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Caring for People with Severe Myalgic Encephalomyelitis: An Interpretative Phenomenological Analysis of Parents' Experiences

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Abstract

Experiences of parents who care for sons or daughters with severe myalgic encephalomyelitis (ME) are rarely discussed within literature. Narratives of parent-carers in *Lost Voices from a Hidden Illness* (Boulton, 2008) were analyzed using interpretative phenomenological analysis. The study aimed to give voices to those who care for individuals with ME and are often stigmatized, and inform future research supporting parent-carers. Results included themes of identity change, guilt, feeling like outsiders, uncertainty, changing perceptions of time, coping mechanisms, and improvement/symptom management. Findings could inform the development of carer-focused interventions and provide vital information to health professionals about parent-carers' lived experience.

Myalgic encephalomyelitis (ME) is a chronic illness affecting multiple systems in the body, including the immune, neurological, and cardiovascular systems (Carruthers et al., 2011). Symptoms of the illness include post-exertional exhaustion, unrefreshing sleep, and neurocognitive symptoms (Carruthers et al., 2011). Various illness labels exist for individuals who experience similar symptomatology, including the labels chronic fatigue syndrome (CFS) (Fukuda et al., 1994) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Carruthers et al., 2003), each associated with specific case criteria. Currently, there is a lack of consensus within the field regarding the most accurate case criteria for the illness, as well as whether the different illness labels represent the same illness or different illnesses with overlapping symptoms (Jason et al., 2004; Peterson et al., 2013). This lack of consensus regarding case criteria, as well as the absence of a confirmed etiology for the illness, contributes to the stigma often experienced by those in the patient community and the difficulty individuals experience in obtaining a diagnosis (Dickson, Knussen, & Flowers, 2006).

Individuals with ME, ME/CFS, and CFS are severely functionally impaired. Research utilizing the Health and Functioning subscale of the Quality of Life Index (Ferrans & Powers, 1985) revealed that the quality of life of a sample of individuals with CFS was lower than that of individuals with stage 1 human immunodeficiency virus (HIV), individuals post-chemotherapy treatment, individuals who received liver transplant operations, and those with coronary artery disease (Anderson & Ferrans, 1997). A longitudinal study (Anderson, Permin, & Albrecht, 2003) found that work-related disability in individuals with CFS increased significantly over time, and many ultimately ceased

working altogether. Komaroff and Buchwald (1991) have found that 25 percent of a representative sample of patients with CFS reported being bedbound. Cox and Findley (2000) have made a distinction between patients with CFS who are “severe” and “very severe,” describing that those in the severe category have the ability to perform simple tasks (e.g. brushing teeth) and those in the very severe category are dependent on others to perform basic tasks of daily living. Research is sparse on people who have the most severe form of the illness, which is likely due to difficulties reaching these individuals who are often bed or home-bound.

Given the severe limitations in functioning experienced by individuals with this illness, there are likely unique challenges for those who act as carers. Currently, most studies focus on the experiences of individuals with the illness rather than that of the carers (Anderson, Jason, & Hlavaty, 2014). Ax, Gregg, and Jones (2002) concluded that carers of loved ones with CFS are forced into an attitude of acceptance due to a lack of both options and resources; this state of acceptance was defined as resignation. Research focused on carers has also been conducted on other chronic illnesses, such as fibromyalgia (Rodham, Rance, & Blake, 2010), Alzheimer’s, cardiac disease, renal disease, and cancer (Davidhizar, 1994). Davidhizar (1994) suggested that not only patients suffer from chronic illnesses, but that significant others and family members in the position of carer suffer from overwhelming feelings of powerlessness. Findings on fibromyalgia (Rodham, Rance, & Blake, 2010) are particularly relevant as spousal carers, as well as patients with fibromyalgia themselves, experience stigma and delegitimation from the medical community, including hostility and a lack of knowledge about the illness. Patients with CFS have also reported facing disbelief from the medical community and loved ones (Dickson, Knussen, & Flowers, 2006).

To date, no previous studies have focused on the experiences of parents caring for people suffering from severe ME. Therefore, the current study sought to better understand their experiences as parent-carers. Accounts of parent-carers were selected from *Lost Voices of a Hidden Illness*, a published book (Boulton, 2007). Published data were chosen as the book contains a wealth of information from the perspective of parents who care for individuals with severe ME. The study contributes to the literature by focusing on what it means to be a parent for someone with severe ME who is housebound, and how this role changes as a result of taking on responsibilities of a carer. An interpretative phenomenological analysis (IPA) approach (Smith, Flowers, & Larkin, 2009) was used as a basis for coding the data. We did not have hypotheses as IPA is not deductive, rather it is inductive as its method is to describe phenomenon found within the data. We sought to answer the following research question: how do parents of people with ME experience the impact of the illness on their lives? The current study’s aims were two-fold: (1) give a voice to those who care for individuals with ME and are often stigmatized, and (2) inform future research to help ensure that parent-carers of individuals with ME have adequate resources and support.

Method

Participants

All accounts ($N=19$) of parent perspectives were selected from the book *Lost Voices from a Hidden Illness* (Boulton, 2008). Accounts from non-parent carers, individuals with the

illness, and other family or friends were excluded from the analysis ($N=35$). Participants included 12 mothers and 7 fathers. Carers in our sample were parents to children of various ages, ranging from a 5-year-old child to adults. Based on the general ages that could be identified, our sample included primarily parents who cared for adult daughters.

Procedures

Data were collected from the public domain, interviews published in *Lost Voices from a Hidden Illness* (Boulton, 2008). The book is a collection of passages from individuals with ME, their significant others, and carers that aims to raise awareness of the impact of ME and to allow individual voices to be heard. Therefore, the book provides valuable insight from the perspective of parents supporting those with severe ME.

Analysis

Parent accounts were scanned and transferred into NVivo 9.2., which was used for the present analysis. The first and second authors served as coders for the text. The coders are new to the area of ME and qualitative inquiry. The second, third, and fourth authors, having extensive research experience in the area of individuals with ME, provided guidance and feedback throughout the project. The coders split up the accounts randomly and analyzed the data separately to avoid influencing one another's codes. Data were analyzed utilizing interpretative phenomenological analysis (IPA) methodology, which is grounded in a hermeneutic theory of textual interpretation (Smith, Flowers, & Larkin, 2009). Phenomenological analysis, according to Heidegger, is the process of "letting things show themselves" (Smith, Flowers, & Larkin, 2009). The phenomenon at hand is the experience of each carer in its totality. This process involved reading and re-reading the accounts case-by-case, initially for descriptive comments and, with later readings, interpretative comments. In other words, with more readings of the text, the coders sought implicit meanings and made conclusions about the participants' sense-making of their lives. The aim of the comments was to remain focused on the participants' voices and represent the meanings in their narratives as accurately as possible. Main comments were selected as superordinate themes, while comments that fell under an existing comment were selected as subordinate themes, creating a hierarchy. A main comment was defined as a recurring idea across the participants or an idea important to a particular parent. While thematic trends were noted, certain themes tended to be present in many accounts while others were present in a few or only one account. The goal of IPA is to represent the variety of experiences described within the population. Therefore, themes that were found in only a few or one account were included. Quotations that best illustrated the themes were selected from parent accounts for the results section.

Reliability—After the initial coding was complete, the coders brought their analyses together and conducted a merging process to consolidate data. The merging process was also used as a measure of reliability as there was consistency across the types of themes that were coded. In other words, similar themes were found across coders. For instance, both coders came across notions such as coping and ideas such as time—one coder termed the theme "changing perception of time" while the other coder titled it simply "time." The coders also identified many similar sub-themes, such as "definition of "normal" has changed" and

“normalcy.” While some themes were less noticeably related across coders, upon further discussion, similar ideas surfaced in certain themes. The coders worked together to identify such consistencies across data sets and merged their themes, selecting the most succinct theme labels. Themes that were not found across both coders were retained, however, as the goal of IPA is to bring to light the various meanings within the experiences of the participants.

Results

A summary of themes can be found in Table 1. INSERT HERE The superordinate themes found in the analysis were identity change, guilt, feeling like outsiders, uncertainty, changing perceptions of time, coping mechanisms, and improvement/symptom management. Each superordinate theme contains more specific subordinate themes. The superordinate theme is briefly described, followed by detailed descriptions and quotes from the subordinate themes. Whenever a direct quote is used from a participant, a pseudonym is attributed to that person. Themes are discussed as they relate to the parent, their family, and the greater community.

Identity Change

The most significant and consistent experience shared by parents was the concept of “change.” Themes that fell under this category described changes that parents experienced as they became carers for their sons and daughters with ME. ME impacted various aspects of their identity, such as their roles within their families, including relationships, and aspects of their lives outside of their families, such as their careers. These descriptions suggest that living with severe ME is totalizing in that their lives were globally affected by their child’s illness.

Changing role—Parents take on roles as carers, serve as advocates for the illness and their children, and support their children as educators.

Elyse wrote, “I have to be on-hand all the time, always forewarned, always prepared, but at the same time trying to help with whatever gives her pleasure, a sense of progress and achievement; sewing seeds and watching the plants grow; keeping the bird feeders topped up; making patchworks where she may help arrange the colours; or now occasionally on the better days going for little slow drives, delighting in the outside world, the light and colours changing, the birds and flowers changing with the seasons.”

For Elyse, being a caregiver also means helping her daughter find enjoyment. While Elyse describe her role as a full-time caregiver, being a carer for someone with ME may also mean being an advocate in ensuring she has the opportunity to continue her education.

Holly reported as to her role, “We put a lot of effort into trying to make it possible for [our daughter] to carry on with her education. The school was happy for her to be absent as she had a doctor’s note and they soon forgot she existed. We did everything we could to make it easy for the teachers to send work home but despite promises it mostly didn’t happen. If we hadn’t persevered the education system would have happily ignored her completely. In the end [our daughter] studied with

the help of us parents and then by herself to get through GCSEs, just the minimum.”

Not only have parents described the ways in which their roles within their families have changed, but also the way this has affected their own well-being.

Erin, who is the sole carer for her daughter, wrote, “As a twenty four hour carer I have little time to think excessively about the future. In some ways my own life is very restricted and inevitably I am constantly exhausted and sleep deprived.”

The parent role is redefined to include caretaking responsibilities, which, as Erin described, may impact parents’ well-being. The role of parental carers is a balance of providing day-to-day care for the person who is ill while also providing affection.. Parents may struggle to find ways to provide affection to their children who are often in great pain; in essence, ME may change the way in which parents relate to their children.

Charlotte described that, “As a mother, the most natural thing in the world is to gather your child in your arms and make everything better with a kiss and a cuddle. For too many years I was unable to do this for my daughter... Every part of her body hurt so much she couldn’t bear to be touched.”

Although others have also reported the level of physical affection being limited due to the son or daughter’s sensitivity, some parents reported focusing on fulfilling needs of their children, particularly in terms of physical affection, and reported needing to establish “contact” themselves.

Amy noted that, “On a good day she would just ‘hold’ my thumb, well I’d ‘rest’ it, between her thumb and finger; it was all she could manage and nothing like the cuddle we both so desperately needed, but it was some level of contact; the contact, the comfort, she so desperately needed, as she felt so desperately ill.”

Parents experience a change in the way they relate to their children as a result of living with ME. This change leads to new roles, which, in turn, affect the way parents relate to others.

Guilt

Parents reported feeling guilt, manifested in terms of neglecting other relationships, not providing enough support to their child with ME, or wishing they had done or could do more. The experience of changing roles, responsibilities, and pastimes not only for the individual, but also in terms of the family as a whole, may have contributed to these feelings of guilt for some parents.

Mia wrote, “I personally have a terrible feeling of guilt, that I am not giving 100% to the rest of my family. I feel like an olive tree with all these branches trying to give enough time and love to everyone else in the family. ME has become my life.”

As reported by Mia, living with ME is totalizing as being a carer means dedicating oneself to various responsibilities that may result in feelings of guilt over neglecting others. Guilt may also manifest in other ways.

Similarly, Jack wrote, “The necessity of a day-job is a double-edged sword. It removes and relieves one from having to see this illness play out its effects on my

daughters during the day - only to replace it with guilt at not doing enough when confronted with it in the evenings or weekends. Guilt becomes a constant shadow for a parent.”

While working may provide a form of escape for Jack, he reports feeling guilt due to being away throughout the week.

Thomas reflected, “With hindsight I am ashamed to say that the first indication I had of [my daughter’s] illness were the days when she wouldn’t go to primary school because she was so tired in the morning; I literally dragged her off to school. Even when she attempted secondary school I had no idea that her best friend was carrying her books *around between lessons*.”

In all three of the above quotes, the phenomenon of guilt is brought to light. One parent feels that she dedicates all of her time to ME and feels guilt over neglecting other areas of life, while another parent feels guilt due to not being involved enough in caretaking duties as a result of his work. And yet another parent feels guilt and shame over the way he interacted with his daughter, mainly for pushing her without understanding the severity of the symptoms. This phenomenon of guilt appears when the carer reflectively evaluates his or her performance as a carer in a negative light.

Feeling like outsiders

This theme presents a phenomenon that was experienced by many of the parents, which can be described as one being isolated, misunderstood, and feeling a general lack of belonging in many facets of his or her life.

Negative responses from others—Parents reported that they were often met with disbelief and hostility from medical professionals. They also reported that close friends and other family members were skeptical and perplexed by the illness.

Andrew described, “It’s not just that the whole bureaucratic machine seems somehow designed to stigmatise the long-term sick, to make them feel that they are second-class citizens, malingerers or at least somehow responsible for their own misfortune. But behind that there’s the way that after a while people - after weeks, months, certainly years - start to give off subtle and not-so-subtle signals that they really don’t want to know about your daughter’s continuing illness or its effects.”

Alice wrote, “[I] cannot emphasise how horrendous they were to us at this hospital; [my son] still has nightmares to this day. They treated us like we were paranoid and were wasting their time...[W]e knew that pushing him beyond his limits had terrible consequences for his health. Others did not see this as we were only able to see them on [my son’s] ‘good days’ so of course they never saw that he paid for those days with weeks of ‘bad days’... There are people that struggle to believe [he] is unwell as they do not see him unless he’s well enough to do so.”

Lastly, Andrew described, “A fear sometimes so strong that even blood relatives would rather believe that you’re making it all up, that it’s your fault, than really

acknowledge the reality of what a long term illness like ME means for those who must live with it day by day.”

Living with ME as a carer may mean coming into contact with skepticism, disbelief, blame and hostility from others, including not only medical professionals, but friends and family as well. As a result, parents find themselves disconnected from others who may not respond well.

Distancing: Taking on a new role results in much of the parent’s time being allotted to caretaking responsibilities. As a result, parents reported being distanced from relationships with other family members, from their hobbies, careers, etc., particularly when they are the primary carers.

Elyse wrote, “I retrained and pieced together a second career that could be continued sporadically and if necessary at home, but that too had to be abandoned as she was now too ill. I’d enjoyed listening to music, but that became impossible; the house must be quiet and I must be ever vigilant and attuned to respond to a faint call or a crash if she passed out...”

Jack discussed his wife’s distance, “I see my wife, her career disappeared, spending countless hours well into the early hours researching this illness, hoping to find something which can help make a difference - her life put on hold while she becomes the unpaid, full-time carer.”

The theme of distancing was also manifested in the relationships within the family unit. Parents describe how their relationships with their spouse and children have changed. In most of these families, one parent takes on the role as primary carer. This often creates a new relationship between the caring parent and the son or daughter with ME.

Max wrote about his situation at home, “My being at home eases the pressure a little on my wife, and gives her a little more freedom, although when [my daughter] is having a particularly bad day, the only person she wants is her mum. Sometimes this hurts but I know I have not been here much and I don’t understand the illness or what she needs like my wife does. [My daughter] trusts her mum, they have been together day and sometimes night for the whole length of [my daughter’s] illness; she knows what [my daughter] needs without her having to say and explain, I don’t. I still have an awful lot to learn, but I’m trying.”

The theme of distancing also extends to the way a family, as a unit, spends their time. Parents report that their family plans and habits have changed.

Emily described her family life, “We are cocooned as a family. There are no family holidays, as [my daughter] is too ill and needs care 24 hours a day. So, she never gets a break from her environment. One of the saddest things for me to watch has been [my daughter’s] friends losing contact one by one. This was one of the cruellest blows.”

As a result of this distancing from their life before ME, others have grown distant from them as well.

Isolation—Parents felt alienated (such as feeling “cocooned as a family” or “prisoners in our own home”) and reported being estranged from friends and family as the role of carers became their priority. Because there is a lack of understanding by those who are not immediately impacted by the illness, carers are left feeling alone in their world.

Elyse wrote, “We cannot invite people back to our house because their everyday detergents and smells precipitate excruciating head-pain for [my daughter], but neither are we free to visit them. Our concerns can not be shared by those who do not understand a situation that doesn’t make sense unless experienced, and cannot be experienced by others without making her more ill. So we are met with disbelief and incomprehension.”

And she continued on by saying that, “[ME] defies all expectations. It cannot be fought in the usual way of struggling with problems. Hardworking confidence, persistence and carefree optimism, become a vicious trap creating further illness, relapses and isolation.”

Emily described her isolation, “I think the main feeling I have about it all is the isolation...there are no family holidays, as [my daughter] is too ill and needs care 24 hours a day. So, [my daughter] never gets a break from her environment.”

Uncertainty

Along with feelings of isolation and invalidation from others, parents also reported feelings of uncertainty in regards to a diagnosis and prognosis, particularly following phases of remission and relapse. Carers report wanting to do something for their son/daughter, but feel they do not know where to turn or what to do.

Holly discussed feeling uncertain, “Time is spent learning about the illness and trying to find answers as no one in the healthcare profession has been able to explain their illness. They were diagnosed and left at that. Any symptom or sign they presented with afterwards was put down to as ‘just ME’. It is hard enough to look after two sick children let alone do the medical problem solving by oneself as well. ”

Mia described her uncertainty, “As a mum the stress and anxiety from living in fear of the unknown, of what ME is going to bring my son next, is unbearable. I’ve forgotten how many times I have thought that I have lost my son to ME.... Everyday is a day of existence, we don’t know what ME is going to bring us today.”

Diagnosis—Parents report difficulty obtaining a diagnosis, such as misdiagnosis and lack of consensus among medical professionals in diagnosing ME.

About an ME diagnosis, Jack said, “Uncertainty surrounding the diagnosis and prognosis keeps the mind in a limbo balanced between previous aspirations and current realities. ME is an illness of changing horizons for a parent. Life goes on - this will be short-lived, over in a month or so. We look for an early recovery but the

realisation gradually forms that it is going to be longer before this illness finally goes.”

For many parents, receiving the diagnosis only perpetuates uncertainty, in that there is no course of action for the individual to follow. The quotes above and below describe the uncertainty that stems from the futility of receiving a diagnosis of ME.

Jack continued to describe the struggle with diagnostics, “Though our GP is sympathetic we find that ME is treated by the healthcare profession with a level of ignorance bordering on negligence and come across innumerable stories of doctors who have closed their minds to the truth about ME. A catch-all name of CFS is given to a dead-end medical diagnosis which the medical profession seems happy to allocate to any patient where the cause of illness cannot be determined. How can healthcare professionals not have a passion for questioning and curing? Our paediatrician may offer CBT or GET, which are either pointless or harmful, but getting a simple blood test performed to look for an infection is refused. A potential thyroid abnormality is left undiscovered for ages.”

Additionally, because there is no cure for ME and often a lack of knowledge in the medical community, parents may encounter difficulty with finding appropriate treatment and support for their children.

Relapse/remission and false hope—Parents discuss difficulty in seeing their son/daughter relapse, particularly when there has been improvement prior to relapse. Parents talk about how a misdiagnosis with a non-life-threatening illness and temporary improvement offered hope. This hope is then lost and causes further grief, exacerbating the anxieties of living in uncertainty.

Amy wrote, “It’s been seven years since [my daughter] became bed bound. Yes, we have, at times enjoyed improvements, but they’ve always been short lived...Despite our very best efforts and guidance from these specialist therapists, [my daughter] has remained intrusively symptomatic and continues to function at a low level. Yes there have been improvements, but, with frequent relapse, there haven’t been significant sustained improvements.”

Prognosis/death—Parents talk about fears of death when their son/daughter was at her/his worst.

Charlotte wrote, “She was so still and her face so grey that her younger brother commented that she looked dead. How I feared she would die. How I prayed that every silent, shallow breath would not be her last.”

And Amy explained, “Throughout the most severe times of [my daughter’s] illness, there have been many times, too many, when I’ve not known whether she was unconscious, or even alive.”

Changing perceptions of time

In the present study, most narratives mention an evolving relation to time. Over the course of years, a parent's identity changes as the role from parent to carer changes. Parents describe some days as being repetitive with long to-do lists and multiple carer responsibilities, resulting in the experience of changes in how time is felt.

Time as stagnant, but passing quickly.

Andrew wrote about life and time, "There are all the obvious emotions. The endless, daily, largely un-sayable distress at the fact that life is passing my beautiful, clever, funny daughter by and that there is very little I can do about it."

For others, days are described as moving slowly; carers strive to make every moment count and enjoy simple pleasures as best they can.

Elyse reported that, "Slowly life now revolves around trying to ensure that each day counts along a path to recovery by whatever means possible - trying to avoid the known pitfalls, the exhaustion and pain caused by too much noise, movement or activity, too much concentration, infections, exposure to chemicals, smells and many foods."

As the person with ME's condition shows little to no improvement over time, the carers' intense involvement begins to wear on his or her well-being; some begin to lose the hope they once had.

Victoria felt that, "After fourteen years there is little light at the end of the tunnel."

Within mentions of time there is a subtext wherein time going by is felt as a loss of time itself. For instance, due to the severity of the son or daughter's illness, intensified by symptoms occurring in lapses and remissions, the majority of time is spent in a state of bedbound immobility. A carer for a loved one in such a state may feel that valuable time of a loved one's life is lost to the illness.

In regards to time and loss Jack noted, "The months come and go. Our horizon of hope moves from months to a year. It will be next term before Carla will go back to school. The school terms come and go."

Coping mechanisms

Parents report optimism, such as hope or enjoying simple pleasures, as ways to continue moving forward regardless of the hardship they and their families are experiencing.

Hope as a necessity to keep going—Although there is currently no known cure, parents report remaining hopeful for recovery and a brighter future for individuals with ME, and hold on to ideas of their child's pre-ME identity as a way to keep moving forward. They also report hoping for change in terms of the way ME is received; they wish for understanding from others, for available treatments, and mainly, for their children to be able to become more independent and be able to make substantial choices in regards to their lives.

Jack described his family's hope, "Are there any positives? Happily, amazingly, we are still a family. Our daughters are positive, funny and warm - when the pain subsides and allows. I never once heard them complain about this illness, or ask why it happened to them, or why nothing was being done about it. They look forward - an antidote to the nonsensical and unscientific somatisation view of this illness systemically embedded in the healthcare service. Through education comes awareness, comes resilience, comes determination. Eventually this battle will be won."

Sophia wrote, "[W]e ask that people try to understand what this illness can do to a person. We don't want sympathy or pity as we don't feel sorry for ourselves, just for people to try and understand what it must be like to have all the things we all take for granted taken away from them through no fault of their own."

Charolette reported, "I long for my daughter to be able to lead an independent life, to be able to follow her hopes and dreams, to have choice."

Redefining "normal."—Parents report that their new life with ME and its limitations have become normal. In a sense, they may modify their understanding of what is "normal" as a way to cope with the sacrifices they, their daughters and sons with ME, and other family members have made.

Jack said that his "Life becomes a routine shared by all. One becomes used to the dark rooms to reduce light-sensitivity, the lack of sound to avoid headaches, the changes to diet, the cost of supplements, the lack of a social life, the lack of family occasions, the removal of all things normal. Everything is reduced - we adapt and learn to cope and reduce our expectations - of friends, of family, of healthcare services, of politicians, of this society. ME rules our lives."

Overall, parents report that although there are limitations and changes associated with the illness, there are moments that feel normal and conceptualizing these limitations as normal appears to be a coping strategy.

Compartmentalizing life with vs. life outside of ME—One parent reports coping by leading two lives: one as a carer and parent, and one immersed in their career.

Lucy explained, "My way of coping was to have friends and family help to look after him whilst I went out to work. It was a necessary therapy for me to have a distraction for part of the day and in teaching there is certainly no shortage of distractions! My colleagues were very good at not asking after him constantly so that I did have the space to break away from the worry of it all. I couldn't afford to spiral down myself as I had to remain supportive and functioning in order to do my best for [my son]."

Simple pleasures—Parents report finding enjoyment in simple pleasures, such as nature or the utility of humor in preserving positivity.

Janis wrote that, "Wildlife in the garden brings me pleasure and satisfaction, and is worth the energy I put into it."

Erin noted, “But we have learned to adapt and vitally ([my daughter with ME] included) have retained our sense of humour.”

Improvement/Symptom Management

Although parents report a lack of treatments and resources for managing ME, one parent did describe effective symptom management strategies and improvement after certain treatments.

Managing Energy Levels—One parent reports that considering her child’s energy expenditure and helping him avoid over-exerting himself was an effective way to manage the illness. This was the youngest individual with ME in our sample.

Alice wrote that as a carer, “We have learned not to use all the energy on a good day and to ‘keep some back’... We run a fairly tight schedule during the day, mostly unbeknownst to [my son], doing activities... that allow him to have fun and learn, whilst factoring in the necessary rest periods. We have learned also that if there is a main activity that he really wants to do (for example, Legoland on his birthday or bowling on a weekend) we ensure we do little for two to three weeks before and after; this all helps manage the illness and allow our son to do the things he enjoys.”

Anti-viral medications—The same parent also talked about seeing significant improvement in their young son when he was treated with anti-virals by a medical herbalist.

Alice reported, “[W]e found that a medical herbalist prescribing anti-virals got [my son] over the very worst, and the onset, of this disease.”

Discussion

There is a lack of research focusing on the experiences of parent-carers for individuals with severe ME. The aim of the present study was two-fold: (1) to give voice to a community of carers who are often stigmatized and (2) to inform future research by exploring the phenomenon of caring for a child with a marginalized illness. The results of this study could inform how health providers, family, and loved ones support carers. This is essential as family caregivers report higher ratings of stress and depression than non-caregivers (Pinuart & Sorensen, 2003); therefore, understanding caregiver experiences is essential to seeking ways to support them.

The experience of identity change has been previously found in studies focusing on individuals with ME (Larun & Malterud, 2007); the current study found carer experiences coded under the thematic sub-category “changing roles,” which describe the different responsibilities of a carer and advocate. Underneath the multitude and often burdensome responsibilities of taking on a carer role, parents reported experiencing guilt. Findings such as guilt align with Ax, Gregg, and Jones’ (2002) conclusions that carers of individuals with ME experience increasing responsibilities and guilt due to a perceived inability to do more for an individual with the illness. Therefore, creating a support network for carers is

essential to their well-being to help with managing stress associated with changing roles (Davidhizar, 1994.)

Parents reported feelings of alienation that were often exacerbated when met with disbelief by the medical community, friends, or relatives. These findings are consistent with research (Ax, Gregg, & Jones, 2002; Jason et al., 2004; Dickson, Knussen, & Flowers, 2006) that describe negative responses from the medical community toward this population, such as carers reporting that clinicians accused the individual with the illness of being a malingerer. Carers for people with fibromyalgia experienced the same phenomenon of alienation due to the perceived illegitimacy of the illness (Rodham, Rance, & Blake, 2010). Carers experiencing delegitimation may feel alone in their roles. In addition, it has been found that those who care for others with chronic illness often suffer themselves (Davidhizar, 1994). This is one of many reasons that the experiences of those who care for others with marginalized chronic illnesses require the attention of the greater medical community to ensure that both the person with the illness and the carer are receiving adequate support.

There is little empirical research on recovery from ME and a general lack of knowledge in the medical community about symptom management (Peterson et al., 2013). Within the medical community, there is little agreement on how to diagnose and treat ME. The diagnosis itself is one of exclusion and case definitions were developed by consensus rather than empirical methods (Jason, Corradi, & Torres-Harding, 2007). There is also no known cure and current treatments offer little relief (Adamowicz, Caikauskaite, & Friedberg, 2014). Due to the lack of a cure, the complex diagnostic process, lack of effective treatments, and the alienation families experience, many parents reported feeling perplexed by the lack of options and the unpredictability of symptoms. This conflicted state resulted in overwhelming uncertainty; for example, carers reported the inability to predict the severity of symptoms on a particular day due to the fluctuations inherent to the illness. Similarly, Dickson, Knussen, and Flowers (2007) found that people living with ME reported anxiety caused by uncertainty. Uncertainty, however, is a two-fold phenomenon in that the illness is unknown to medical professionals and also unknown to those who both have and live with the illness. A lack of consensus on a case definition for ME, as well as the unknown etiology and difficulties finding effective treatments, are likely to exacerbate the state of uncertainty of carers and those who are ill.

Time was mentioned by the majority of parents. Some parents mentioned that time moved slowly and that their days were monotonous and repetitive. Others reported that life was passing them by or, in other words, that time was moving quickly. Within phenomenology, time-consciousness contributes to the understanding of one's self-identity (Kelly, 2014). In Heidegger's phenomenology, the possibilities of the future are always directing our being in the present moment. Parents' experiences of time changed the way they reported thinking about the illness. In the initial stages of being a carer, some parents reported that they thought their son or daughter would improve after a few months of treatment. In the later stages, as time moved on with little improvement in their child's health, some parents reported feelings of resignation, such as feeling forced to accept their circumstances. Over time, the way the carer felt and thought about the illness changed.

Overall, carers adopted an attitude of positivity despite difficult circumstances, and most carers noted that an attitude of optimism was crucial to adjusting to difficulties. Reported coping strategies included remaining hopeful, redefining their new experience as normal, and finding simple pleasures. Previous research (Ax, Gregg, & Jones, 2002) has found that familial carers of those with the illness enter a stage of acceptance which allows them to cope with the illness by living each day at a time and reducing high expectations for the future. The current study provided further evidence for coping by focusing on each day at a time since parents reported enjoying simple, daily pleasures. However, parents in the current study reported remaining hopeful as an essential coping strategy which was not consistent with research (Ax, Gregg, & Jones, 2002) indicating that familial carers were cautious about thinking about the future. It could be that due to the severity of the illness experienced, coupled with the illness itself being contentious among medical professionals, that parental-carers are left with no choice but to accept the circumstances and adopt living a day-by-day mentality.

Although there is currently no cure for the illness and a dearth of effective treatments available, one notable effective symptom management strategy is based upon the energy envelope theory in which patients monitor their energy levels to avoid overexerting themselves (Jason, Benton, Torres-Harding, & Muldowney, 2009). One parent described helping her five-year old son with ME manage his symptoms by managing the way he expended his energy, much like the energy envelope theory. It may be the case that other parents find energy management a useful strategy in managing symptoms. However, in cases where people are affected by a severe form of ME—being home or bed-bound—managing energy levels may not be possible. Perhaps this is why it was only mentioned among one parent in our sample.

Limitations of the analysis stem primarily from the use of public data; original interviews were not conducted. The larger family dynamic is likely lacking depth, as the focus here is strictly the parent-carer experience, restricted by what each carer felt comfortable sharing in the book. The goal of the source book to raise awareness about the hardship of living with and supporting someone with ME is therefore reflected in our results. It is recommended that future studies focusing on carer experiences and particularly the experiences of people with severe ME conduct original interviews when possible and with care for the well-being of individuals with the illness.

The editor of the source book, a parental carer herself who compiled the narratives of the other carers for publication, was contacted to ensure that carer experiences were accurately represented and to provide support for the validity of findings. The editor provided feedback on whether the presented themes aligned with her understanding of the content of the book as well as with her experience as a parent carer. She agreed with “much of what [was] written,” such as parents’ experience of isolation and establishing a sense of normality to cope with their experiences. She also offered a few suggestions in regards to aspects of the experience that may have been missed, mainly that being a parental carer for this illness is a traumatizing experience. Other themes suggested by the editor included loss, bereavement, powerlessness, feeling trapped in time, living in the “real world” and the “home world” resulting in contradiction, and utilizing rigorous and organized timetables so as to avoid

amplifying symptoms by overexertion. As the current study did not conduct original interviews, future studies might explore these themes in qualitative interviews with parents.

Another potential area for future research might be how experiences differ for parents who take full-time carer roles versus those who take on part-time carer roles, particularly when they are providing income for the family, as such roles were reported in the current sample. Future studies could also explore how spousal relationships are affected as a result of these role changes. Although we found that some parents felt distanced from their spouses as a result of role changes, future research could focus on how this process occurs and whether certain factors are associated with positive change, such as closeness, while others contribute to negative change, such as feeling distanced. Future research could also focus on various coping strategies. It may be that other parents feel similarly; as a result, larger sample sizes are needed to evaluate the types of coping mechanisms that parental carers utilize. Furthermore, determining whether these coping mechanisms are useful over time would also be essential to developing potentially efficacious interventions for this population.

Results regarding parents' feelings of identity change are particularly relevant to mental health professionals working with parents to reconcile their feelings about changing roles and coping with these changes. Because some parents take on the role of a full-time carer and this may distance them from their spouse, working with spouses to find a way to maintain their relationship may be helpful to parents. Furthermore, because taking on a carer role may mean leaving a job, some parents may need more resources to support these changes, particularly to ensure that they have options. For instance, some parents may need help accessing carer benefits, such as Caregiver Allowance in the UK (Carer's Allowance, 2014) which allows eligible carers to receive financial support. Another option might be utilizing a "buddy intervention" (Jason, Roesner, Porter, Parenti, Mortensen, & Till, 2010), meaning weekly visits from a paraprofessional, which has been shown to significantly reduce fatigue severity in people with ME by aiding the person who is ill stay within their energy envelope (Jason et al., 2010). Weekly visits may alleviate some of the burdens of full-time caring. Furthermore, since parents overall reported a perceived lack of knowledge about the illness by the medical community, educating medical professionals about the illness itself and the energy envelope theory may be helpful in improving the lives of severely affected patients and their families.

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Table 1
Super- and Sub-ordinate Themes Identified through the Analysis, their Descriptions, and Occurrence

Super-ordinate Theme	Sub-ordinate Themes	Theme Description	Occurrence n (%)
Identity change	<ul style="list-style-type: none"> • Changing role 	Describes changes that parents experience as they become carers for their sons and daughters with ME.	10 (52)
Guilt		Parents reported feeling guilt, manifested in terms of neglecting other relationships, not providing enough support to their child with ME, or wishing they had done or could do more.	6 (31)
Feeling like outsiders	<ul style="list-style-type: none"> • Negative responses from others • Distancing • Isolation 	Reports carers being isolated, misunderstood, and feeling a general lack of belonging in many facets of his or her life.	13 (68)
Uncertainty	<ul style="list-style-type: none"> • Diagnosis • Relapse/remission & false hope • Prognosis/death 	Parents describe feelings of uncertainty in regards to diagnosis and prognosis, particularly following phases of remission and relapse.	10 (52)
Changing perceptions of time	<ul style="list-style-type: none"> • Time as stagnant, but passing quickly 	Interprets any mentioning that which describes the carers outlook in relation to time (past/future).	12 (63)
Coping mechanisms	<ul style="list-style-type: none"> • Hope as a necessity to keep going • Redefining normal • Compartmentalizing life with vs. life outside of ME • Simple pleasures 	Reports a variety of coping mechanisms and strategies that parents reported, usually in an effort to take care of both themselves and their loved ones who are ill.	12 (63)
Improvement/symptom management	<ul style="list-style-type: none"> • Managing energy levels • Anti-viral medications 	Reports any mention of attempts to manage and curb intrusive symptoms whilst describing any improvement in daily functioning.	5 (26)