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# There but not really involved: The meanings of loneliness for people with chronic illness

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A R T I C L E   I N F O

A B S T R A C T

Loneliness is one of the most pressing and rapidly growing contemporary social challenges around the world. Yet we still lack a good understanding of how loneliness is constituted and experienced by those most affected. We conducted semi-structured interviews with 40 people with chronic illness who were experiencing loneliness to explore what loneliness means to them and how it impacts in their daily lives. Drawing on ideas around liquidity and performativity, we identified the relational, temporal and social layers of loneliness. Our analysis revealed the interconnectedness of chronic illness and loneliness in participants' daily lives, as well as how chronic illness shifts temporal orientation, and transforms interpersonal relationships and relationship with self, contributing to the experiences of loneliness. Though participants described the many social conditions that restricted their opportunities for social participation, giving them a sense of being left behind and spectating the social life of others, a rhetoric of loneliness as a problem and responsibility of the individual was still prominent. A narrative of the need to perform social connection emerged in the absence of meaningful social bonds with others. We argue that normative ideals of wellness and positivity circulating in chronic illness communities and society more broadly are implicated in the experience of loneliness for people with chronic conditions. We conclude by considering how more expansive representations of how to live well with chronic illness may be important in reducing personal and collective loneliness.

## 1. Introduction

Loneliness is one of the most pressing and rapidly growing social challenges of the 21st century globally, contributing to a range of health and social problems for individuals, communities and health- and social-care systems (Holt-Lunstad et al., 2015; Hawkley and Cacioppo, 2010). Loneliness is described as the distressing feeling that arises when there is a felt discrepancy between desired and actual social relationships (Peplau and Perlman, 1982; Russell et al., 1980). People with long-term health conditions are at high risk for loneliness and its attendant health impacts (Lim et al., 2023). Although the negative consequences of loneliness on health and wellbeing are well known, finding effective responses to the problem remain an ongoing challenge. We currently

lack a good understanding of what loneliness means; how it is constituted and experienced by those who are most affected, and how complex interwoven individual, interpersonal and structural factors are implicated in lived experiences of loneliness (Barjaková et al., 2023; Hajek and König, 2020; O'Sullivan et al., 2022; Prohaska et al., 2020).

While closely related to concepts like social isolation and disconnection, its meaning differs. Social isolation is an objective measure referring to lack of social connections, whereas loneliness is the subjective experience of dissatisfaction a person ascribes to their social connections (de Jong-Gierveld et al., 2006). A person can feel lonely because they are socially isolated, but those with large social networks can also experience loneliness. Scholars have identified different kinds of loneliness including emotional loneliness (absence of intimate

relationships) (Weiss, 1973), social loneliness (absence of wider social networks/groups) (Weiss, 1973), and existential loneliness (feeling separateness of self or alienation from others) (Bolmsjö et al., 2019).

Loneliness is inherently a social condition, linked to increasing individualisation and digitalisation, and changes in values-systems and in work, family and social infrastructures (Putnam, 2000; Bauman, 2000). Such changes have markedly shifted how we care, live and relate to others (Franklin, 2012). Despite these changed social conditions and wide recognition of the social and psychological complexities of loneliness, there is little that moves beyond individualised solutions. Loneliness is still treated, primarily (but not always) as a personal deficit to be fixed by an individual, with support of health professionals (Malli et al., 2023). Thus, individual counselling and social prescribing have been touted to be potential solutions to loneliness as they give individuals the tools they need to become more socially connected and better cope with their loneliness (Hawkley and Cacioppo, 2010; Liebmann et al., 2022). Yet, such interventions have lacked potency, in part because they have not sufficiently addressed the complexity of loneliness as both a personal and a collective problem (Masi et al., 2011). Nor, have these interventions adequately addressed the social forces driving loneliness, including the social conditions that can work against lonely individuals' ability to connect meaningfully with their communities.

Contemporary research has demonstrated that there are individual, interpersonal and social processes that underlie the diverse meanings individuals give to their experiences (see Malli et al., 2023, as an example). Building on this research and capturing the meanings of loneliness, in this paper we examine how people living with a chronic health condition experience loneliness in their daily lives, and what meanings they give to loneliness, attending to its relational, temporal and embodied facets (Franklin and Tranter, 2021).

## 2. Background

### 2.1. Conceptualisations of loneliness

Considerable research spanning psychology, sociology, health sciences and disability studies has highlighted the interrelationships between loneliness and chronic illness (Barlow et al., 2015). Loneliness has been associated with limitations imposed by various chronic physical and mental health conditions (Christiansen et al., 2021; Fagerström and Frisman, 2017; Allen et al., 2020). A recent study (Lim et al., 2023) found that compared with those without a long-term health condition, those experiencing chronic ill health had twice the risk of chronic loneliness. This is due to complex interwoven factors associated with chronic illness, including substance abuse (Smith, 2009), identity (Walden, 2009), carer roles (Hash, 2006), socio-economic status (Van Wilder et al., 2021; Kung et al., 2022), and disruptions to social relationships (Marcille et al., 2012). The interrelationship between chronic illness and life circumstances can lead to a decline in social status and resources, as individuals are forced to limit their engagement in work and leisure activities, which over time is likely to contribute to loneliness (Daker-White et al., 2014). Disability studies scholars have further contributed to understanding the relationship between loneliness and chronic illness, highlighting the role of the social environment (social model of disability). Rather than seeing loneliness as an outcome of bodily impairments that limit social activities and participation (medical model of disability), they emphasise that loneliness is the outcome of negative stereotyping, stigmatisation and oppression that place obstacles to social inclusion (Hogan, 2019; Burholt et al., 2017).

Despite recognition of the importance of understanding and responding to loneliness as having both psychological and social dimensions, the ways in which much recent psychological, health and social science literature has sought to conceptualise loneliness is singular in nature, rather than multidisciplinary. Thus, approaches to understanding loneliness remain largely positioned in opposition or in tension with one another. It is unsurprising, therefore, that proposed solutions that follow these approaches focus on specific aspects of loneliness, and its attendant causes (be they psychological, social, or medical), but often fail to recognise how these causes are intertwined in producing loneliness and its effects in individuals' daily lives. An exception from the population-based Framingham Heart Study used network linkage data to draw connections between social and psychological causes of loneliness, showing that loneliness occurs in clusters and spreads through social networks (Cacioppo et al., 2009).

### 2.2. The sociality of loneliness

Those conceptualising loneliness as a social issue emphasise its relational dimension (see Rogers and Pilgrim, 2023). Loneliness is not only the plight of an individual but a description of their social-psychological context and implies the presence or absence of others (Rogers and Pilgrim, 2023). Thus, attending to social context is vital to understanding how individuals experience such presence or absence. For example, Bauman (2000, 2003) argues that the shift in relationships within the social sphere, once deemed "solid" (i.e., stable and fixed) are now "liquid" (i.e., uncertain and flexible). Citing neoliberalism, consumerism, changed communication, and ideologies of choice and freedom, Bauman (2000) argues that relationships are now fragile, temporary, and vulnerable to constant change and this has a disruptive impact on how people are able to engage with each other, especially in the digital age (p.64). Franklin (2009) too argues that attention to the social processes inherent within social structures provide the key to understanding widespread loneliness in many contemporary societies:

> In liquid modernity loneliness is the price we pay for our freedom and choice since, given that it is extended to everyone, there is nothing at all to stop those who love you now, who support you now, who employ you now, from dumping you the minute they become bored of you or find a better alternative (p.352).

### 2.3. Performativity, identity work and loneliness

Relationships between the self, society and performativity are also important to contemporary understandings of loneliness (Bell, 1999; Goffman, 1959; May, 2011). Within Bauman's (2000) liquid society, social interactions are no longer fixed and somewhat predictable, they are an ongoing task to be performed. Understandings of loneliness thus require consideration of the acts performed (across front and backstage contexts) and how these performances are embedded in habitual practices, processes of socialisation, and cultural expectations that extend beyond individuals and their interpersonal relationships (Goffman, 1959). The formation of social selves involve particular performances that are produced through social interactions within social spaces (Goffman, 1959). Social actors construct multiple selves as they move between different situations and spaces (Scott, 2015). Moreover, social identities are managed in relation to the roles that individuals are expected to play in these different contexts. This involves what Goffman (1959) refers to as impression management, whereby individuals actively manage what they show in the public realm about who they are, what they feel, and how they act, in relation to what others expect of them. As Emejulu and Bassel (2023) argue:

> Rather than loneliness being an individualised feeling of aloneness, in fact it is the manifestation of deep alienation in spaces ostensibly constituted by egalitarianism, camaraderie and solidarity. Loneliness is that emotional gap – a structure of feeling, perhaps – between the desire for community and companionship and the stark reality of how that longed for community actually operates. (p.4)

The imperative to be seen as companionable in public spaces, while on the surface can seem to be a basis for social connectivity, can in actuality serve to silence individuals with chronic illnesses, and render

them lonely. Ableist norms of behaviour and expression, such as being self-reliant, can powerfully shape how individuals with chronic illnesses feel. When feelings of loneliness must be managed and hidden from public view, this may further exacerbate their loneliness.

Cultural assumptions about chronic illness – a problem of the individual that requires 'fixing' through self-management – also shape the experience of loneliness and its meanings. Relationships between individuals with chronic illness and others are what Sointu (2016) describes as "affect-laden encounter [s] where the social subtly entwines with the emotional" (p.315). The entanglement of assumptions with affect – related to for example, understandings of responsibility, deservedness and agency – carry important implications for these relationships, affecting how loneliness circulates these relations, and how others respond and relate to those with chronic illnesses. Both biomedical classifications and social meanings associated with chronic disease entwine in the generation of loneliness and its negative health and social effects.

While Sointu's (2016) work on the entanglement of affective experience with social meaning is pertinent, understandings of how the symbiotic relationship between loneliness as an emotional and social issue unfolds in individuals' experiences and expressions of loneliness remain limited. How people make sense of loneliness in their everyday lives and the meanings that they give to their experiences is important in capturing how social meaning and affective experience come together in the experience of chronic illness. This paper draws out the various dimensions or layers of loneliness that individuals articulate in their daily lives, paying particular attention to the emotional, temporal, existential, and structural facets of the experience.

## 3. Method

This article draws from a multi-stage qualitative study exploring the experiences of individuals with a chronic health condition who were experiencing loneliness, and the meanings they gave to these experiences (Moensted et al., 2023). Our approach was informed by interpretivist and constructionist traditions of qualitative research as we wanted to examine how people construct meaning and experience their social world (Creswell and Poth, 2016; Denzin and Lincoln, 2011). Ethics approval was provided by the University of New South Wales Human Research Ethics Committee (HC200333).

Participants were purposively sampled from a range of geographic locations (e.g. urban, regional, rural), socio-demographics (e.g. age, relationship status, ethnicity, socio-economic status), and time since diagnosis of their condition. Recruitment materials developed were aimed at individuals who were 18 years or older who had been diagnosed with a chronic health condition and were experiencing loneliness, social disconnection or social isolation. Participants self-identified for the study. They were recruited via advertisements; presentations to social care and chronic illness organisations and associations; direct recruitment via clinicians; and snowball recruitment. We did not limit the study to particular chronic illnesses. Sampling and recruitment strategies were aimed at recruiting participants with diverse experiences of living with chronic illness and loneliness.

Data collection took place between November 2020 and April 2022. After participants provided informed consent, an interview was conducted one-to-one, either face-to-face in a location convenient to the participant (e.g. the participant's home), or via video-conferencing (e.g. Zoom). To capture the interrelated emotional, temporal and social dimensions of loneliness, where possible we interviewed participants (in person or online) on one or two more occasions during a 12-month period. A semi-structured interview guide was used for each interview. In the first interview, questions explored: experiences of health, illness, healthcare, and loneliness, strategies for managing feelings of loneliness or social isolation, and beliefs about loneliness. During the second interview, participants were asked about social networks and experiences of social relationships and supports as well as places that

were meaningful to their experience of chronic illness and/or social connectedness. The third interview provided further opportunity for participants to reflect on their experiences and any changes in these experiences since the previous interviews.

Interviews were conducted with 40 people (28 women, 11 men, and one non-binary person), ranging in age between 19 and 83 years, and residing in a range of metropolitan, regional and rural areas in Australia. Participants were living with various chronic health conditions including chronic fatigue, osteoarthritis, chronic back pain, multiple sclerosis, chronic obstructive pulmonary disease, diabetes, fibromyalgia, depression, and anxiety. Forty people participated in one interview, 30 in two interviews, while three people participated in a third interview. Participants were given a gift card to thank and compensate them for their time. Two authors (both white women and experienced qualitative researchers and social scientists) conducted all the interviews. After each interview, they wrote detailed fieldnotes, including impressions and reflections on their role in co-producing the data relationally with the participant. Interviews were professionally transcribed, reviewed for accuracy and then de-identified. A pseudonym was assigned to each participant.

Analysis was thematic and inductive, guided by a reflexive approach to thematic analysis (Braun and Clarke, 2019). Our interpretations reflect our position within the narrative, and our active role in producing knowledge (see also Riessman, 2008). We chose this analytical approach as we wanted to deeply explore the meanings of loneliness to participants, including underlying, covert or implicit meaning of this social phenomenon. Transcripts were read repeatedly to gain familiarity with the data, and then coded in nVivo for recurrent ideas to create emergent codes. A central point of our research interest is the social construction of meaning and how discourse, social relations, and lived experiences of illness shaped the meaning participants gave to loneliness (Charmaz, 1990). All data that related to how participants described loneliness and its meanings, in relation to their daily lives were then extracted and analysed by one author to identify substantive conceptual patterns. The author met regularly with the wider research team to discuss their interpretations, ensuring rich interpretations of meaning. Through this process, data were synthesised into broader topic categories and themes. Themes identified were then compared across transcripts to identify points of commonality and difference and explored in relation to theoretical and empirical literature on emotional, social, and existential dimensions of loneliness (Green and Thorogood, 2018).

## 4. Findings

Three themes developed through our analysis revealed the dimensions of the loneliness experience of our participants. First, loneliness was conceptualised relationally as 'invisibility of self'; second, the temporal dimension of loneliness was encapsulated in the idea of 'being left behind'; and a third dimension, living life on the periphery, was evident as participants described how they were 'spectators of social life'.

### 4.1. Theme 1: the relational dimension: loneliness as invisibility of self

Participants' accounts illustrate the social embeddedness of loneliness and how experiences of loneliness are nested within relational and interpersonal dynamics (or in the felt absence of these relations). Loneliness arose in social encounters where participants felt a lack of meaningful connectedness with another person, and the absence of their gaze, validation or esteem (Franklin et al., 2019). Loneliness as the absence of recognition and value within social relationships, and feeling overlooked, diminished or misunderstood is articulated below by Tina. For Tina, loneliness is the absence of someone to witness both pain and triumphs, and is interconnected with the experience of chronic illness:

… loneliness is not feeling heard or seen. It's not having a connection to somebody who makes you feel like you have inherent value, that you're worth talking to, worth being around. It's not having your pain witnessed […] or your triumphs witnessed. Have someone to pat you on the back when you've overcome something. I think we all want people around to validate our experiences, and loneliness is an absence of that. (Tina age 34, multiple conditions including fibromyalgia, intestinal disorder and post-traumatic stress disorder)

This interconnectedness is also evident in Elizabeth's account. Elizabeth describes loneliness as having no one to share their illness experiences with, and she feels especially lonely when her symptoms are more severe:

There are times when I feel lonely […] because I can't share with other people. Especially being in hospital … and not having visitors can be really lonely. Even just being sick at home by yourself can be really quite lonely […] not being able to share parts of yourself … (Elizabeth age 31, chronic bowel condition)

In a similar vein, Michella below, describes how being in physical pain intensified the felt absence of someone to provide comfort. While Michella desired partnership, her fear of dependency on others and what that signified (e.g., pity, shame, helplessness) was an obstacle to seeking new social connections:

The fact that I'm doing it on my own, that I don't have someone that I can just curl up into and say, "I'm in pain." That just represents being alone and dealing with it on my own. I don't want to be a burden on anyone. I don't want somebody's pity, but I do want somebody here to be able to share and talk with. A partner. That is something that I crave very deeply. (Michella age 50, autoimmune condition)

Though participants generally expressed a desire to improve their situation and become more socially connected, cultural narratives of loneliness as an individual deficit appeared to permeate some participants' accounts and were experienced as shameful and burdensome. Holly for example, characterised herself as deficient and morally responsible for not being connected with others:

Sometimes it feels like it's a shame, like I'm defective, that, "What is wrong with me that I can't manage relationships?" or, "Why am I feeling like this? I'm faulty, I'm to blame for something." (Holly age 62, multiple conditions including incontinence, chronic pain, sleep apnoea and anxiety disorder)

Being dependent on others for connection as something to be avoided was also reinforced in some of the messages that participants received from their family members or friends. Elizabeth recounted that when she sought emotional intimacy from her family, she had been instead given advice about how to individually fix her loneliness through doing particular activities or adjusting her mindset. Elizabeth rationalises below that the responses of others might be traced to misunderstandings of what loneliness is and how it is experienced, and thus what remedies might be needed:

… sometimes when you do reach out when you are lonely, I think people […] can't grasp that maybe. And instead of the company that you need, they might withdraw or send you down different directions and be like, "Oh, you need to do this or that." When it's like, "Actually, it would just be really nice to hang out for five minutes and talk." (Elizabeth age 31, chronic bowel condition)

As Elizabeth described, directives toward particular activities or behaviours (while well-intentioned) did little to tackle social loneliness and the felt absence of meaningful connections with others. Elizabeth's quote illustrates the risks involved in seeking social connection with others, such as others rejecting them, or casting them as unmotivated or lazy. This finding challenges the idea that loneliness is within personal control. Positioning loneliness as an individual concern and

responsibility can be counter-effective and harmful by preventing individuals from seeking out social support, as well as characterising those who are lonely as lesser within society:

… doing it all on your own just amplifies it. It really does. And I have trouble asking for help and it's just easier to do it on my own. (Michella age 50, autoimmune condition)

The interpersonal dynamics of loneliness were also evident when participants described loneliness as not feeling important or significant in the life of another. The belief that no one thought of them was a central feature of the loneliness that participants like Freya, below, experienced. For her, loneliness was not just the absence of a close individual (e.g., a partner or a friend), but of being abandoned by the collective that created a sense of insignificance; something that Freya had experienced across her entire life:

Loneliness is very closely associated with the sense of abandonment and neglect and just that insignificance, and nobody will really notice if you're there or not kind of thing, an invisibility and just a lack of value and worth to others. (Freya age 44, multiple conditions including chronic pain, post-traumatic stress disorder, arthritis and endometriosis)

While Freya describes loneliness as a feeling of insignificance from another person, Bruno similarly describes loneliness as being unimportant within his social group and society more broadly:

… if I were to try and distil the feeling of loneliness down … I would say that it arises from a sudden feeling of being peripheral and unimportant to my social group, and by extension, to greater society. (Bruno age 32, multiple conditions including chronic fatigue syndrome, nervous system disorder and anxiety disorder)

The lack of consideration or acknowledgement described by participants seemed to be reinforced by the felt need to "not draw attention" to their illness and perform 'wellness' when socialising with others. They rationalised that hiding symptoms was a strategy to belong – to be seen as a member of the 'well society' and not be stigmatised as sickly, frail, difficult or narcissistic:

Like that feeling of just wanting to be like everyone else and not stand out, and not draw attention is a big thing. And that's a large part of it. I think why I just keep going and push through even when I'm having really bad days. I'm like "I don't want to be difficult. I don't call up sick, I don't want to draw attention to myself, I don't want to be a problem." (Elizabeth age 31, chronic bowel condition)

Participants frequently reported being abandoned or neglected by family members, peers and within wider communities and networks such as social clubs or support groups, when their illness-mediated "stage presence" drifted outside of prescribed social roles. As Tina, below, illustrates, failing to perform *for* others or deviating from an expected family script could lead to social rejection or withdrawal:

What every human being wants is to feel seen and understood, and I don't think I was ever understood by my family. I think they've got me in a very narrow set of parameters as to what role I need to perform for them, and if I'm not playing that part then I'm maligned, and that hurts. (Tina age 34, multiple conditions including fibromyalgia, an intestinal disorder and post-traumatic stress disorder)

Finally, loneliness was conceived as not just alienation from both familiar and unfamiliar others but also from self. Loneliness as emanating from disconnection with self is captured in the following extract, where Zarah describes feeling lonely when their sense of self and embodied experience of illness became detached or misaligned:

When I feel connected to myself I feel less lonely. Because sometimes you can feel lonely with yourself. But you're just uncomfortable in your body. (Zarah age 21, multiple sclerosis and depression)

Similarly, Adelaide, describes loneliness as associated with not knowing their new embodied self:

Grief and loneliness tend to go hand-in-hand. […] I didn't understand for myself that my loss of identity, as in my working life and my part as a partner and a mother, et cetera, et cetera, was part of my ID. That was my identity. (Adelaide age 83, lung condition and osteoarthritis)

Thus, loneliness is conceived as the absence of meaningful relationships at different relational dimensions: the personal—a detachment from self; the interpersonal—a chasm existing between self and close others; and societal—a distance from those in the community less familiar to them.

### 4.2. Theme 2: the temporal dimension: loneliness as being left behind

Loneliness was also described as having a temporal dimension: as arising when past belonging is lost or absent in their present realities (see May, 2017). Participants frequently described loneliness as the experience of "feeling out of touch", being left behind, stranded or stuck in time, as they watched their peers move forward on a conventional (linear) life course, accomplishing significant milestones like finding a partner, entering the job market, or becoming a parent, seemingly with ease, which participants said were difficult or impossible for themselves to achieve due to illness. The inability to keep up with peers and fulfil their own hopes for the future are evident in Tina's account of loneliness. She describes loneliness as more than the absence of meaningful relationships but also missing out on the life imagined for oneself:

You feel like you're frozen at the point you got your disability. I don't have a career, I don't have children, I don't have these bucket list of things that I can do or have under my belt, like I never went travelling […] you do have a sense of missing out and not ever really being in the same river as everyone else is flowing down. (Tina age 34, multiple conditions including fibromyalgia, intestinal disorder and post-traumatic stress disorder)

The temporal dimension of loneliness is also demonstrated in Bruno's account, who describes being left behind by friends as the demands of chronic fatigue and co-morbidities limited their capacity to participate in social events:

I feel lonely and isolated when I cannot attend a social event or find out what great things my friends are up to. This makes me feel like a stationary object, and others are leaving me behind. This experience is also typical of holiday seasons, which are particularly exhausting for me, and I often decide to stay home instead of attending. (Bruno age 32, multiple conditions including chronic fatigue syndrome, a nervous system disorder and anxiety disorder)

Without achieving important cultural expectations that anchored individuals in time, participants articulated a sense of becoming untethered, not just from peers, but also from a community – the loss of "feeling a part of something" – as illustrated by May:

I guess, the whole world is shut off. You're kind of the only person that exists at the time. It's dark and, I mean, you feel really small, but it's just this vast amount of just emptiness. It's just completely disconnected. No sense of anything that kind of tethers you to anyone or anything else. (May age 22, rare inflammatory disorder and attention deficit hyperactivity disorder)

While the idea that memories of past belonging can be an antidote to present loneliness has been described in the literature (e.g., May, 2017), in this study participants' narratives suggest that the relationship between past and present loneliness and belonging is more complicated. The memory of past belonging was a reminder of what had been lost, and thus could intensify loneliness in the present for some participants. Grieving past connectedness is discussed by Rory, who talks about the pain of family estrangement:

… family I do have, I'm either distant from geographically or emotionally or they're just non-existent. And that's something that I do think of a lot. When I was younger it was like my family was much more connected. I was more connected to [them] […] there was really always someone that I could talk to whenever I wanted to talk to someone. […] And that is, I suppose, one of the factors that I consider that drives my loneliness, not having those people, them not being close as well. (Rory age 59, fibromyalgia)

Conversely, the accounts of others suggested that past loneliness (often cemented in childhood through trauma) haunted the present. Participants who reported childhood loneliness said that moments of social rejection in the present triggered the memory and feeling of loneliness from the past, revealing how the experience of loneliness traverses different time-scapes, including present experiences:

I was quite sick with that feeling of loneliness, but it wasn't as if it's the first time. Because what it did was it triggered my experiences of what it was like during the marriage, if you know what I mean. I've had intense periods of loneliness and isolation and feeling abandoned […]. So, it was triggering childhood stuff too. (Holly age 62, incontinence, chronic pain, sleep apnoea and anxiety disorder)

As well as their vision of the future:

The thing that scares me the most is that […] down the track I am really going to be isolated and lonely because obviously my young daughter will want to leave and pursue her own life and I don't know what I'm going to do then. I don't know what the future will unfold then. (Jasper age 55, epilepsy)

Nostalgia for a previous version of themselves was also important in understanding loneliness. Participants who traced their loneliness to their diagnosis of chronic illness described loneliness as the gap between their current lived reality and the imagined life they *could* or *should* or *hoped* to have had. Rosemary describes feeling alienated from their current life and those they shared their life with:

… if I see a couple our age that look like they're retired and they're off walking their dog, it never goes away. I always just look and think, "That should be us. We should be walking the dog or going for a walk." […] I'm always stuck there and I'm always having this constant feeling of grief of that, and that makes you feel isolated. It's just hard to embed yourself in what's going on, because you know you're not quite able to do what you want to do. (Rosemary age 66, neurological disorder and tick-borne disease)

The inability to do activities that previously gave their lives meaning and purpose left many feeling disillusioned with their current situation. The sense of a stolen future was difficult to share with others, or for others to understand, contributing further to participants' sense of disconnectedness.

### 4.3. Theme 3: the social dimension: loneliness as being a spectator, not a player in social life

In addition to the relational, temporal and existential layers of loneliness, participants conceived loneliness as being a spectator rather than an active participant in social life. Many participants said that loneliness emanates from observing the social interactions and happenings of others, seeing the connection they have, and the associated pain of feeling excluded from social participation. Participants, like Jasper (below), recounted that loneliness was painfully heightened in spaces where people gathered together and socialised be it at parties, dinners, the dog park, or at home, because it drew attention to what they did not, and would never, have:

I witness families, all doing something together and I see how happy they are, and that's very good. But when I look at myself, I turn a blind eye to the fact that I've simply got nowhere near any prospects of ever getting like that. (Jasper age 55, epilepsy)

For Jasper, loneliness arose when there was a deficit between the imagined social connectedness of others, and their own lived reality. Moreover, and illustrative of the spatial facets of loneliness, public spaces were also sites where there was an ever-present threat of social rejection. As Michella described, one's desire for social connection through being among others, needed to be continuously assessed against the potential threat of social judgement or ridicule:

Every Saturday I go into town, have a bit of a look around the shops, buy my groceries, and I sit and have a coffee and read the paper. There's other people that do it, so that connects me with them. […] The fact that I do it on my own and I think that people look at me and think, "Oh, she's a bit tragic." (Michella age 50, autoimmune condition)

While for Michella the social benefits of enjoying her weekend café routine outweighed the social risk of being judged by others, this was not the case for everyone, and there were participants for whom, the threat of social alienation in public spaces was a greater social harm than any benefits drawn from "being out":

The loneliness of "being on the sidelines" was closely related to the experience of chronic illness or disability; of not feeling part of the wellness community or the "able-bodied world". This sense of being on the periphery of mainstream (well) society is illustrated by Rosemary. Rosemary describes how socialising with people without lived experience of chronic illness, regardless of the efforts or affordances made by others to try to include her, served as a constant reminder of what she could not do. Upward social comparisons constrained her ability to participate in social events leading to self-imposed isolation:

… you can never be completely engaged with the group that you're in because you know that you can't be always part of the activities that they're talking about or the experiences that they're having or things that they're doing or whatever. (Rosemary age 66, neurological disorder and tick-borne disease)

The loneliness of being physically present but unable to meaningfully participate was also experienced within immediate family interactions. As Tammy describes, living with chronic illness sometimes demanded self-isolation as a form of self-protection and self-care, but that this left her feeling lonely as she was missing out on engaging with her partner and children:

I'll have to retreat to my room because I'm tired at that point in the day. And that can feel lonely even with people around you. […] Because whilst they're physically next to me and they're with me and they're trying to engage with me, I'm hindered by my own ability to really take part in the conversation. (Tammy age 48, multiple sclerosis)

Tammy touched on how living with chronic illness sometimes required acts of *performing* social engagement. The performative aspects of social interaction, are also noted by Holly, who describes going through the motions of social connection:

… everything is such a huge effort and empty and sad, extremely sad. But, at the same time, you're still performing, like jumping hoops. You're still going through the process of being connected in the community space, but actually not being able to feel healthy about that. That's not a healthy connection. There's no sense of joy, there's no sense of laughter, no sense of relief, no sense of ending, [its] a constant experience of discomfort. (Holly age 62, multiple conditions including incontinence, chronic pain, sleep apnoea and anxiety disorder)

Holly's reflections on loneliness and un/healthy connection, reveal both the entanglement of chronic illness and loneliness, but also about the shortcomings of well-intentioned directives of others to fix loneliness through individual actions (e.g., joining a walking group or a club). Holly describes the "huge effort" and struggle of "going through the process of being connected in the community space", but that ultimately these efforts, which leave her feeling empty and ill at ease, may work against belonging and social wellbeing.

Yet revealing of the complexity of living with chronic illness, participants frequently commented that they not only felt outside of the "able-bodied world" but also that they did not belong to the disability or chronic illness community. In a sense they were trapped in-between these spaces of belonging:

I just can't find a slot to fit into. [..] I've looked for something around the fact that I have a disability, something that I could do and be involved with, but I can't find it. I just can't find what that is. I don't know what it is. […] You really do either have to be able-bodied or you have to be an elite disabled person. (Rosemary age 66, neurological disorder and tick-borne disease)

Here Rosemary, describes how the fluctuation, unpredictability and invisibility of symptoms (hallmarks of many chronic illnesses), can make one feel like an outsider to an imagined disability community. Rosemary resists the able-bodied/disabled binary. Their narrative disrupts the normative idea that "disability is a cohesive identity and community" as feminist and critical disability scholars have also argued (Simplican, 2017 p.46). Rosemary's account also highlights that how 'fixed' or stable one's identity of disability and/or chronic illness (and how visible it is to others) could be important to the experience of loneliness.

The struggle to find alternative and more diverse representations of how to live well with chronic illness was also described by Verna, who was reliant on a mobility scooter due to the severity of her multiple sclerosis symptoms (e.g., pain, fatigue and muscle weakness). Verna found it hard to see representations within both the mainstream and the multiple sclerosis community about wellness and positivity that did not align with her own lived experience:

I try not to [compare]. But since it's what's in the mainstream, you're bombarded with it time and time again. All the stories are about family and children. […]And in the disabled community, well, in the MS community, there are others doing very well with exercise and all the rest of it. You get the picture and twist it in there, "Well, you don't have it as bad as I do." (Verna age 68, multiple sclerosis)

Despite participants describing the social conditions that closed down opportunities for their social participation, they still often conceived loneliness as within their personal control. Tammy captured this idea below by attributing loneliness to her lack of effort and inaction, as well as her dependence on others for connection:

I felt lonely because I wasn't putting myself out there and making an effort. I wasn't finding the right social group. And that was my own fault and I should have just pulled my finger out and called some people up and planned something and stopped sitting back and waiting for someone else to do it for me. (Tammy age 48, multiple sclerosis)

At the same time, what appears to be unresolved in Tammy's narrative is that "forcing yourself" to socialise can amplify rather than remedy one's loneliness:

… not really wanted to be there and not really felt like I connected, that's far more palpably isolating [than sitting at home]. […] forcing yourself to do it when you're not right, it actually makes it far worse. (Tammy age 48, multiple sclerosis)

Participants like Elizabeth were highly critical of discourse that located loneliness as a problem and responsibility of the individual. She argued that this was victim-blaming as it oversimplified a complex social

problem that was mostly outside of one's personal control:

> I think there's been a lot of this finding yourself positivity around you shouldn't feel lonely if you've found yourself. But I just think, yeah, there's a lot of expectation of people to not be lonely and just to cope and that they should be able to cope. But I don't think it's that simple at all. (Elizabeth age 31, chronic bowel condition)

Elizabeth went on to say that when we conceive loneliness as a problem of the individual's making and for them to solve, this serves to shift responsibility for addressing the problem from being a collective issue to be addressed, to being an individual one:

> It's kind of accepting it as a problem, as opposed to what can actually be done to address that or looking at what does this person actually need? It's identifying there is an issue, but not taking any further steps kind of to. […] it's just like a too hard basket. (Elizabeth age 31, chronic bowel condition)

## 5. Discussion

This paper builds on recent sociological work on the meanings of loneliness (see Malli et al., 2023), responding to the call from sociologists (e.g., Franklin et al., 2019) to understand loneliness through a wider social lens by capturing the complex and interwoven relational, temporal and social dimensions of loneliness experienced by individuals in their daily lives. While Franklin et al. (2019) focused on gender influences to consider societal changes associated with increased loneliness for men (see also Ratcliffe et al., 2023), our research advances sociological understandings of loneliness, showing that chronic illnesses are a significant factor that contribute to how participants define and experience loneliness. This paper makes two main contributions. First, advancing sociological understandings of the relational, temporal, and social bases of loneliness by revealing the different ways loneliness is conceived in the daily lives of people living with chronic illnesses. Second, shedding light on how chronic illness and loneliness intersect, including how loneliness is shaped by personal histories of illness, social interactions and dominant ideas about individual responsibility.

Expanding on conceptualisations of loneliness as deficiencies in real and desired social relationships, our findings reveal that for people with chronic illness, loneliness emanates across different registers (temporal, relational, social), and is produced across different deficits and misalignment. First, loneliness is experienced when there is a deficit between how they desire to be seen, recognised and valued by others, and the reality of their experience. Second, loneliness is produced when there is a sense of temporal dislocation: both between the trajectory of their life, and that of both their peers (imagined or real), but also between their own anticipated or hoped for life trajectory if they had never experienced chronic illness. Finally, loneliness existed in the gap between 'real' and 'performed' social connectedness; when one was not being a meaningful participant in social life, but instead watching from the side.

Findings also reveal the circular relationship between loneliness and chronic ill health, and how chronic illness and loneliness reinforce each other. Manderson and Warren (2016)'s concept of recursive cascades is useful in thinking about the cyclical nature of chronic conditions and the social conditions that give rise to them. While Manderson and Warren's (2016) research focused on interlinked trajectories of increasing illness and poverty, our findings reveal how chronic illness, and the responses of others to chronic illness, contribute to loneliness, and vice versa, to produce a loneliness/illness recursive cascade. The denial of dependency is also important in understanding this recursivity (Peacock et al., 2014). Participants described pressure to present a healthy, resilient self. But presenting an inauthentic version of the self to the world was experienced as a cut or a severing of their relationship to themselves (and to their communities). An inability to find balance between acknowledgement of their chronically ill identity *and* being

seen as having an identity outside of chronic illness was implicated in their sense of loneliness (Charmaz, 1983). The fluctuations of chronic illness meant that self- and social-identities were continuously in flux, with participants feeling caught between communities of illness/disability and wellness.

Finally, we show how wider cultural understandings of chronic illness imbue it with meaning and are important forces underpinning the experiences of loneliness. With wellness, healthiness and fitness being currency for social connectivity, chronic illness becomes socially alienating (Lewis et al., 2023; Moensted et al., 2023). Neoliberal ideals of self-responsibility for managing illness also permeate experiences of loneliness and its meanings. Loneliness was still situated within a rhetoric of individual responsibility, despite the relational, temporal and social dimensions of loneliness that were articulated by participants. Findings draw attention to the harm of individualising discourses of loneliness including responsibility of self, blame and denial of dependency on others. These discourses infuse individuals' understandings of themselves, and how others (in their social network and community) understand them, thus shaping how individuals with chronic illnesses interact with their social worlds, and how social others interact with them (Peacock et al., 2014). The need to perform wellness poses a challenge to people with chronic illness. If we are to accept Bauman's (2000) claims that liquid modernity is characterised by fragility of social bonds, then continual performativity is required in order to be social and meet the ideals of relationships, with little regard given to the constraints that people with chronic illness experience in doing so. Those who will not (or cannot) perform the roles that are demanded of them by society, are left on the sidelines.

## 6. Conclusion

Although we know that responding to loneliness requires a social approach, it is still primarily treated as an individual problem in discourse and interventions. We find that locating loneliness (and its solutions) within the individual is problematic (Malli et al., 2023). Despite the dominance of an individualistic rhetoric, our findings emphasise the value of relational approaches to loneliness, whereby attention is given to the importance of recognition, visibility and value in the lives of others. Our work proposes new avenues for considering both conceptual as well as lived experience aspects of loneliness not previously explored; and argues that rather than perpetuating loneliness as primarily an 'I' problem, it is an 'us' problem. We argue that the enmeshment of the experience of chronic illness with loneliness demands that responses to loneliness also meaningfully address how chronic illness, and those who are affected by chronic ill-health, are treated in societal discourse. This includes consideration of the social harms, including loneliness, produced in a context that highly privileges independence, able-bodiedness, and wellness. Here, more research is needed into the impacts of stigma in relation to loneliness (Barreto et al., 2022), particularly how loneliness and stigma interplay with intersecting forms of discrimination (like ableism) in the daily lives of people with chronic health conditions. Understanding and effectively responding to stigma will likely be critical in developing effective community responses to loneliness.

**CRediT authorship contribution statement**

**Sophie Lewis:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Karen Willis:** Conceptualization, Funding acquisition, Writing – review & editing, Investigation, Writing – original draft. **Lorraine Smith:** Conceptualization, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Leslie Dubbin:** Conceptualization, Funding acquisition, Investigation, Writing – original draft, Writing – review & editing. **Anne Rogers:** Funding acquisition, Investigation, Writing – review & editing. **Maja Lindegaard**

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