13 Thus, the perceived social stigma of ME/CFS distresses carers as well as patients and
14 contributes to social withdrawal. Carers are the care-recipient's main source of social and
15 emotional support and yet they are receiving reduced support themselves, leading to
16 emotional vulnerability and isolation.

17 Role and identity changes

18 The theme of changing roles and identities was significant. As their caring
19 responsibilities increased, many aspects of carers' previous familiar lives gave way to
20 accommodate their caring role. This was seen as two related sub-themes: changes in how
21 carers saw themselves as a result of their shifting roles and the relational impact of
22 caring.

23

24 Carers' shifting roles

25 Carers experienced role changes within relationships or families. Most took over a larger
26 proportion of household responsibilities, often alongside work or other caring
27 responsibilities. Carers saw themselves in new ways as they took on new responsibilities
28 or lost roles that had been important to them. Scott explained how taking on the bulk of
29 parental responsibility made him feel "like a single father", while John was obliged to
30 take over house repairs, something his wife had always been good at and which he
31 "hates". Scott used a social comparison to show how his wife's ME/CFS has changed his
32 life beyond recognition:

33 I look at friends and colleagues around the office, and what they're doing,
34 they've got a totally different life to what I've got. (Scott)

35 Caring had changed what was possible for carers in their lives, both now and in the
36 future. Christina gave up a newly launched career as an artist to focus full time on caring,
37 while Marcus had always assumed he would be a father one day but has accepted this
38 won't happen:

39 I always assumed I would have children, you know, I love being an uncle
40 and that's a great source of joy for me, you know, having nieces and
41 nephews that I could spoil. But, you know, I never really had the choice to
42 have children ... um... I think that's been a difficult thing. (Marcus)

1 Parental carers were surprised at finding themselves back in a caring role for their adult
2 children. For Christina this meant treading a fine line between providing care and
3 respecting her daughter's independence:
4

5 You can't decide for her because you've got to let her decide, so we talk
6 about things in a group. As a family, because we can't revert her back to
7 being that child, because she's not, she's an adult and she's a person in her
8 own right, but she's dependent on us, which really, really upsets her.
9 (Christina)

10
11 Not all carers were content to see themselves as a carer. Liz preferred to view her and her
12 husband as equal partners, "you know, we're still husband and wife". However, as her
13 husband's dependence increased, she was beginning to recognise a shift in her
14 perspective on this in which she was taking on a carer identity, "I know that our
15 relationship is not... it's different to how it used to be". She described how she
16 increasingly needed to spend time "with other people who aren't ill", suggesting that she
17 was seeking social support to help her cope with her shifting identity.
18

19 Thus, the life restrictions and challenges of caring can lead carers to question their own
20 identity and feel that they have lost important aspects of themselves in the process of
21 caring.
22

23 Relational impact

24 Carers reported ways in which they perceived the care-recipient's identity had changed.
25 Many described a sense of grief or loss of the person they had loved before ME/CFS. Liz
26 used a powerful metaphor to illustrate this, when she described her husband
27 "disappearing" into his ME/CFS. Andrew described adapting to the loss of previous
28 routines with "the old Samantha":
29

30 It will be... at a weekend, we're getting past that, but it was that feeling
31 obliged that she still needed to be the old Samantha because it was the
32 weekend and I was at home and we were together and it's like 'well, you
33 know, you can't be...' and I'm learning to understand that because I'm
34 learning more about it. (Andrew)

35
36 Parental carers grieved over their child's previous identity as well as the life their child
37 could be leading. Christina uses repetition to emphasise her heartbreak over wasted years
38 of her daughter's life:
39

40 You've got a beautiful person that you gave life to who is just wasting
41 away here, in isolation, and it breaks your heart, it breaks your heart.
42 (Christina)
43

1 Spousal carers also described sadness that activities previously enjoyed as a couple had
2 been lost. For some this challenged how they viewed their relationship:
3

4 The woman I married was very active. And we were both very active. We
5 did a lot of walking, we did a lot of, um, well we were both Scout leaders,
6 we did a lot of camps and things like that as well, and something like,
7 everything that we used to do together that was us, has changed and gone.
8 (Scott)

9
10 In saying “the woman I married” Scott showed that he no longer saw his wife as the same
11 person she was. He also recognised that the activities they enjoyed together were a
12 central part of their identity as a couple (“that was us”) and losing these has changed the
13 identity of their marriage.
14

15 Overall, carers lost aspects of their shared lives to ME/CFS, and had to adjust to the loss
16 of the person they knew before the illness. Spousal carers were also forced to re-evaluate
17 relationships.
18

19 Coping with change and uncertainty

20 A common experience was adapting to the uncertainties of ME/CFS. Although most
21 carers held hopes of improvement in the future, they had also learned to set themselves
22 realistic expectations that kept these hopes in check. Key coping strategies were
23 acceptance and problem-solving and these were explored as separate sub-themes.
24

25 Acceptance

26 Carers believed it was important to accept their day to day caring and were in various
27 stages of acceptance, which appeared to involve acknowledging their situation, finding
28 new routines and setting realistic expectations. Some carers could even identify positives
29 of ME/CFS, for example spending more time together. Some spousal carers felt their
30 relationships were still rewarding, or even stronger than before, and viewed caring as a
31 chance to show their love and commitment:

32 And okay it’s not been a good time, so I do it because I love her, I want...
33 you know, I want to support her, you know, etc, so I don’t feel any sort of
34 resentment or anything like that. (Andrew)

35 I know people that it’s happened completely the opposite – that the caring
36 partner has not been able to cope with it and they’ve split up you know,
37 after a year or so. But that didn’t happen with us – I mean exactly the
38 opposite to us, it’s brought us really close together. (Marcus)

39
40 Acceptance was easier for some carers than others. Andrew acknowledged that his wife’s
41 ME/CFS has been “not that detrimental” to him since the limitations on their lives were
42 relatively minor. In contrast, Christina, who provides extensive full-time care for her

1 daughter, described having gradually reached a state of “numbness” about her caring
2 situation, as though reacting to a shock or bereavement. Scott also described a high carer
3 burden. He felt frustrated about juggling full-time work, caring and raising their children
4 and this sometimes caused friction with his wife. He described how he had accepted the
5 situation but it appears to be out of resignation and a sense of duty. He feels he must
6 accept it to keep their family together:
7

8 I think the biggest thing for me is I’ve accepted it, I think I could’ve quite
9 easily said this isn’t for me and walked off, and gone, and then it would
10 have been a different situation. (Scott)

11 To manage his uncertainty Scott redefines his idea of “normal” in response to changes in
12 his wife’s condition:
13

14 I’d hope she’d get more energy, does that make sense, and improve
15 further. But I can’t see it improving anymore. This is the new
16 benchmark... Yeah, and at some point she’ll get worse again, potentially,
17 and then we’ll re-establish a new normal. (Scott)

18 Scott appears to hope that his wife will improve, but immediately contradicts this by
19 stating that he doesn’t see how that will happen, suggesting conflict between his hopes
20 and his expectations. He seems to feel he cannot allow himself to hope for a positive
21 outcome that he fears will not happen. He reported how a recent improvement in his
22 wife’s symptoms was reflected in his own wellbeing: “I’ve started to, as she’s got better,
23 I’ve got better”. This suggests that Scott does not feel in control of his own wellbeing.
24 His emotional state is closely tied to his wife’s health, making him vulnerable to further
25 distress if his wife’s health worsens.
26
27

28 Those carers who reported a greater sense of acceptance did not perceive it as permanent.
29 There was a fine line between day to day acceptance and keeping up hope:

30 Not that we’ve ever accepted it that this was going to be it forever... but,
31 but I think we are both resigned to some extent that that a cure’s not going
32 to be found for this. (Marcus)

33 There might be a potential cure on the horizon in the future but if not, I
34 generally think that my caring role will extend really. Erm... cos you
35 don’t just get better from it. (John)

36 Acceptance was therefore important in helping carers cope with everyday life and with
37 the possibility of short-term fluctuations in the care-recipient’s symptoms. It was viewed
38 as a temporary coping strategy because carers did not want to give up hope. For some
39 spousal carers it also allowed them to see positives in their situation. There was not a
40 clear relationship between length of caring time and acceptance; instead it appeared that
41 acceptance was more difficult the greater the impact on carers’ lives.
42
43

1 Problem-solving coping

2 Most carers employed problem-solving coping to address specific tasks or improve their
3 day to day lives. One carer described plans to move to a bungalow to allow him and his
4 wife to share a bedroom again for the first time in over 10 years, which was an important
5 personal goal. Carers also made activities, socialising and holidays possible by building
6 in resting time before and afterwards:
7

8 You have to plan out things, um, so that she can try and cope with, you
9 know, maybe having a friend round, um, for a short time then she has to
10 rest up even more beforehand and rest up afterwards. (Helen)

11 Careful planning and organisation also meant carers didn't have to lose out on
12 activities that were important to them. For Liz this amounted to a form of self-
13 care that allowed her to protect herself from the disappointment of cancelling
14 activities:

15 I think you know, going back to this self-care, I think what I need to do
16 more of is make sure we plan things but there's I suppose, have things that
17 have got more flexibility in them. (Liz)

18 Using a problem-solving style of coping therefore helped carers to live day to day
19 with the unpredictability of symptoms and also to achieve some of the things that
20 were important to them, while helping the care-recipient to live as normal a life as
21 possible.

22 Information and support seeking

23 Carers felt a strong need for support and information about ME/CFS. This was explored
24 under two related themes: the perceived lack of formal support from healthcare services,
25 and seeking support and information online.
26

27 Lack of professional support

28 Most carers were frustrated by a perceived lack of professional knowledge and support.
29 Although some carers reported that doctors had been helpful, they had all encountered
30 ignorance and scepticism about ME/CFS. It was common to see general practitioners
31 (GPs) and other health professionals who they felt knew less about ME/CFS than they
32 did:
33

34 Some of the occupational health nurses were, "oh you know, you've just
35 got to... you've got to beat it out yourself..." and it's like, "really?"
36 (Andrew)

37 Even back then, we were aware that we felt that we knew more about the
38 disease than the doctor did. (Liz)

39 There's no... as I said, you're just left at home, dealing with it, cos there's
40 nowhere out there to help her. She's just got to get on with it really.
41 (Helen)

1 In this extract, Helen appears bewildered that they had found themselves facing the
2 illness alone. She conveys her sense of abandonment when she says “left at home”, as
3 though they have been forgotten by healthcare services. Marcus echoed this by saying
4 they had been “let down badly by the medical profession”.

5
6 Carers reported some positive experiences using specialist services. Three carers reported
7 that specialist ME/CFS clinics had provided positive support and helped the care-
8 recipient cope with symptoms. However, travelling to clinics that were not local was
9 difficult and impractical for some:

10
11 He decided not to go because it was more for somebody if you’re not
12 coping very well with the disease, um, and the problem is he would have
13 to travel to go there so it wasn’t that local, so we kind of weighed up the
14 benefits of going. (Liz)

15
16 Carers voiced a need for specific formal support for ME/CFS carers, as many had been
17 unable to find anything useful. Andrew reported that information for carers from their
18 specialist ME/CFS clinic was too broad as it tried to cover the whole spectrum of severity
19 of ME/CFS. Scott described his need for both practical and emotional support. He
20 recognised that he was struggling with his own mental health but did not know who to
21 ask after an initial visit to his GP did not help (“I pretty much got told, ‘why are you
22 coming to me?’”).

23 24 Online ME/CFS community

25 Almost all carers used online ME/CFS forums to find out more about ME/CFS and how
26 others manage it. They read information online in the hope of learning about effective
27 treatments or cures. In the absence of definite answers from healthcare services they used
28 the experiences and opinions of others to help with their own sense-making about
29 ME/CFS. Online self-education and information seeking was consistently described as an
30 important basis for hope:

31
32 When you use some of these forums and do things, that there are people
33 that do get better, you know, everybody’s different. (Helen)

34 I follow stuff on the ME Association because again, and as part of what
35 we’re talking about, there is very little for carers, but I want to try and
36 understand, obviously, what Samantha’s going through, what some of the
37 difficulties are that she potentially could experience. (Andrew)

38 Carers found it comforting to ask questions and share experiences with the online ME
39 community, which helped them feel they were not alone in dealing with the difficulties of
40 the condition. Although some carers reported that care-recipients used face to face
41 support groups carers themselves did not – these were not convenient for those carers
42 who were working. Some carers felt there was a need for specific online support groups
43 for ME/CFS carers and a couple of carers were thinking of setting up their own informal
44 online support groups locally.

1
2 Thus, carers searched for their own information and support when they felt professional
3 help and advice was lacking. Sharing experiences online provided a coping resource and
4 social support for carers isolated by the social stigma of ME/CFS who find it difficult to
5 attend support groups in person.

6 Discussion

7 This study explored the lived experience of caring in ME/CFS and found that the caring
8 role disrupted multiple areas of carers' lives, including their identities and relationships,
9 and had a negative impact on most carers' quality of life. Significant emotional distress
10 was caused by others questioning the legitimacy of the condition. ME/CFS is a contested
11 illness, and even after NICE published practice guidelines on its treatment and
12 management there has remained scepticism among some healthcare professionals that it
13 is a distinct condition (Broughton et al, 2017; Horton, 2010). The distress experienced by
14 people with ME/CFS when the legitimacy of their illness is questioned has been well
15 reported (Anderson, et al, 2012; Dickson et al., 2007; Drachler et al., 2009) but this study
16 found that carers also experience this distress acutely. In this study, carers had the double
17 burden of supporting their loved one through a debilitating illness while being forced to
18 defend its legitimacy to others, including GPs, employers, work colleagues, friends and
19 family. The stigmatisation of ME/CFS could therefore be a significant contributor to the
20 higher levels of distress and poorer wellbeing reported in ME/CFS carers compared with
21 carers in other chronic conditions and the general population (Harris et al., 2016; Nacul et
22 al., 2011).

23
24 Carer identity is another key theme that has not been well explored in the ME/CFS
25 literature, which has explored identity change primarily from patients' perspectives
26 (Anderson et al., 2012; Dickson et al., 2007; Larun and Malterud, 2007). Many carers
27 struggled to adjust to shifting roles within their households or other areas of their lives. In
28 particular, those carers reporting the highest care burdens seemed to struggle to recognise
29 their own lives. Difficulties in adapting to shifting roles was also reported by Mihelicova
30 et al. (2015) who reported that parents of children with severe ME/CFS struggled to
31 reconcile an identity transformation from a parental role to a multifaceted role as carer,
32 educator and advocate (Mihelicova et al., 2015). Carers in cancer and COPD have also
33 reported a loss of self-identity, leading to a sense of isolation that increased their
34 emotional burden (Simpson et al., 2010; Ugalde et al., 2012). Identity change may be a
35 contributing factor to the isolation reported by some carers in this study, and this is likely
36 to be compounded by the reduced social support reported by carers. Future longitudinal
37 studies with a focus on how identity change affects ME/CFS carers' wellbeing could help
38 to inform carer interventions.

39
40 Acceptance was a central theme because it was seen by all carers as important for day to
41 day coping. Acceptance is described as an 'adaptive' emotion-focused coping strategy
42 because it is effective at minimising a stressor (Lazarus and Folkman, 1987). Effective
43 coping is thought to involve both problem-focused and emotion-focused strategies
44 (Lazarus and Folkman, 1987) but active problem-solving is often associated with better

1 psychological outcomes than avoidant coping (Ogden, 2012). Williams et al. (2014)
2 noted that acceptance enabled carers to take proactive approaches to caring demands;
3 therefore, acceptance may facilitate problem-solving coping. It has been suggested that
4 carers adopt acceptance when they perceive that they cannot improve the situation but
5 want to move on rather than dwell on losses (Ax et al., 2002; Williams et al., 2014). In
6 line with this, many carers reported a resigned sense of acceptance; however, all carers
7 had also adopted an active problem-solving approach to help them achieve things that
8 were important to them or to the care-recipient, and were strongly motivated to explore
9 new information or potential treatments in ME/CFS to improve their current situation.

10
11 There was no clear relationship between length of caring time and acceptance. Ax et al's
12 longitudinal study reported that carers reached acceptance over time, but the authors
13 reported that carers had adjusted to ME/CFS relatively easily. This may have been in part
14 because care-recipients were not severely disabled, and the authors postulated that
15 acceptance was easier when caring had less impact on carers' lives. In this study too, the
16 carers who described difficulties in accepting ME/CFS and showed the most severe
17 distress were those with the highest perceived caring burden or whose care-recipient had
18 disabling or deteriorating symptoms. For example, Liz was struggling to adjust to a more
19 intensive 'carer' role as her husband's symptoms worsened, while Scott felt overwhelmed
20 by working full time, raising a young family and caring for his wife.

21
22 It was clear in these findings that caring affected spousal relationships. Relational identity
23 conflict has been reported as distressing for spousal carers in COPD, fibromyalgia and
24 multiple sclerosis (Simpson et al., 2010; Soderberg et al., 2003; Topcu et al., 2016).
25 Horrocks and Ward (2015) observed that ME/CFS causes role changes in both partners
26 and forces a realignment of relationships. In some studies role changes have strained
27 relationships and resulted in a loss of intimacy. In this study, shifting roles within the
28 household caused tensions between couples. Some had found new ways of being together
29 despite ME/CFS and appeared to still find their relationships rewarding and
30 mutually supportive. Accepting changes to their relationship helped them to still look
31 forward to their future together. However, others were struggling to navigate changes to
32 their relationship, with some carers finding it difficult to manage a dual role as both
33 'spouse' and 'carer'. It is important in IPA research to explore ways in which
34 participants' experiences both converge and diverge within themes (Smith, 2011) and it
35 seemed that carers were at different stages in relation to acceptance. Acceptance has been
36 described as a long and difficult journey for ME/CFS patients, but it makes life easier
37 once reached (Edwards, Thompson and Blair, 2007). Part of this involves 'letting go' of
38 old identities and accepting new selves (Arroll and Howard, 2013; Dickson et al., 2008).
39 It's possible that a similar process of letting go is just as important for carers and spousal
40 relationships. In light of this, it would be helpful to investigate further in future how
41 carers experience acceptance and positive relational growth to more effectively support
42 couples living with ME/CFS.

43
44 Carers were not asked explicitly about their quality of life because this was not a
45 specified aim of the study, but several acknowledged concerns about their mental or
46 physical health and may have had reduced quality of life across emotional and social

1 domains. This would be a useful topic to focus on in future qualitative studies. A recent
2 study proposed a conceptual quality of life model for carers in multiple sclerosis, based
3 on themes drawn from a qualitative meta-synthesis (Topcu et al., 2016). Carers' coping
4 resources, motivations for caring and support experiences mediated effects from
5 'stressors' of caring and determined carers' quality of life. Future research could apply a
6 similar model to investigate factors influencing ME/CFS carers' quality of life; future
7 qualitative studies focusing on quality of life would inform this.

8 Implications for practice

9 Carers had unmet needs for emotional, psychological and practical support. Although
10 carers' needs have been pinpointed as a public health concern (Department of Health,
11 2014), this study suggests the delegitimisation surrounding ME/CFS is a particular source
12 of distress for carers and means they have a more acute need for validation than carers of
13 people with more visible health conditions. Recognising both the important role that
14 carers play in providing informal care for loved ones with ME/CFS, and the demands
15 they face in this role, could help to validate their caring burden and improve their
16 wellbeing.

17
18 Although NICE emphasises the role of primary care in supporting people with ME/CFS
19 and their carers, some carers who felt they were not coping well did not know where to
20 turn for help, especially as their GPs were not always helpful. It has also been reported
21 that many GPs do not record ME/CFS carers on carers' registers (Hannon et al, 2012).
22 GPs have reported struggling to define their role in managing ME/CFS and believe the
23 condition should be managed by specialist services (Bayliss et al., 2016; Chew-Graham
24 et al., 2010). Although specialist care has an important and beneficial role in treatment
25 and support, people with ME/CFS have reported barriers to accessing specialist clinics
26 (Broughton et al., 2017) and this was echoed by carers in this study. Good quality
27 information and support in primary care could play a key role in dispelling social stigma
28 and providing empathy and legitimacy to both patients and carers (Broughton et al.,
29 2017). It is therefore important for GPs and other primary care staff to identify ME/CFS
30 carers, assess their needs and give them good information, support and advice, including
31 offering referral to other services if needed, such as mental health and social services. All
32 carers have a legal right to an assessment of their own support needs under the Care Act
33 2014, although pressure on social care budgets has meant long waits for assessments and
34 many carers not receiving enough support, particularly respite breaks (Carers UK, 2018).

35
36 Carers would also benefit from education and training designed specifically for them,
37 which includes accurate information about the condition and strategies to tackle social
38 stigma. This could include advice and training on explaining the condition to families and
39 friends and how to target misconceptions, such as that ME/CFS is psychological in
40 origin, or can be overcome through exercise. Wherever practical, information aimed at
41 ME/CFS carers needs to be targeted to different illness severities so that carers recognise
42 it as meeting their needs. Other potentially useful interventions could be coping skills
43 training, or peer support programmes, in which carers receive mentoring and support
44 from more experienced ME/CFS carers, which have proved helpful to dementia carers

1 (Greenwood et al., 2013). Carers in this study preferred seeking information and support
2 online, so online interventions might prove most helpful to ME/CFS carers.
3

4 Limitations

5 One possible limitation was that carers self-selected and were recruited online,
6 introducing bias towards carers who seek information and support online. Acceptance of
7 the carer role and identity were relatively high – perhaps because participants responded
8 to an advertisement for ‘carers’; this was partially offset by some carers being alerted to
9 the advertisement by care-recipients. It has also been suggested that recruiting via support
10 groups may introduce bias towards carers who have adjusted to ME/CFS, compared with
11 recruiting carers of newly diagnosed patients, for example from specialist clinics (Harris
12 et al., 2016). The format of data collection could also have held limitations. In conducting
13 interviews by telephone or skype rather than face to face, the first author could have
14 missed visual cues that might have assisted interpretation of meaning or emotions.
15 However, although bias against telephone interviewing has been reported in qualitative
16 research there is little formal evidence to suggest data collected by telephone is less rich
17 in quality than from face-to-face interviews (Novick, 2008). As well as being more
18 convenient for carers, it may also have allowed them to talk more freely in a less
19 confrontational format.
20

21 While this study has added to the knowledge base about caring experiences in ME/CFS,
22 caution is recommended in generalising the findings of IPA studies, in which the core
23 purpose is to explore individual experiences (Smith, Flowers and Larkin, 2009).
24 Recruiting a more homogenous sample would have allowed more in-depth analysis of a
25 particular subgroup but time constraints during recruitment led to heterogeneity within
26 the sample in the length of caring time, relationship to the care-recipient and severity of
27 symptoms. Focusing on spousal or parental carers; carers of people with severe ME/CFS;
28 or either long-term or more recent carers in future studies could enable more specific
29 conclusions to be drawn. Another potentially useful line of research would be exploring
30 gender differences in caring since it has been reported that male and female carers
31 experience the role differently (Sugiura, Ito, Kutsumi and Mikami, 2009).

32 Conclusion

33 This study extends our understanding of caring experiences in ME/CFS and emphasises
34 the importance of improving support and education for carers, tailored to illness severity.
35 Caring for a loved one with ME/CFS can be distressing and disruptive, particularly when
36 symptoms are severe and the perceived caring burden is high. Accepting their caring role
37 and the new identities emerging from it seems to be an important coping mechanism for
38 carers. In-depth focus on this in future would help to inform interventions to help carers
39 manage their care burden and improve their wellbeing. GPs need to recognise the crucial
40 role that carers have in ME/CFS and address their health and support needs.
41

1 **Table 1. Participant characteristics**

2

Pseudonym	Relationship to person with ME/CFS	Age of carer	Years of care	Employment status of carer	Diagnosis and illness severity of care-recipient
Liz	Wife	43	10	Part time	CFS Moderate
Marcus	Husband	54	25	Part time	Diagnosis not specified Moderate to severe*
Andrew	Husband	53	6 months	Full time	CFS Mild to moderate*
Helen	Mother	58	1	Not working	CFS/ME Moderate
Christina	Mother	62	4	Retired	ME Moderate to severe
Scott	Husband	34	7	Full time	CFS/ME Moderate*
John	Husband	59	12 years	Retired	Diagnosis not specified Moderate

* Information not supplied by carer but estimated by applying NICE criteria to carer descriptions

3

1
2

3 **Table 2. Brief definitions of themes**

Superordinate theme	Subtheme	Theme description
Relations with others	Negative reactions	Carers were distressed by misunderstanding and scepticism from family and friends about ME/CFS. Carers found it hard to explain its effects to people and felt forced to defend its legitimacy as a physical illness, which invalidated their caring burden.
	Reduced social networks	Carers received limited social support because social contact was more restricted than before and carers felt isolated when their caring burden was dismissed. Some carers reacted by withdrawing into their family units to protect themselves from negative reactions.
Role and identity changes	Carers' shifting roles	Carers experienced confusion about their identity when they took on new roles and responsibilities and lost previous roles or identities that were important to them.
	Relational impact	ME/CFS changed the care-recipient's identity and carers experienced this change as a form of bereavement; identity changes had a relational impact on couples because they could no longer enjoy shared activities or relate to each other in the same way; parental carers mourned the perceived loss of their child's future.
Coping with change and uncertainty	Acceptance	Carers believed acceptance was an important coping strategy and it allowed some carers to adapt to the uncertainty of their situation and even to find some positive aspects; acceptance was easier for carers with lower perceived caring burden. Day to day acceptance was counter-balanced by maintaining hope for the future.

	Problem-solving coping	Carers used active problem-solving to deal with specific challenges and improve their quality of life, for example, making holidays or social visits possible by building in flexibility to plans, making lifestyle changes to address symptoms or to make the caring burden easier.
Information and support seeking	Lack of professional support	Carers had encountered healthcare professionals who were sceptical or ill-informed about ME/CFS. Specialist ME/CFS clinics had helped some care-recipients with coping and symptom management but did not offer tailored, useful information for carers and were not always easy to access.
	Online ME/CFS community	Carers sought information and support from the ME/CFS community by researching and sharing experiences with others in online ME/CFS forums. Information-seeking helped carers maintain hope and provided social support.

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5 Declaration of conflicting interests

6 The authors declare that there is no conflict of interest.

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24

25 Appendix 1. Interview schedule

- 26 1. Could you please tell me about your experience as a caregiver for someone with
27 ME/CFS?
- 28 2. Please explain what support you give to your family member.
- 29 3. Please explain how your family member's ME/CFS has affected you.
- 30 4. Could you please explain what effects ME/CFS has had on your family life together?

- 1 5. Please explain how you manage with day-to-day changes in your family member's
2 condition?
- 3 6. Could you please explain how people outside your family have reacted to your family
4 member's illness?
- 5 7. Could you please explain how your experiences as a caregiver have changed over time
6 since your family member was diagnosed?
- 7 8. Please explain how you feel your experiences as a caregiver might change in the
8 future?
- 9 9. What advice would you give now to someone who has just become a caregiver for a
10 person with ME/CFS?
- 11 10. What support or information, if any, have you received from professionals to help
12 you understand your family member's illness, and has this been helpful?
- 13