



Successful Psychological Strategies of Experienced Chronic Fatigue Patients: A Qualitative Study

Journal of Patient Experience
Volume 8: 1-7
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DOI: 10.1177/23743735211034962
journals.sagepub.com/home/jpx


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Abstract

Trying to care for patients with medically unexplained symptoms (MUS) can lead to frustration and disappointment for both patients and health care professionals alike. Learning positive ways to assist patients avoids professionals collapsing into therapeutic nihilism. We sought to understand how people with such symptoms can live well despite (or even because of) their condition. Chronic fatigue was chosen as the exemplar symptom. Participants were invited to join the research if they, themselves, considered they were living well with this symptom. One-on-one interviews using an appreciative enquiry approach were performed and thematic analysis undertaken. Twelve participants were interviewed before data saturation occurred. The emotional stance or relationship a participant had with, and towards, their illness was the primary determinant underlying their interpretation of “living well.” Five major themes of this meta-theme were identified: (1) engaging with elusiveness, (2) befriending uncertainty, (3) reflecting on self, (4) living creatively, and (5) moving in stillness. Encouraging patients who are struggling with MUS to consider how they emotionally engage with their illness via these 5 positive dynamics may lead to better health outcomes for patients and happier, more fulfilled health care professionals.

Keywords

challenges, chronic fatigue syndrome, clinician–patient relationship, long-term care, patient/relationship-centered skills, patient engagement, patient perspectives/narratives, qualitative methods

Introduction

Living with an invisible, profoundly disabling health condition that is not well articulated in the medical literature can be very difficult (1–6). Medically unexplained symptoms (MUS) are defined as “conditions where the patient complains of physical symptoms that cause excessive worry or discomfort or lead the patient to seek treatment, but for which no adequate organ pathology can be found” (7). For health care professionals, looking after people with these conditions can be difficult, frustrating, and sometimes provoking intense antipathy (7–10). Medically unexplained symptoms are often linked to “contested diagnoses” (11), involving uncertain etiology, limited medical research, and limited treatment options, including chronic fatigue, chronic pain, fibromyalgia, irritable bowel syndrome, and pseudo-seizures (12).

Consultations can fruitlessly cycle between the patient seeking a biological cause and the health care professional

seeking a wider biopsychosocial or psychological explanation (13). Excessive specialist referrals and investigations can occur (8–9). Frustrated patients can disengage with established medicine and/or try alternative therapies (14,15). They can become marginalized and isolated in society, feeling delegitimized, self-doubting, and suffering a loss of self-identity (16–18). Further difficulties occur when these health care providers are also gatekeepers to accessing specialist review and external financial supports, forcing

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reengagement onto patients and practitioners and resulting in further unhappy consultations for both (15).

Research can feed into a negative perception of MUS by focusing on the difficulties (19,20). This article aims to study these issues from a different perspective, utilizing the expertise of patients who are living successfully despite, or even perhaps because of, their illness. Investigating these patients' expertise from this perspective aligns with both Carel's concept of "health within illness" (21) and O'Riordan et al stating "the doctor is the expert on the disease but the patient is the expert on their own illness" (22). The hypothesis is that an in-depth analysis will help understand the reasons for their successes and yield insights into how to improve care for those struggling with similar conditions.

We chose to study patients living with undiagnosed chronic fatigue as our exemplar study group, fatigue being one example of MUS. When there is no clear diagnosis, patients may then be diagnosed as having chronic fatigue syndrome/myalgic encephalitis (CFS/ME), defined as "disabling, unexplained fatigue that is not alleviated by rest and lasts for at least four months" (23). Although there is increasing evidence for a biological basis for this syndrome (24), this is still a contested diagnosis with no definitive diagnostic test, and many health care providers are uncertain of its veracity and treatment (25,26). This group was also chosen because a well-developed patient self-support network could facilitate the recruitment of participants. We considered that the nature of the challenges of having chronic fatigue (with or without a formal diagnosis of CFS/ME) was sufficiently generalizable such that meaningful information could be gleaned to help people suffering from other types of MUS, as well as this particular symptom, in that it was invisible to others, fluctuating in its course and severity and had no definitive diagnostic test or treatment available.

Methods

Qualitative research was performed using a thematic analysis (27) based on open-ended interviews with people who considered themselves successfully living with CFS/ME. Coresearchers with different academic backgrounds increase the validity of qualitative research (15), and our team encompassed skills and expertise in general practice, decision-making, bioethics, phenomenology, medical anthropology, and medical sociology.

The interview structure was based on an "appreciative inquiry" approach. This has its roots in action research, an approach that acknowledges the symbolic nature of the human world (28). Appreciative inquiry was initially developed to complement problem-oriented approaches that had become common in "traditional" action research projects. Liebling et al observed that "whether intentional or not, mechanistic causal investigations... have inevitably led to a research style that is problem- or deficiency-focused... [where] the object of research has been to locate the problem, analyse it, and suggest a solution" (29). A problem-

oriented approach is hindered from generating a holistic understanding because it is less adept at elucidating what is already working. Appreciative inquiry seeks to redress this imbalance by grounding the inquiry into the "best of what is" within the situation that is being explored. Its mode establishes a particular interviewer-interviewee dynamic that "takes research participants seriously as people in their own subjectivity" (30). The empathetic nature of appreciative inquiry is valuable in exploring an area historically characterized by tense, stressful clinician-patient relationships, and clinical encounters. Also, relating one's story has a proven therapeutic value in and of itself (17).

Formal ethics approval was obtained from the University of Otago Human ethics committee (approval number 17/035) and the Ngāi Tahu research consultation committee. Fully informed, written consent was obtained from participants prior to the commencement of the interview, and no incentive was offered to participants for taking part in the project. Formal inclusion criteria were as follows: participants 18 years or older, living currently with chronic fatigue for a minimum of 2 years, and considered themselves to be living well with this symptom. An additional exclusion criterion was that the participant could not be, or have been, a patient of the researchers. Convenience sampling and initial recruitment occurred by advertising via general practices, community newspapers, and the local CFS/ME society. Multiple recruitment sources were necessary to try to reach possible participants who may have disengaged from general practices and to avoid the potential for bias if limited to patient support groups only (31). This enhanced the variation in the sample.

Interviews were organized at times and places of mutual convenience for both the interviewee and interviewer, audio-recorded with permission, and later professionally transcribed. Interviews began under the rubric of "Tell me the story of your fatigue and help us to better understand it." The interviewer followed the person's trail of thought as the conversations unfolded and generated questions from the contexts that arose. The interview ran until it reached a natural close as judged by the participant. To minimize participant fatigue, sometimes multiple, smaller interviews were held with a participant rather than a single, long interview.

Enrolment continued until data saturation was reached, as indicated by the results of the thematic analysis performed concurrently with data collection (27). C.A. performed the initial analysis and undertook multiple readings of the transcripts constructing a preliminary coding system. Codes were then organized into a rubric of meta-codes or major themes. Cross-checking and validation was performed by the other 3 authors and any discrepancies resolved by mutual discussion. Each individual participant checked the accuracy of the analysis of their own transcript as further validation.

Results

Twelve participants were interviewed before data saturation was reached, 4 men and 8 women. Ages varied from early

30s to mid-70s. Participants were unemployed or retired or in part-time or full-time employment. They were single, married, or divorced: most were parents and some grandparents. Those employed worked in areas of health care, academia, and business management and administration. None were employed in physically demanding jobs. None were currently bed-bound, although all had been at some point(s) in their illness. Gender-congruent pseudonyms, approved by each participant, are used in the presentation of the results.

The analysis revealed that although participants had made many different decisions regarding how they lived with their illness, the key determinant to their ability to living well was their emotional stance or relationship with their illness. Five major themes encapsulating the essences of this meta-theme in the interviews in a cogent and structured manner were identified, each illustrating an aspect of how to live well with fatigue. These were as follows: (1) engaging with elusiveness, (2) befriending uncertainty, (3) reflecting on self, (4) living creatively, and (5) moving in stillness. By engaging with these themes, a new or renewed sense of personhood and purposefulness could be attained, which closely mapped onto participants' conceptions of the term "living well."

Engaging with elusiveness: Diagnosis of an illness that waxes and wanes over months and years was highly problematic, as self-image could cycle repeatedly back and forth between constructs of normal/old-self/disease-free and abnormal/new-self/diseased. For participants, their illness was a slowly emerging, subtle, and nuanced narrative until their self-awareness of the situation became fully conscious. This might have occurred suddenly, as for Jane when she was walking to work and suddenly thought "What on earth is wrong with my body? I cannot get to where I need to be." Or it could take much more time:

... it's been a process of evolution. I've tried to understand it more and more [for myself], rather than just seeking other people's advice. (Daniel)

The subtleties were often shifting and elusive, requiring patience and gentleness to discern, something that did not always happen when presenting to health professionals:

The running was getting a bit much for me. The doctors were not very impressed with that as a symptom, but it was significant for me because it was different for no apparent reason. (John)

Being elusive, not made up of clear cut, linear chains of cause and effect, this tended to manifest slowly and obscurely even to the person affected:

But I didn't notice it, even though it did have a very clear turning point. It didn't appear that way to me. It appeared very gradual[ly]. (Peter)

Coherence tended to appear in hindsight, meaning that a conscious effort had to be made to join the dots. The ability to articulate this coherence, to either oneself or others, was a process and skill, refined over time and experience.

I always had a sense that there was something wrong, but I didn't know what it was... So, it helped to explain, and after the initial shock it was almost like [a] sense of "Ok, now I know. I know what my story is, it all makes sense." (Lucy)

By reaching a point where one could make these connections, this gave a measure of peace about the situation, even if nothing else had altered from an external perspective. Self-image became stabilized around a new self-construct, one that took into account all the possible states of the illness in their lives, in an and/and rather than an either/or position.

Befriending uncertainty: Uncertainty, particularly at the start of the illness, could be extremely difficult, toxic, and corroding to participants' lives. Becoming at peace with this aspect of the illness was instrumental in constructing a sense of wellness. In order to do so, it was essential to have a clinician comfortable with uncertainty, preferably one who could model this for those seeking help:

It was actually helpful for someone to say, "We don't know what it is, but we are quite happy to keep seeing you while things are uncertain." (Sandra)

In doing so, accepting medicine's limitations could provide freedom and, paradoxically, healing:

He said something that was helpful in a way—that people [both patients and clinicians] that [sic] give up looking for a diagnosis, [rather than] people [who are] overly focused on a diagnosis, tend to do well: people who are just quietly open-minded, they do best. (Sandra)

For some, the situation called for letting go and looking beyond one's usual expectations and ways:

So I've listened to things that have just opened up my, my [sic] eyes [to the] spiritual sides... I'm listening to all this stuff, reading all this stuff... some of it must be rubbing off because I definitely do feel calmer. (Maria)

Becoming more comfortable with the perpetuating uncertainties of life freed patients from pursuing answers where none existed, allowing the precious resource of their own, limited energy to be used in less futile ways.

Reflecting on self: Participants described a process where their focus of their reflection shifted from externally derived or externally motivated stimulus (eg, demands of a job or family) to an internal or introspective stance. Having chronic fatigue highlighted the need for self-reflection and self-understanding, taking a compassionate position toward

oneself. For some, the illness provided the impetus to do this for the first time in their recollection. It could underscore a need to see the bigger picture of the world in order to make sense of the symptom properly, sometimes acknowledging that a symptom may be warning about an unhealthy way of life, from which one should move away from:

Some people try to grab everything—collect money, collect houses, collect so many things—and they just run fast through all these things . . . just collecting stuff and stuff and stuff and stuff . . . all those things . . . they will all, I think, take a part of our mind, our energy. (Daniel)

Chronic fatigue brought into focus the need for self-questioning, helping to integrate different aspects of life into a coherent whole:

I would say that I'm progressively healing internally, progressively realizing that taking care of myself isn't selfish in a negative way but in a very positive way, because without me being well I can't take care of everyone else either . . . (Lily)

This also required an ability to perceive when one is overdoing or overthinking this and knowing when to draw the line:

So I was on a roller coaster for quite a while. And [now] once I figure out that I'm on one. . . . I can intentionally modulate that, moderate it, try to reduce the peaks and elevate the troughs. . . . Maybe what I've learned by being around for this many years is what does work for me. (Peter)

Self-awareness and defining one's own values more coherently provided some bedrock from which the stresses of the symptoms could be more easily managed and also created a psychological space of solidity untouched by the fatigue.

Living creatively: Rather than going through each day, living in an unreflected-upon way, wellness was associated with a present-moment mindfulness, which was always open to new possibilities of doing old things in new ways, and even new things despite their illness. Participants identified a need for both clinicians and patients to move with the ebb-and-flow of the condition as it unfolded and to let go of a fixed end point—a "solution":

The main thing I had to learn is to accept my limitations, first of all. And that's been really hard. It took me a long time to adjust to that—years really. . . . But once you get over the worst of it, then you have to appreciate the small things you can do, the small joys of life . . . (Sarah)

Instead, the stance became a feeling of one's way intelligently and intuitively through the activities of daily life, keeping in mind that sideways, creative thinking was good—even essential—in order to live well:

I function because I have everything around me . . . you know, like this chair, and the bed, and the height of the bed, raised toilet seat . . . and my car, I don't have to sit down into it. . . . Out in the garden, I love gardening; I've got an elevated garden so I can garden . . . so you know I have a full life. (Angela)

That creativity can be enlivening and restorative:

. . . one of the big problems of my condition is that it constantly distracts me, and the way I overcome that is by distracting myself [from the illness] with other things that I like. . . . And by having things [around me] that I can associate with in the long-term . . . things that are beautiful and nice and intricate and complicated. (Peter)

Flexibility of thinking, cognitive nimbleness, and imaginative solution-making were all ways in which to creatively find new ways to live with and within the symptom.

Moving in stillness: Chronic fatigue may render a person physically motionless at times, but even in these moments of stillness, movement in one's thoughts could occur which would allow wellness to be present. For example, through this process, diagnosis could become regarded as a verb, not a noun—that is, a creative responsive, ongoing conversation, rather than a static, immutable conclusion reached. The process of diagnosis thus became a dynamic, always evolving, increasingly nuanced, and attuned conversation, a responsive discernment of life, open to change when needed. Illness and suffering allowed deeper, more enduring parts of life to move into focus, as illustrated by this metaphorical example:

. . . when you take a road every day in a car to come to work, for example. If you walk that way once, you see so many other things you haven't seen in 10 years and . . . most of those things, if you look at it through a snail's lens might be really, really good—really, really something . . . (Daniel)

Acknowledging the valuable insights gained by this slower mode of life, insights that may never have occurred otherwise, led to an appreciation for life and that sustaining gems could be found even within the physical immobility enforced by the situation.

Discussion

We studied people successfully living with chronic fatigue as an exemplar of MUS in order to identify reasons for experiencing "wellness within illness" (19). We started the research holding as open an approach as possible, discussing the limitations of our various lenses that we brought to the study, and developing ways in which these could be mitigated (such as using the appreciative enquiry approach). During the analysis, it became clear that the meta-theme of the emotional stance or relationship toward their illness underpins each participant's construct of living well; however, that may be outwardly expressed or sited in activities

(eg, like yoga, meditation) or in strategies (eg, using pedometers) in their lives. By consciously developing the themes we identified, patients regained previously lost or impaired senses of their personhood and purposefulness for living. We are aware, however, that one limitation of the study was that we were unable to interview currently or permanently bed-bound participants, so that it is possible that these results may differ for the most severely afflicted.

“Engaging with elusiveness” illustrates the importance of a consistent and well-understood internal narrative for the patient. Sometimes, the patient’s story or medical history may not yet have been achieved, be incoherent or difficult to articulate, due to its elusiveness. A sound, sustainable understanding arises from seeking emerging coherence. This emergence can be stifled by the lack of a sustained, positive relationship with a health care practitioner. Referrals and referrals to new health carers, rather than clarifying the elusiveness, tend only to accentuate it, fracturing its growth and exhausting the patient from having to continually retell their story.

Fatigue, and the lack of language to name the elusive nameless in their narration, means silences can be prominent during a clinical encounter. This, in turn, places a vulnerable and delicate process at risk of being easily disrupted by attempting to fill in blanks for the patient by health professionals, thinking that this will help patients out, but instead, inadvertently putting “metaphors in the person’s mouth” that may silence them further and which makes patients’ tasks of trying to articulate themselves even more difficult (32). The doctor–patient relationships in this sample that worked best were those that did not rush this process, as the work of finding one’s voice and finding one’s feet as a patient in a clinical conversation is a process that takes time to effectively “set its own pace.” Understanding that sitting in silence, waiting for the elusive to be articulated, is a therapeutic action in and of its own is an important clinical lesson.

“Befriending uncertainty,” “reflecting on self,” and “living creatively” all illustrated 3 core activities patients undertook to resolve the tensions between biographical disruption (33) and the necessary biographical revision (34) induced by their symptoms. The biographical disruption associated with illness implies a deficit, yet coming to terms with chronic fatigue also indicated strength, resilience, and grace. The reconciliation and freedom from seeking an unobtainable diagnosis liberated people from a futile cycling for unobtainable certainty and cure.

Foucault described the “clinical gaze” supporting the scientific legitimation of illness through technologies that render illness identifiable, measurable, and quantifiable (35). This helps explain the importance of a diagnosis for sufferers of undiagnosable illnesses who commonly seek legitimation for their suffering via this construct. Our participants’ narratives offer alternative gazes—discourses that support uncertainty, self-awareness and legitimacy, and creative solutions to one’s dilemma—as an escape from this Escher-print existence.

Havi Carel writes, “Even in cases of extreme physical disability there is always freedom of thought, imagination, emotion, and intellect” (19, p. 83). If health care professionals can lead, encourage, and nurture patients to explore these possible routes for freedom, then much suffering may be allayed, even if the physical manifestations of illness continue. Carel’s concept of “health within illness” can be achieved despite, or even because of, physical suffering.

These themes reach their epiphany in the final, paradoxical concept of “moving in stillness.” In order to reach a state of imaginative freedom and acceptance, a person needs to travel far but not in the physical dimension. This psychological movement is in contrast to the innate stillness brought about by the experience of, and reaction to, chronic fatigue, a reaction that can also occur with chronic pain and other undiagnosed symptoms. Freezing in response to threat, in response to drained energy, can also psychologically freeze people in place more thoroughly than any prison. Clinicians need to be aware when moments for potential psychological movement exist and be ready to support this process. This may not happen quickly, and much patience may be needed to avoid thinking that one is doing nothing for the patient, but the wait is therapeutic in itself.

Conclusion

By learning from people who have transcended, at least in part, some of the suffering induced by their symptom(s), clinicians can develop skills and avoid the sense of impotency and experience of heart-sink with other patients with MUS. By thinking beyond the concepts of diagnosis, investigation and cure, and instead aiding narrative consistency, modeling comfortableness with uncertainty, encouraging self-reflection and stimulating creative solutions, clinicians can facilitate a therapeutic movement through stillness to a place where patients can live well despite, or because of, being unwell.

Authors’ Note

KH Hall performed the conceptualization, methodology, validation, resources, writing—original draft, writing—review and editing, supervision, project administration, and funding acquisition. C Amos contributed to methodology, formal analysis, investigation, data curation, and writing—review and editing. C Jaye contributed to conceptualization, methodology, validation, writing—review and editing. J Young contributed to methodology, validation, and writing—review and editing.

We confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story, to the best of our abilities.

This work is not under review with any other journal currently.

This study was approved by the human ethics committee (Health) of the University of Otago (approval number 17/035) and by the Ngāi Tahu Research Consultation Committee.

No animal subjects were used in this study. All interviews with human participants were performed according to the specific

requirements of the Human Ethics Committee (Health) of the University of Otago.

Informed consent was obtained from every participant prior to interview. The process for obtaining informed consent was reviewed and approved by the Human Ethics Committee (Health) of the University of Otago prior to commencement of enrolment of participants.

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Acknowledgment

The authors thank the generous donation of information and time from all our participants in this research.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Dr Amos's position was funded via 2 joint awards (New Researcher Start-up Award and Research Support for Newly Appointed Clinical Academics Award) from the University of Otago awarded to Dr Hall for 2017 and 2018.

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