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ORIGINAL ARTICLE

Compelled loneliness and necessitated social isolation: “It’s like being on the other side of a mirror, just looking in”

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Abstract

This article develops the conceptualisation of loneliness by drawing on 42 accounts of myalgic encephalomyelitis (ME). While illness experience is a central concern of the sociology of health and illness, experiences of loneliness alongside contested and chronic illness have received less attention. The analysis illustrates how loneliness can be an integral part of living with ME and offers two novel conceptual contributions - necessitated social isolation and compelled loneliness. Necessitated social isolation concerns how ME symptoms can make social lives increasingly restricted. Compelled loneliness highlights how the combined experiences of both stigma and contested illness can lead to social withdrawal and rejection, which create a sense of loneliness. The article argues that loneliness and social isolation can be conceptually distinct yet recursive and overlapping. With the worsening of ME, the participants experienced a cycle of loneliness, in which social isolation and loneliness reproduced each other. Three key themes draw attention to how loneliness is affected by the situational aspects of living with a chronic and contested illness: (1.) spatial and temporal restrictedness (2.)

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communicative alienation and (3.) discreditation. The article highlights how health challenges can impact on loneliness and how the stigma of contested illness exacerbates loneliness.

KEYWORDS

chronic illness, loneliness, myalgic encephalomyelitis, social isolation

INTRODUCTION

Even before the COVID-19 pandemic, loneliness was a public health concern (Holt-Lunstad, 2018) and an alleged epidemic (Kar-Purkayastha, 2010). It has been framed as a negative product of modern Western living, including materialism (Jaspers & Pieters, 2016) and individualism (Putnam, 2000). The social restrictions imposed by governments during COVID-19 lockdowns propelled loneliness to become a critical issue, making it even more crucial to understand the nuanced contours of this experience. Despite the apparent prevalence of loneliness, neoliberal discourses on the subject have tended to be excessively pathologised and focused on individuals' personal responsibility to overcome and withstand loneliness (Duggan, 2021; Jones, 2022).

This article invests in a sociological approach that situates loneliness within the wider social environment in which it is experienced (Franklin et al., 2018), rather than pathologising loneliness. While loneliness is an unpleasant feeling experienced by individuals, this article draws attention to how loneliness shapes and is moulded by social factors which are influenced by chronic illness and disability. These include sociocultural norms/expectations (Neves et al., 2019), living arrangements (Schmitz et al., 2021) and access to public/social spaces (Bergefurt et al., 2019; Victor & Pikhartova, 2020).

The temporal, spatial, stigmatised and communicative aspects of (myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome) illuminate the social lives of the interview participants. ME can be chronic and/or disabling with a wide range of symptoms including, but not limited to, persistent fatigue, joint and muscle ache, sore throat, painful lymph nodes and cognitive dysfunctions (NICE, 2021). There are no biological markers, and the diagnosis is one of exclusion. Despite being recognised by medical bodies, such as NICE (2021), ME is a medically contested illness (Clarke & James, 2003; Dumit, 2006). The ways of understanding and treating the condition are fiercely disputed, particularly whether the condition is psychological or somatic (Spandler & Allen, 2018). Patients often experience scepticism about the legitimacy of their illness from friends, family and health-care professionals. This article highlights the challenges that can impede people with ME from being able to act upon the distress of loneliness. Such an analysis is salient on the basis that loneliness interventions have often overlooked health challenges (Bound Alberti, 2019).

In this article, the pervasive yet hidden presence of loneliness is brought to the forefront of analysis within the sociology of health and illness through accounts of ME that illuminate daily experiences. The conceptualisation of loneliness and social isolation is discussed by considering scholarly literature within loneliness studies, before reflecting on research which incorporates illness, loneliness and ME. The findings are divided into three thematic sections which capture combined experience of ME and loneliness. First, restrictedness points to how the experience

of ME symptoms constrained the temporal and spatial aspects of the participants' lives which reduced their social contact. The first section also highlights how social isolation is often an unavoidable consequence of living with ME. The second section focuses upon communicative alienation which highlights a deficiency in interpersonal relationships. The final theme explores the perceived (il)legitimacy of ME and how the stigma attached to ME perpetuates the loneliness of living with a chronic and disabling condition. The article does so by showing how the participants were compelled to loneliness through stigma, social rejection and social withdrawal. The article contributes to loneliness studies and the sociology of health and illness by offering two novel dimensions to understanding loneliness: necessitated social isolation and compelled loneliness. The two concepts will be shown to overlap and impact on one another in a cyclical process.

CONCEPTUALISING LONELINESS AND SOCIAL ISOLATION

A key issue in loneliness research is that definitions of loneliness and social isolation have often been conflated and confused within academia, policy and practice (Wigfield et al., 2022; Yang, 2019). Distinguishing between the two concepts is important because socially isolated people do not necessarily feel lonely and a high number of social connections does not necessarily allay loneliness (McInnis et al., 2015). Social isolation therefore “concerns the objective characteristics of a situation and refers to a small network of kin and non-kin relationships” and “persons with an absence or a small number of meaningful ties are, by definition, socially isolated” (de Jong-Gierveld et al., 2018, p. 391). Social isolation is both objective and possible to quantify based upon a lack of social connections.

Loneliness is more complex and there is no universally agreed definition. Mijuskovic (2012) has questioned whether it is possible to define loneliness given that it is a feeling and an emotion. However, this article identifies four different perspectives on loneliness: existential, cognitive, social needs and experiential. Existential loneliness is regarded as being essential to the human condition, inherent in human existence (Moustakas, 1961) and is more associated with being separate from others and the rest of the world (Applebaum, 1978). This does not mean that loneliness is experienced in the same way everywhere. Bound Alberti (2019) has been critical of loneliness being portrayed as a universal experience, arguing that doing so overlooks the disconnect between the individual and social structures as well as the ways people engage with the social world. Moreover, our subjectivity is continuously altering with our environment and other people.

One of the most widely used academic definitions of loneliness in empirical social research is a cognitive perspective provided by social psychologists, Perlman and Peplau (1981:31) who propose that loneliness is “an unpleasant experience that occurs when a person's network of social relationships is deficient in some important way, either quantitatively or qualitatively”. However, dissatisfaction with relationships does not necessarily lead to loneliness (Stein & Tuval-Mashiach, 2015). Preceding this cognitive definition of loneliness, Weiss (1973) suggested emotional loneliness results from the lack of a close, intimate attachment to another person. Social loneliness, Weiss (1973) claimed, is caused by lacking a network of social relationships in which the person is part of a group of friends who share common interests and activities. Social and emotional loneliness often occur due to reduced social activities, or increased physical disabilities (Aartsen & Jylhä, 2011) amongst other reasons. This article pays particular attention to experiential loneliness, which is to be alone in one's experiences because others will not or

cannot try to understand (Stein & Solomon, 2017). Experiential loneliness relates to the quality of relationships and encapsulates the need for understanding and empathy from others.

Although loneliness is a painful experience, it can have positive outcomes including personal growth (Ettema et al., 2010) and triggering us to reconnect with people (Cacioppo & Patrick, 2008). Bound Alberti (2019) has been critical of portraying loneliness as a purely negative experience, referring to loneliness as an emotion cluster which is “not a single emotion, but a feeling state or emotion cluster ... describing experiences that incorporate many separate and even competing emotions” (Bound Alberti, 2018, p. 243). This understanding of loneliness speaks to Flora’s (2019) anthropological insight that loneliness cannot be defined as one thing, and loneliness is never experienced in the same way. Scholars (Boulazreg & Rokach, 2020; Malli et al., 2022; Sagan, 2020) have called for more insight into the subtleties and shades of loneliness, which this article hopes to illuminate.

Loneliness has also become increasingly medicalised, evidenced by a growing body of research indicating that loneliness has harmful health consequences (Hawkey et al., 2010; Holt-Lunstad et al., 2015). Rather than seeking to understand how loneliness impacts on our health, this article investigates how chronic illness and disability affects our sense of loneliness by exploring experiences of ME. Bound Alberti (2018) has suggested that loneliness being understood as a medical issue is a recent development in the history of Western loneliness. Parallels can be drawn between loneliness and the history of obesity (Bound Alberti, 2018), a condition which is thought to be epidemic, medicalised, stigmatised, pathologised and understood to be a product of Western living (Gilman, 2008). The meanings attached to loneliness have changed over time (Wood, 1986) and the current medicalisation and pathologising of loneliness is historically and culturally contingent.

ILLNESS AND LONELINESS EXPERIENCES

The previous section discussed how loneliness and social isolation have been theorised. Now attention is turned to loneliness and illness. Within the sociology of health and illness, experience of illness (Charmaz, 1995, 2002; Frank, 1995; Kleinman, 1988; Williams, 1984) has long been a principal subfield. Scholarly attention has been paid to changes in social relationships and social roles resulting from illness and disability. Charmaz (1991), for example, highlighted how people with multiple sclerosis lean into their close social circle and pull away from others to focus their strength on the illness. Charmaz (1991) found social isolation to be the result of prolonged illness characterised by reduced relationships and shrinking social worlds, which translated “directly into emotional isolation and loneliness”. However, focusing explicitly on loneliness and contested conditions is currently underexplored and requires sociological attention. Concepts related (and sometimes overlapping) with loneliness have featured in experiential research, including social loss, alienation and isolation, but loneliness has rarely been a focus.

While there has recently been increased attention paid to loneliness within the sociology of health and illness (Achdut & Refaeli, 2020; Malli et al., 2022; Petersen et al., 2020), the field has tended to concentrate on bereavement, ageing and the effects of social restrictions following COVID-19 (Gustafsson et al., 2022; Patulny & Bower, 2022). Lockdown research is driven by an exceptional social, medical and political event, rather than the everyday experiences of people living with contested chronic and disabling conditions. White (2022) has called for more sociological attention to focus upon how people with illnesses and disabilities experience daily life and temporalities, which could be extended to include everyday experiences of loneliness and

how it manifests in experiences of ME. A sociology of health and illness perspective is especially important considering that existing literature on loneliness is often dominated by other disciplines, such as psychology (Qualter et al., 2015), social policy and gerontology (Walker & Hennessy, 2004).

ME AND CONTESTED ILLNESS

As doctors cannot biomedically verify the cause of the condition through diagnostic testing, ME is often met with disbelief and scepticism (Trundle et al., 2014). ME was found to carry more perceived stigma than other conditions with multiple unexplained symptoms (Looper & Kirmayer, 2004). Patients experience being trivialised and stigmatised (Cooper, 1997; Ware, 1992) through the psychologising of ME (Lian & Nettleton, 2015; Spandler & Allen, 2018), being blamed for their condition (Larun & Malterud, 2007) and having their morality questioned (Asbring & Narvanen, 2002). People with ME often experience difficulties receiving legitimisation for their suffering. They are sometimes accused of faking, imagining or making up their illness (Clarke & James, 2003; Guise, McVittie and McFinlay, 2010).

Due to the stigma of ME, patients struggle both accessing (Anderson et al., 2012) and inhabiting (Cheshire et al., 2021) Parsons' (1951) sick role. The sick role (Parsons, 1951) concept concerns the social role of being sick which includes a set of expectations and obligations in return for privileges, such as patients being exempt from their normal social roles. Drawing from the work of Freidson (1970) ME might be perceived as an illegitimate stigmatised illness, which provides few sick role benefits if any. Although there are limitations to the sick role, the concept highlights the limited legitimacy given to the ME diagnosis and how it ranks low within disease prestige hierarchy (Album & Westin, 2008; Blease et al., 2017) because it is contested with no biological markers. The low status accorded ME plays a role in preventing patients access to the sick role. Individuals who feel they are treated as illegitimate patients might experience worsened feelings of loneliness because they lack acknowledgement of their suffering and are unable to fully inhabit certain social roles, such as working.

The theorisation of stigma is well documented within the sociology of health and illness. Early stigma theory by Goffman (1963) defined stigma as a social characteristic that is discrediting for an individual or group. Stigma is typically regarded as having a negative impact on self-concept and identity formation (Link & Phelan, 2014; Scambler, 2006). Such is the stigma attached to ME that the updated NICE guidelines (2021, p. 9) for the condition urge health-care professionals to "recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people...who do not understand their illness". Scepticism surrounding ME has been found to lead to a sense of isolation and stigma (Dickson et al., 2008) and those living with stigmatised contested conditions, such as chronic pain (Rokach et al., 2018), may be especially susceptible to feeling isolated and lonely. Connectivity and sociability are expected and required in modern society, thus stigmatising loneliness (Sagan, 2017) makes it a taboo subject (Lasgaard et al., 2016). The stigma attached to loneliness might prevent people from seeking help (Barreto et al., 2022) particularly when combined with the stigma of ME.

However, there is limited research examining experiences of loneliness and ME, especially in relation to stigma. Psychologists, Boulazreg and Rokach (2020) suggest the lonely, isolating and alienating aspects of the ME are largely missing from current research. Experiential accounts of ME have acknowledged loneliness (Asbring & Narvanen, 2002; Parslow et al., 2017), withdrawal (Dickson et al., 2008), loss of friendship (Reynolds & Vivat, 2010; Travers & Lawler, 2008) and

decreased loneliness during COVID-19 government lockdowns (Brewer & Stratton, 2020). There are some common approaches to loneliness and ME including the individual incurring blame for their state/condition, being portrayed as products of modern living and being subject to trivialisation. Yet, an explicit focus on the situational and social aspects of living with ME and loneliness is under explored.

THE STUDY

This article draws from a broader study that sought to explore the diagnostic experiences of people with ME which was informed by the sociology of diagnosis, a subfield within the sociology of health and illness. Jutel and Nettleton (2011) have suggested that a diagnosis can be understood as a label and a process with social consequences. Amongst most of the participants, loneliness was found to be one of the significant ramifications of living with ME and experiencing the diagnosis. The study took place before the COVID-19 pandemic and loneliness was an unexpected recurring theme within the data.

Ethical approval was granted by the University of Sheffield. Each participant gave informed consent. After reviewing the literature, the recruitment of the interview respondents was conducted through snowball sampling, social media and local face-face ME groups. The initial snowball sampling was done through word of mouth and eliciting six interviews. The next stage of the participant recruitment involved the local ME patient groups from the website of the ME Association based in three different geographical locations. The leaders of the local groups forwarded my introduction letter to their members. The final stage of recruitment was conducted through the assistance of the ME Association by advertising on their social medical sites (Facebook and Twitter) and the ME Association newsletter.

The participants in the study had been diagnosed with ME by a doctor in the United Kingdom. The mean average time that it took to receive a diagnosis was two and a half years, the shortest duration was 3 months and the longest time to receive a diagnosis was 15 years. The ages of the respondents ranged from age 18 to 60, with a mean average of 38 years old. 36 women were recruited to the study, and 6 men, making 42 respondents overall. Although the number of men is low, many studies on ME focus exclusively on women and it is estimated that there are 2.4 times more women affected than men (NICE, 2021). The interview participants included 39 people who identified themselves as White British, two women who stated that they were White Irish and one woman who did not disclose her ethnicity. Accordingly, the study is limited by the lack of ethnic diversity in the recruitment sample.

Twenty one semi-structured interviews were conducted face-to-face, 8 were done via video conferencing and 13 were conducted over the telephone. I had intended to do all the interviews face-to-face, but telephone interviews were sometimes preferred by participants because they required less energy. Holt (2010) has suggested that telephone interviews should not be considered second best when there are practical reasons for using them. Interview scheduling was largely contingent on the participants' health status and self-care routines. The shortest recorded time was 40 minutes and the longest was nearly 4 hours (inclusive of comfort breaks and across several weeks). All the interviews were recorded and transcribed.

A thematic analysis of the data (Braun & Clarke, 2006) was undertaken while being reflective and reflexive in my approach. The interview transcripts were categorised using a descriptive coding scheme and separated thematically. The identified main themes included: loneliness, social isolation, diagnostic testing, decision-making, mental illness, legitimacy, gender, stigma,

patient responsibility and interactions with health-care professionals, friends and family. Not all the identified themes could be discussed in this article. Three of the subthemes capture participants' experiences of loneliness: restrictedness, communicative alienation and social withdrawal/rejection. Pseudonyms have been used to protect the participants' anonymity and the quotations are unaltered to maintain data authenticity and transparency.

FINDINGS

Restrictedness: Social reshaping

The interviews highlighted how, with the worsening and fluctuation of symptoms, the participants saw both their time and space increasingly restricted, and they became more socially isolated and lonely. Most of the participants prioritised conserving their energy for work or familial responsibilities over socialising outside the family. The severity of the ME symptoms meant no participants were able to work full time and the majority rarely socialised face-to-face outside of their homes. The loss of work left the participants more confined to the home and isolated. Changes to jobs or loss of employment had a profound effect on the loneliness experienced. They missed the friendships and the "thin ties" (Henning, 2017, p. 1404) (i.e. acquaintances) connected to their working roles.

ME had altered Josh's life (see Table 1) from being busily employed to being unable to work. He especially missed workplace friendships which dissipated once he became ill. As with all of the participants, life became increasingly temporally and spatially constrained.

Natalie: How has your life changed since becoming ill?

Josh: Err quite dramatically I've found. I used to work a lot of hours and I had a good social circle as well and I went from that to pretty much erm seeing no people but my wife everyday erm and sometimes the children but I can't really deal with that...one by one friends disappeared I suppose and yeah.

Josh saw his social contact largely reduced to his immediate family and he was mainly confined to his bedroom feeling isolated. Josh became more spatially restricted, and the structure of his day ran to a slower tempo due to illness routines and spending many hours in a quiet and darkened room. While Josh lived with his three children and wife, he felt emotionally distant through being unable to take part in his family's daily practices such as mealtimes, homework and play. He felt guilty about not being able to parent his children or support his wife in the ways he wished. Josh therefore experienced a deficit in the quality of and the quantity of this relationships (Peplau and Pearlman, 1981), which were tied to his social roles and expectations of himself as a father, husband and employee. He also experienced social loneliness (Weiss, 1973) through no longer being connected to his former workplace friendships.

ME permeated the minutiae of daily living for most of the participants and this is exemplified by Evelyn, who had severe fatigue and struggled to care for herself.

Evelyn: I'm housebound... I've also become a bit of a recluse because I find socialising very exhausting and it's cut me off a lot from friends and family...I couldn't be any more different to the person I was before really. Extremely bubbly and now being like a recluse.

Evelyn presents herself in stark contrast to the "bubbly" person she was before the onset of ME. Evelyn had to become a more passive version of herself to live with ME. The sustained demands of ME reduced social contact and limited the activities important to individuals' self-identity

TABLE 1 Interview participants' details.

Pseudonym	Age	Gender	Ethnicity	Previous occupation	Current occupation	Interview type
Alex	60	F	White	Social worker	Unemployed	In person
Amy	32	F	Declined	Student	Unemployed	In person
Becky	40	F	White	Administrator	Administrator	Phone
Cara	40	F	White	Student	Unemployed	Video call
Clare	42	F	White	Teacher	Unemployed	In person
Dave	43	M	White	Student	Unemployed	Phone
Dawn	21	F	White	Student	Student	In person
Donna	30	F	White	Student	Charity administrator	In person
Emily	43	F	White	Teacher	Teacher	In person
Emma	27	F	White	Administrator	Student	In person
Erica	57	F	White	Nurse	Unemployed	Phone
Evelyn	37	F	White	Dental nurse	Unemployed	Phone
Fiona	50	F	White	Nurse	Unemployed	Phone
Fran	55	F	White	Police officer	Unemployed	Phone
Georgia	46	F	White	Teaching assistant	Unemployed	In person
Gill	57	F	White	Administrator	Administrator	Video call
Gina	31	F	White	Marketing manager	Marketing manager	Phone
Grace	27	F	White	Teacher	Teaching assistant	In person
Harriet	57	F	White	Teacher	Unemployed	In person
Heather	37	F	White Irish	Nurse	Unemployed	In person
Jenny	47	F	White	Occupational therapist	Unemployed	Video call
Josh	37	M	White	Financial advisor	Unemployed	Phone
June	27	F	White	Administrator	Unemployed	Phone
Katie	40	F	White	Teacher	Teacher	Video call
Kirsty	30	F	White	Nurse	Unemployed	Phone
Laura	45	F	White Irish	Project manager	Unemployed	In person
Lauren	48	F	White	Nurse	Unemployed	Video call
Leanne	30	F	White	Architect	Architect	Phone
Libby	19	F	White	Student	Student	In person
Louise	55	F	White	Financial analyst	Unemployed	In person
Lucy	50	F	White	Health manager	Unemployed	In person
Marjorie	45	F	White	Teacher	Teacher	Video call
Martin	36	M	White	Teacher	Unemployed	Video call
Melissa	45	F	White	Barrister	Unemployed	Phone
Mike	43	M	White	Engineer	Engineer	In person
Miriam	41	F	White	Student	Unemployed	In person
Peggy	30	F	White	Nursery practitioner	Unemployed	In person
Phil	31	M	White	Fundraiser	Unemployed	In person
Rachael	36	F	White	Student	Volunteer	Video call

TABLE 1 (Continued)

Pseudonym	Age	Gender	Ethnicity	Previous occupation	Current occupation	Interview type
Rosie	31	F	White	Student	Unemployed	In person
Serena	59	F	White	Administrator	Administrator	Phone
Simon	43	M	White	Engineer	Engineer	In person

(Charmaz, 1991). This experience highlighted the negative impact of chronic illness identity and the “loss of self” (Charmaz, 1983). Evelyn used a management technique called pacing which requires a balance between expending energy and resting. Pacing affected the temporal aspects of her life, altering how she performed tasks and when. In her work on fatigue and chronic pain, Sheppard (2020, p. 43) describes how pacing can be “an ableist rejection of chronic pain and fatigue, but also a crip embracing of living with chronic pain and fatigue...but it can also be a site of conflict, of internalised ableism simultaneously”. Pacing and the social isolation of being immersed in chronic illness might be seen as both constraining or releasing (or both) for Evelyn.

After becoming housebound and unemployed, Evelyn rarely ventured into public areas where she might interact with people. In “The Loneliness of the Dying”, Elias (1985) described increasing isolation as the dying get sicker and more isolated in modern Western societies. In a similar way, the worsening of ME accompanied being increasingly invisible to the rest of society. Many of the participants spent most of their time at home, often in their bedroom, inhabiting private spaces rather than public areas, structuring their time around rest and necessary tasks. Online interactions rarely featured in the interviews outside of the context of researching ME.

In each interview, the participants reported dramatic changes to their lives, including no longer being able to sustain the social life they held prior to having ME. The changes brought on by living with ME might be seen as a form of “biographical disruption” (Bury, 1982), but the ebbing of relationships was more akin to a gradual erosion. Social isolation was necessitated through time and space being restructured as the individuals found themselves increasingly absorbed by illness. Requiring isolation for recuperation and illness routines was entangled with feelings of loneliness that emanated from wanting to socialise and connect yet feeling unable to fully do so. The more socially isolated the participants became, the more lonelier they felt. Social isolation and loneliness appeared to frequently engender each other and overlap. The competing and contrasting social and health needs impacted on the participants’ sense of loneliness, as did the loss of self-identity and changes to social roles.

Communicative alienation

Social expectations, roles and norms played an integral role in the social isolation and loneliness experienced by the participants. Feeling different from others is highlighted by the concepts of normality talk and communicative alienation. ‘Normality talk’—has been applied in different SHI contexts (e.g. Nettleton et al., 2013) but within my study, normality talk refers to when judgements were made comparing themselves (the participants) with their expectations of what their peers might be expected to be doing. Normality talk created a social distance between the participants and people without ME, affecting the quality of relationships and exacerbating feelings of what Weiss (1973) referred to as social loneliness, when we do not feel that we belong to a wider social network. Melissa had a professional job and lived alone until she relapsed with

ME which resulted in her being unemployed and living with her parents. She made comparisons between her current situation and the life trajectory she had previously hoped for.

Melissa: I mean I haven't had a relationship for years. They're just too tiring, too much. Most women of my age are settled but I won't be able to, not if I want to work. The most important thing is to work. A normal life has been taken from me. It's like being on the other side of a mirror, just looking in.

Other peoples' lives appeared multi-dimensional to Melissa, but her own felt focused on being financially independent and trying to manage her symptoms. Melissa's experience evokes what Charmaz (1991) referred to as "pulling in" when, during intrusive illness, people reorder their priorities and rank their relationships. "Pulling in" was a common experience amongst the participants. Melissa felt that a seemingly normal life was an illusionary goal. Melissa provided the quotation in the title "it's like being on the other side of a mirror looking in", which points to feelings of social loneliness through being on the peripheries of social life and lacking sharedness with others. Stein and Solomon (2017) found war veterans experience experiential alienation and a lack of belonging when they return home after service. There is a sense that their military world and home cannot be combined. Experiential alienation can be applied to experiences of living with ME through the contrast between the illness world and seemingly normal world.

In the following excerpt, Alex conveys how she felt on the margins of society rather than an active part of it. Alex previously had a demanding professional career and raised her children alone. She was no longer working due to ill health, feeling frustrated by constant illness and fatigue. Alex's experience was typical of finding it challenging to sustain friendships and make new ones.

Alex: I'm slowly getting to know people but I don't really get to see them and when I do see them they're like 'oh, how are you?' and I don't know what to say anymore. I just don't know what to say. I just don't have the conversation and you don't live in the normal world anymore. You're not going out there and doing a job and that sort of having interesting stimulation, keeping up with things. And sometimes you know I think, what am I going to say? I've never been like that, I'm a talker, it drives me mad.

Alex was acutely aware of lacking social commonalities with new acquaintances through being unable to partake in discussions that included hobbies or work. She spent most days resting in bed or trying to do everyday tasks such as wash herself. Alex found the crucial social and cultural prompts to guide interaction and conversation were scarce. Her main carer was her partner who believed ME was not a real illness but, despite this tension in their relationship, they remained emotionally connected. Alex did, however, lack people who could share or empathise with her experiences of ME, which points to experiential loneliness.

Drawing from the work of Little et al. (1998, p. 1486) the concept communicative alienation "expresses a state of variable alienation from social familiars brought about by the inability to communicate and share the nature of the experience of illness, its diagnosis and treatment". Alex highlights how her communicative alienation is punctuated by the loss of language and the sense of being left behind by the "normal world", living a liminal existence. Alex lacked the language to communicate her everyday routines and practices, which were temporally and spatially different to those around her. A sense of communicative alienation can also be seen in the following excerpt from Rosie, who was untypically bedbound for 5 years.

Natalie: Did your relationships change when you became ill?

Rosie: Yes, yeah I think they would anyway I'd kind of got used to people not seeing me. It was incredibly lonely the first few years that I was ill and I didn't know how to communicate with people either. People would visit me and I'd feel incredibly guilty about people with you know doing things in their lives that I'd missed out on that I'd missed out on stages in their life. I was quite envious of people.

Rosie's feelings of jealousy originated from her peers reaching milestones, such as graduating and moving out of the family home, while Rosie remained ill in bed at her childhood home. Rosie encountered communicative alienation when she was unable to relate to the lives of her peers and vice-versa.

For Melissa, Alex and Rosie, the absence of people who can provide empathic understanding and validate their identity creates what Stein and Solomon (2017: 42) describe as experiential loneliness, which is "failed intersubjectivity, denoting the expectations that others will share one's subjective state, but they do not or are incapable of doing so". As the participants became more isolated because of their illness, the communicative alienation worsened and perpetuated loneliness. Stein and Solomon (2017) found communicative barriers exacerbated failed intersubjectivity in their research on loneliness experienced by veterans with post-traumatic stress disorder. In a similar way the communicative alienation of ME perpetuates feelings of loneliness because there is a lack of empathy and understanding from others, either because they cannot or will not try. The next section expands on experiential loneliness through focusing on rejection and social withdrawal connected to the stigma of ME.

Discreditation and social rejection

Scepticism and disbelief about the reality and nature (psychological or somatic) of ME, placed a strain on relationships. Friends and family severed ties, or the participants socially withdrew to avoid continuing with negative interactions. Sometimes, there was mutual retreat from a relationship. Amy's interview is illustrative of how the stigma of ME impacted on participants' sense of loneliness.

Amy: Well the family were not convinced of what I had again they didn't believe in ME it was a fake illness. Y'know that kind of stuff.

Natalie: Was it just your immediate family?

Amy: Everybody (nods) it was. Erm friends I had at the time slowly disappeared. They used to visit me and they slowly disappeared but life goes on I suppose. Any relationship I've had in recent years it's always had a negative impact on. It's almost impossible to have decent relationship.

Amy had experienced disbelief in ME and the psychologising of the illness from health-care professionals, friends and family, including those who provided her personal care. Consistent with previous studies (Asbring & Narvanen, 2003; Spandler & Allen, 2018) psychologising ME was one of the most stigmatising aspects of the illness experience. Barker (2005, p. 106) coined the phrase "epistemological crisis" to capture when a patient is left to process the embodied and subjective feelings of their illness, which medicine is unable to objectively verify. When health-care professionals, family and/or friends voiced their distrust about the legitimacy of the

ME diagnosis, the participants felt epistemically invalidated (Wendell, 1996) and alone in their belief that they were genuinely ill. Accounts of being alone in one's experiences is, to an extent, captured by experiential loneliness (Stein & Solomon, 2017) but the concept does not sufficiently describe the experience of being stigmatised and lonely in our beliefs and illness narrative.

Social withdrawal from negativity and stigma was sometimes necessary to avoid worsening loneliness and to preserve a sense of self-identity and illness narrative. In many cases, social withdrawal and loneliness were the least negative option when faced with humiliation and stigma. Both situations were lonely but withdrawing often seemed less painful than continuing with harmful relationships. In the extract below, Evelyn describes the devastating impact that ME had on her relationships which highlights this common experience amongst the participants.

Natalie: Has your illness had any impact on any of your relationships, friendships?

Evelyn: ... Erm a lot of them have disappeared really my friends because they can't understand why I can't always see them and they take it personally...So there's not one relationship that the ME hasn't affected which is why I'm quite a recluse.

Symptoms of ME necessitated Evelyn's isolation as she rarely left the house because of pain, fatigue, mobility and cognitive problems. From Evelyn's perspective her friends and family were unable to accept that she was genuinely ill so they were offended by her lack of effort. Evelyn socialised less as she became more ill because of her symptoms (necessitated isolation) and the stigma she experienced. A spiral of loneliness (Malli et al., 2022) ensued wherein social isolation and loneliness perpetuated and overlapped with each other. ME might be perceived to be an illegitimate stigmatised illness (Freidson, 1970), which provides few sick role benefits, if any. Evelyn was not relieved of her usual roles and responsibilities within her friendship group but treated with scepticism and rejection. She was not exempt from the normal social roles or able to access the sick role because of the stigma attached to ME.

Although there are limitations to the sick role, applying the concept highlights how Evelyn's loneliness was exacerbated by a misalignment between the expectations placed upon her (to socialise) and her inability to meet them (due to being ill). Amy's and Evelyn's experience of having their illness discredited, being socially rejected and needing to socially withdraw echoes in many of the interviews. They were compelled into loneliness through stigma and a mismatch between expectations and social roles. Compelled loneliness can be seen to be a social consequence of the stigma attached to ME as well as the result of the social isolation necessitated by the symptoms. The next section discusses the conceptual contribution in more detail.

DISCUSSION

This article offers two novel conceptual contributions to the study of loneliness: necessitated social isolation and compelled loneliness. Necessitated social isolation was not always accompanied with wanting to be alone, but it was often necessary when living with the symptoms with ME. Time and space became increasingly restricted for the participants as the illness worsened. Loneliness frequently followed and overlapped with the unwanted but necessary social isolation frequently needed to live with the symptoms of ME. The need to socially withdraw and pace are examples of *crip time* when the participants lived their lives by their needs. While *crip time* can be seen to reject ableist notions of time, it is also illustrative of the broader influences of living with ME, which can impact on loneliness and social isolation.

Loneliness was shown to be one of the most significant social consequences of living with ME. Isolation and loneliness can potentially accompany any chronic illness but the stigma of a contested condition, such as ME, incorporates disbelief, scepticism and rejection. Discourses on loneliness have emphasised individuals' responsibility to improve their loneliness which suggests agency and choice regarding how lonely we feel (Duggan, 2021; Jones, 2022). Yet, when faced with illness and stigma participants had limited choices in how they responded. The participants' ability to overturn stigma was limited by the contested medical knowledge of the condition and prevailing medical scepticism (Asbring & Narvanen, 2003) about the illness.

The second novel concept, compelled loneliness, attempts to capture how stigma contributes to loneliness. The participants were induced into loneliness through social withdrawal and social rejection attributed to the stigma of living with ME. Social rejection was not sought or especially controllable. Social withdrawal was sometimes required to avoid further negativity and sustain a positive identity and illness narrative. This is not to suggest passivity in relationships but instead acknowledges social and situational aspects of loneliness which might affect a person's capacity to overcome or withstand loneliness. Doing so, moves away from blaming the individual for their loneliness. Compelled loneliness can be a mixture of being freeing, constraining, frustrating, sad, welcome, unwanted and pragmatic. This conflicting and contradictory experience of compelled loneliness is reflected in how Bound Alberti (2018) conceptualises loneliness as an emotion cluster which is multifaceted. Moreover, the article has shown that there is not one way to experience loneliness, but it has drawn attention to both necessitated isolation and compelled loneliness which can be social consequences of living with ME and the diagnosis.

Compelled loneliness also sheds light on experiential loneliness, which is when others do not understand or share our experiences. Experiential loneliness is applicable when others do not empathise or understand the experience of being submerged in debilitating illness. Communicative alienation (Little et al., 1998) demonstrated how some of the participants felt left behind and marginalised through necessitated isolation and growing loneliness. With increased social isolation and submersion into illness, it became increasingly difficult to find commonalities and share similarities with the lives of others and vice versa, which is particularly poignant when living with an illness which is contested and stigmatised.

Although more research is needed, the article shows how it can be difficult to break a loneliness cycle when people have prolonged health challenges that can prevent them from acting upon loneliness. Isolation and loneliness have been shown to overlap and recursively produce one another. In their research, Malli et al. (2022) highlighted a cycle of loneliness which is a downward spiral of becoming increasingly lonely as an individual becomes more isolated and further removed from the rest of society (Killeen, 1998). In a similar way, the participants became increasingly compelled into loneliness as their social isolation became more necessitated. The more they were socially rejected or withdrawn the more isolated and lonely the participants became.

CONCLUSION

This study contributes to understanding how loneliness and social isolation are experienced by people who have been diagnosed with ME, and potentially other contested conditions. The stigmatisation of ME and loneliness can result in the needs of people with ME being overlooked and marginalised. Interventions that aim to support ME patients experiencing loneliness need to consider incorporating individual's social needs *and* their health challenges. Promoting meaningful and empathetic relationships should be prioritised over increasing social connections.

AUTHOR CONTRIBUTIONS

Natalie Wotherspoon: Conceptualisation; data curation; format analysis; funding acquisition; investigation; methodology; project administration; supervision; validation; visualisation; writing - original draft; writing - review and editing.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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