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Friendship, connectedness and (in)authenticity for those with chronic illness: Trading in one social gain for another

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ABSTRACT

Friendship, a key element of social networks, has been under-studied in the social sciences. Chronic conditions can disrupt many aspects of life including identity, anticipated life trajectories and social relationships. Friendship relationships are important sources of support for chronic condition management. However, for individuals with chronic conditions, developing and maintaining close friendships may be particularly difficult. Despite significant scholarship on chronic health conditions, we know less about the ways in which chronic conditions impact the maintenance of long-standing friendships or the cultivation of new ones. Drawing on sociological theories of friendship and chronic conditions, we aim to advance knowledge of how people who live with chronic conditions navigate friendship. Data were drawn from a qualitative study with 40 people with a chronic condition and who also reported experiences of loneliness. Findings from interviews highlight the significant personal labour and performative identity work required to maintain connectedness within friendships. Normative expectations about able-bodiedness may hinder the continuation of friendships by limiting opportunities for social participation for those living with chronic conditions. Participants discussed both the emotional and physical 'work' necessary to maintain even tenuous social connections, hampering one's ability to cultivate emergent friendships. This work included having to trade authenticity for other desirable social gains, such as a desire for social inclusion. This research offers a nuanced exploration of how friendships are created, nurtured, maintained and dissolved and the role they play in the life trajectories of those living with chronic conditions.

1. Introduction

Friendship, defined as an active and freely chosen platonic relationship between two equals (Vela-McConnell, 2011), plays a vital role in supporting wellbeing, protection from physical and mental health deterioration, and reducing loneliness throughout life (Cluley, Martin, Radnor, & Banerjee, 2021; Yang & Grol-Prokopczyk, 2020). Much of the research showing the health benefits of friendships has focused on the experiences of children and young people (Forgeron et al., 2010) and older people (Blieszner, Ogletree, & Adams, 2019; Han, Kim, & Burr, 2017). Although these studies show the protective factor that friendship plays against declines in physical, mental and cognitive health, studies

examining the reverse direction are scarce (Yang & Grol-Prokopczyk, 2020). Despite the illumination of the relevance that friends play in the work of illness management as part of people's social networks (Rogers et al., 2014), less attention has been paid to the impact of chronic conditions on friendship. We know little about how health conditions shape people's ability to develop and sustain friendships, or how friendship, in turn, shapes the experience of living with a chronic health condition. The few studies that have been conducted in this area come to seemingly opposite conclusions. Some research suggests that the onset of a chronic health condition leads to reduced social engagement with friends (Ha, Kahng, & Choi, 2017; Sander, Schupp, & Richter, 2017), while other research suggests that crises can lead to an activation of social networks,

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resulting in a higher number of friends (Latham-Mintus, 2019). The type of health condition appears to be crucial, as the onset of life-threatening diseases is associated with an increase in number of friends, while onset of disability is not (Latham-Mintus, 2019), suggesting that the chronic nature of some conditions are a particular strain on previously held friendships. Specifically, there has been very little research about how friendship is experienced for people with chronic conditions who describe themselves as lonely. A deeper understanding is needed, not just of the benefits of friendship but also of its social costs and burdens that may hinder the cultivation and maintenance of friendship. In this paper we examine how people living with chronic conditions who experience loneliness navigate social connectedness with friends, and what friendship means to them in living with chronic illness.

Whilst friendship relationships differ according to degree of commitment, choice, and suffusion (i.e. the extent to which friends and family play overlapping roles) (Pahl & Spencer, 2004) friendships are voluntary, mutual, flexible, and terminable (Amichai-Hamburger, Kingsbury, & Schneider, 2013). Unlike work and familial relations, friendships are freely entered into, maintained and terminated. Friendship has been understood as "an active and freely chosen platonic relationship between two equals demonstrating a high degree of commitment toward each other and relating to one another in a variety of ways" (Vela-McConnell, 2011, p. 23). Such a definition emphasises the egalitarian nature of friendships, as friends recognise one another as equals. Friends have been found to often contribute more positively to psychological well-being than family relations in older adults (Huxhold, Miche, & Schüz, 2014). Informal social bonds ensure the continuation of a friendship through reciprocity, trust, care, intimacy and closeness. From a sociological perspective, friendships can be viewed as integral to the social fabric of society as friends connect individuals into much larger social networks, contributing to maintaining social cohesion (Vela-McConnell, 2017).

Friendship further has a dignity-evoking, liberatory potential (Blatterer, 2015) assisting individuals to maintain a sense of stable identity, which is particularly important for people living with chronic conditions (Greco, Holmes, & McKenzie, 2015). Feeling socially connected is associated with the ability to make sense of one's life in the context of others, to feel valued, recognised and mirrored, and able to participate in meaningful activities. Honneth (1995) proposes that feeling worthy, esteemed and respected are the basic conditions, functions and purpose of friendship; indeed social recognition is key to friendship. Social recognition, (e.g. being seen, appreciated and witnessed by another) enables individuals to perceive their own self-worth (Honneth, 1995). The experience of misrecognition is also possible in social interactions. To be misrecognised is to be denied the status of being a full partner in a social interaction, to be deemed less-than, valueless or invisible. For Honneth (1995), individuals' demand for social recognition drives both the development of autonomous identities and holds the possibility of social change. When individuals demand recognition for their uniqueness, they also seek to change the patterns, expectations and conformity on which recognition is granted. It is in the "interplay between the dependence of identity on the recognition of others and individuals' demands for the recognition of their unique characteristics, capacities, and circumstances" that forms of social injustice can be mitigated (Blatterer, 2015, p. 28). Life events such as chronic conditions have the potential to influence all dimensions of friendships as needs, friendship opportunities, other relationships, and life circumstances modulate social interactions.

2. Friendship and loneliness for people living with chronic conditions

There is a considerable body of sociological literature on chronic illness and social connectedness, emphasising the importance of social relationships when living with a chronic condition (Bury, 1982; Carter, Qualter, & Dix, 2015; Charmaz, 1983). 'Loss of self' (Charmaz, 1983),

'biographical disruption' (Bury, 1982) and readjustment to new identities (Goffman, 1963) are well-documented features of this scholarship. Bury sees the onset of a chronic condition as a disruptive experience involving changes to body, self, and social resources, and creating a disjuncture between past/healthy and present/ill self (Bury, 1982). Bury discusses the process of mobilisation of social resources, as an example of alterations to individuals' social life due to chronic conditions, in which the individual is "inevitably drawn into rearranging his or her wider personal and community involvement" (Bury, 1982, p. 175).

Loneliness is a largely under recognised component of the experience of living with a chronic condition, although attention is growing on the topic (Band et al., 2019; Ellis et al., 2022). For individuals with chronic conditions, the task of developing and maintaining close relationships may be particularly difficult, threatening both established friendships and posing a challenge to the establishment of new relationships. A common conceptualisation of loneliness emphasises that loneliness results from the perceived discrepancy between desired and actual social relationships (Peplau & Perlman, 1982). Whilst loneliness and social isolation are related and often confused with each other they differ in meaning. Weiss (1980) distinguished between the experience of emotional loneliness and social isolation. The first form indicates a qualitative lack of intimate social connections, while the second indicates a quantitative absence of wider social networks. Loneliness arises as a longing for different types of social connections. Moreover, loneliness is related to the judgement of others and the absence of their attention or gaze (e.g., feeling invisible or worthless) (Franklin et al., 2018). Lack of recognition and legitimation of lived experience (e.g., due to invisibility of pain and assumptions about culpability for illness, self-care and social engagement) (Broom, Kirby, Adams, & Refshauge, 2015; Franklin et al., 2019) are pertinent to understanding the experience of loneliness. Contagion within networks perpetuates both loneliness and by implication the inhibition of the making of new friendships or maintenance of existing ones. This is because over time, loneliness establishes norms of negative social reactions resulting in the loss of habitual social contact. Distancing from other people is provoked by the cognitions of loneliness. Shyness, anxiety, social awkwardness and homophily (the choice to be with other like-minded lonely people) forms the bases of a shared environment within which connected individuals experience concomitant exposure which contributes to the spread of loneliness (Cacioppo, Fowler, & Christakis, 2009).

Much existing research has treated social connectedness as an aggregate or assemblage of the various social relationships in a person's network (Pinquart & Sorensen, 2003). There is still relatively little focus specifically on the role of friendships, how people navigate friendships while managing various chronic conditions, and how this affects their experience of social connectedness. The studies that have looked at this issue have often been in relation to experiences of specific conditions such as cancer (Drageset, Eide, Dysvik, Furnes, & Hauge, 2015; Rosedale, 2009), stroke (Hinojosa, Haun, Sberna Hinojosa, & Rittman, 2011), HIV/AIDS (LeGrand, Muessig, Pike, Baltierra, & Hightow-Weidman, 2014) and brain injury (Salas, Casassus, Rowlands, Pimm, & Flanagan, 2018) exploring how different experiences of illness and healthcare can lead to or compound loneliness. In this paper, we build on this existing research by focusing on how people with chronic conditions experience friendship, and in turn how their experience of friendship shapes how they live with and manage their chronic conditions.

3. Methods

3.1. Study context and participants

This article draws on the findings from a qualitative study examining the experiences of loneliness and social dis/connectedness of people living with chronic health conditions. The broader study was underpinned by an interpretivist approach, well suited to explore the subjective and socially constructed perspectives of those with lived experience

of the phenomenon under investigation (Bradshaw, Atkinson, & Doody, 2017; Denzin and Lincoln, 2017). The study involved a combination of in-depth, semi-structured and walking interviews and photo elicitation with people with chronic conditions, and interviews with health and community-care workers. In this article, we focus on data generated through the semi-structured interviews because we wanted to explore participants' experiences of friendship and how they perceived their chronic condition(s) shaped these friendships. It was in the indepth interviews where these issues were primarily explored with participants

We purposively sampled to include participants with diverse socio-demographic characteristics (e.g. age, relationship status, ethnicity, socio-economic status), from a range of geographic locations (e.g., urban, regional/rural), and who had been living with their chronic health condition for different lengths of time. Recruitment materials were aimed at people who were 18 years or older, who had a diagnosis of a chronic health condition, and who described themselves as lonely, to explore their experiences of social connectedness, loneliness, and social isolation.

The sample of 40 people comprised 28 women, 11 men, and one non-binary person, aged 18–83 years who self-reported a range of conditions and co-morbidities including HIV, post-traumatic stress disorder, chronic obstructive pulmonary disease, diabetes, multiple sclerosis, osteo-arthritis, chronic pain, chronic fatigue, depression and anxiety. Participants resided in a mix of urban, regional and remote areas in Australia. The study was approved by the University of New South Wales Human Research Ethics Committee (HC200333). All participants provided informed consent prior to their interview. We offered a gift card to thank and compensate participants for their time.

3.2. Data collection

An interview guide was developed using topic discussion areas identified from the literature to explore participants' experiences of managing their health condition(s), experiences of loneliness and social isolation and how they cope with these experiences, and about their social networks and social relationships. Participants were interviewed up to three times over a 12-month period, with interviews conducted approximately three months apart. Interviews were conducted, face-to-face in the person's home, via video conferencing or telephone, according to participants' preference. With participants' permission, interviews were digitally recorded and later professionally transcribed. Following each interview, the interviewer (the first and second author) wrote detailed fieldnotes for each participant to provide contextualising information.

3.3. Data analysis

Our analytical approach focused on the lived experiences and the social construction of meaning combined with attention to the relations of power, place and discourses that shape the meaning participants give to their daily lives (Charmaz, 1990; Clarke, 2003). Transcripts were read repeatedly and coded for recurrent ideas. NVivo was used to organise the data. Thematic analysis techniques (both inductive and deductive) were used to identify substantive and conceptual patterns in the data (Pope, Ziebland, & Mays, 2006). Themes included experiences of health and illness, perceptions and experiences of social relations and friendships, stigmatisation and isolation. Once key themes were established, we revisited the literature and conceptual tools to make sense of the patterns that emerged from the data, which resulted in three overarching themes discussed below.

4. Findings

4.1. Overview

Most participants recounted how the onset and progression of their chronic conditions led to related disruptions in their experiences of friendships. All participants talked about loss of friendships since becoming chronically ill, as well as declines in the closeness or relatability they felt with remaining friends. This relational loss contributed to feelings of loneliness and misrecognition. Participants' accounts revealed an awareness of their own marginal social position, and a corresponding sense of vulnerability to future additional social losses. This vulnerability and history were central to how they experienced and navigated their friendships in the present as most participants described the compromises that they felt were necessary to maintain friendships. Maintaining connection was seen as something valuable in and of itself, irrespective of the relationship quality or dynamics. A narrative of trading certain desired social gains for others in friendships emerged (Spencer, Lewis, & Reid, 2021). Maintaining connection with friends often came at the expense of physical and/or emotional wellbeing. Three themes were identified about how participants experienced and navigated friendships: 1) balancing the need for social connection against bodily limitations; 2) weighing up concealment and authenticity to preserve social dignity; and 3) demanding recognition and authentic relating.

4.2. "They're just not in your shoes": balancing the need for social connection against bodily limitations

Negotiating social relationships, bodily limitations and concerns about letting others down featured strongly in participants' accounts. Participants spoke of how bodily limitations (such as pain, fatigue and immobility) associated with their chronic conditions made many of the previous "normal", routinised ways of being together with friends like walking, playing sports or going out for dinner, inaccessible. They articulated frequent struggles in how to balance the normative demands of friendships and their personal need for social connection with the physical and emotional limitations of their chronic conditions. Many participants grieved losing the ease of their pre-diagnosis social life, when they could spontaneously meet up with friends. They discussed the struggles of socialising with friends while managing unpredictable symptoms, which often meant that they had to cancel pre-arranged social events. Rather than accommodating for bodily limitations, participants reported that their friends were more likely to stop inviting them to social activities. As Verna's quote below illustrates, loss of employment and financial constraints limited opportunities to socialise with friends, contributing to a cycle of increasing social exclusion with increasing illness.

… with something like MS, any chronic illness, you don't turn up at everything. You say yes to something, and it turns out on the day you just haven't got the wherewithal to get there. So, once you start cancelling on people, they stop inviting you. So therefore, that thing comes in again. And if you don't have the money to go out for dinners, even if it's only to the local Thai then […] you can't go along and be miserable. It's not on, apparently. (Verna, multiple sclerosis)

Similarly, Rosemary recounted how friends did not make accommodations for her changed physical capabilities. She attributed this to their lack of awareness and understanding of her chronic condition, which left her feeling lonely and emotionally isolated.

I don't think they understand it because they're just not in your shoes … they don't understand. It isolates you from the mainstream. Emotionally, not physically. I don't physically isolate myself. But emotionally, I feel isolated from mainstream. (Rosemary, tick-borne disease and other co-morbid conditions)

In the absence of friends making accommodations for their illness, the burden of maintaining friendships became more unevenly distributed. Participants described needing to put in more effort and make many accommodations to maintain their connections with friends. All participants described undertaking considerable labour to maintain a degree of social connection with their friends, often to the detriment of their own

health. Some participants observed that their labour went unnoticed by friends. Tammy, for example, describes the backstage physical and mental effort of preparing for a social event that was invisible to her able-bodied friends.

> *I don't think people realise that actually getting myself ready and getting to the event, I've already used up half of what I've got for the night. I don't think people see that as an effort. Able-bodied people don't see the amount of physical and the effect on my mental, cognitively, how much it actually takes out of me to shower and get ready and dressed and physically get to an event. They don't appreciate the fact that I've actually already been hard at it for a couple of hours before I've even stepped foot in to cross the threshold. (Tammy, multiple sclerosis)*

Fear of social exclusion in the future meant many participants continued to participate in social activities central to their friendship, if at all possible, even when their symptoms were exacerbated. As is evident in the below quote from Freya, attending social events with friends and "acting normal" by diminishing or hiding pain or discomfort were seen as necessary and/or justifiable, despite the huge personal toll this placed on the body for some participants.

> *It doesn't matter what's going on. It could be someone's wedding or I could've spent a couple of hundred dollars on my favourite band or something and I won't be able to go. So, there's a lot of things that I've missed out on. And when I was made a bridesmaid at my friend's wedding, I got there, but I was on morphine to get there. (Freya, multiple conditions including fibromyalgia, arthritis and endometriosis)*

While many participants expressed their frustration and disappointment with friends' unawareness, participants rarely vocalised these concerns to their friends. Partly stemming from their vulnerability about losing friends, the inability to express unmet needs, contributed further to friendships gradually becoming more unequal (and less satisfying) as the person with the chronic condition was required to be progressively more accommodating and flexible to maintain the friendship. Bianca, for example, discussed feeling let down by her close friend who was unwilling to reposition their friendship away from activities that they "used to do together". While Bianca still described this friendship as close, the characteristics that she valued had been negatively affected, such as reciprocity, mutuality and empathy.

> *Well, one of my friends, I'm a bit disappointed, because she goes, "I want to go for a walk." and mainly, "I need to go for a walk," and that's what we used to do together. And now I'm just thinking, because I can't go for a walk - I mean, we do talk on the phone and she's a close friend, but I just feel frustrated that she hasn't said, "Oh, we can't go for a walk. I'll come over and visit you," or something. But yeah, so that's where some relationships get affected, depending on what you can do. (Bianca, multiple conditions including autoimmune conditions and chronic pain)*

Others whose friendships were built around physical activities (surfing, running and bushwalking), recounted how friendships fell away over time due to their inability to mask their pain and discomfort. Greg, who lives with chronic back pain, talked about being hyperaware of how others saw him in social encounters.

> *I'm not a social person, as in I don't go to coffee shops and I don't go to pubs. I did that when I was a young fella and had guys I was surfing with and things like that. I just can't do that. Part of it is because I can't sit. I'm very fidgety when I'm sitting, and I think people think that I'm not concentrating on them. But I'm just in pain. (Greg, chronic back pain).*

He traced this feeling back to being humiliated by a lecturer during a class for "showing his disinterest" and boredom:

> *I'm standing like this because I am in pain […] because we're only supposed to go for an hour and have a break and we've been going for an hour-and-a-half and I'm ready to run out of the room in pain […] he ended up*

> *apologising. But it's just that I've always felt that. And whether it's my back or not, I feel like I'm from another planet, personally. (Greg, chronic back pain)*

Similarly, Tammy recounted how despite efforts to push her body and fight against physical discomfort, in order to maintain social connections, eventually these efforts failed. Over time, she could not mask her discomfort, which she felt contributed to an atmosphere of discomfort and estrangement within the friendship that could not be recovered.

> *… it was not easy to see how friendships fell away when I could no longer participate in the things that we had in common. […] it very quickly became obvious that I couldn't walk as far and do as many things. I'd get tired. If it was a really active conversation, I would lose the rhythm of it and would struggle to keep up. So, I just found it more and more uncomfortable and I think that probably, obviously, would be sensed by the people with me. My friends would sense that change. You'd just feel a level of discomfort that just made it not natural anymore. It didn't feel like a flowing friendship in that way. (Tammy, multiple sclerosis)*

Tammy's account reveals how divergence from normative friendship expectations challenge closeness and continuity of friendships, but also the importance of flexibility in friendship. Maintaining continuity in friendships was dependent on how willing both parties were to adapt to or accommodate for participants' changing physical abilities. Many participants expressed feelings of disappointment and frustration that friends rigidly held on to past patterns of social engagement.

4.3. "You don't want people to see you at your worst": preserving social dignity: balancing concealment and authenticity

Participants described how the need to preserve social dignity in friendship required a delicate balance between a desire to maintain social standing and be seen as independent, capable and likeable by friends, versus the desire for social recognition of the realities of living with a chronic condition. While participants valued authenticity in friendships, fears of being diminished, or pitied by others, closed off opportunities for open and authentic displays of vulnerability with friends.

All participants discussed the need to hide socially undesirable aspects of their experience of managing a chronic condition. Their accounts reveal tensions around sharing experiences, but not sharing too much. This is captured in the extract below from a young woman with a gastrointestinal condition who describes the careful considerations she makes about what she chooses to share about herself and her illness with friends. Concealing "ugly" parts of her condition was a strategy used by Elizabeth to maintain social dignity:

> *You don't want people to see you at your worst, health-wise especially. I've had horrible things happen in the hospital and I've shared some of that. I've shared that with my friends in a laughing joke, but when you've thrown up and pooed on yourself, there's part of that you don't want to share with people because there is an ugly side to it. I think I do also, in some cases, want to keep parts of myself to myself. There are parts of my story that I don't tell my friends because that's my – Yeah, it's not that it doesn't paint me in a good light, but you don't want people to see you on your worst day kind of thing. (Elizabeth, gastrointestinal condition)*

Revealing the degree of performativity that was required in social interactions, Elizabeth went on to talk about the importance of positivity to forming and maintaining friendships. Being happy, content, energised, and 'normal/able-bodied' was viewed as important to maintaining friendships. Conversely, being seen as sick, fragile, or disabled, threatened friendship bonds.

> *I think it's hard, especially with new people, to let anybody in, because you want to keep that facade of just like, oh, I'm just a happy, normal person. (Elizabeth, gastrointestinal condition)*

Many participants discussed compromises and pressures to perform 'positivity' and minimise discomfort, to safeguard friendships and maintain social dignity. Verna talked at length about hiding struggles and hardships including loneliness from friends and needing to appear positive and happy when socialising. For Verna, loneliness was associated with shame and personal failing. Disclosing her loneliness, she felt, would jeopardise friendships and further alienate her from others:

I think if somebody really knew everything that was happening with you every day like that, like the challenges you face, I think that's that guilt aspect that we spoke about earlier. Friends just go, "Wow, that's shit. I wouldn't want to walk a day in that." And it doesn't get better. It just doesn't. You have good and bad days for sure, but it doesn't get better overall. So, it's a fait accompli. (Verna, multiple sclerosis)

Other participants also carefully concealed the signs and symptoms of chronic illness that could be viewed negatively by others and/or mark them as different (e.g., pain, fatigue, melancholy, use of medications and walking aids). Participants who were able to hide these 'markers of difference' generally described their actions as forms of resistance and means of promoting agentic choice about how they were seen and treated by others. Michael described turning down an invitation to go to a friend's house because he did not want her to see him out of breath:

… a friend. She lives up on the top floor of a building and there's no elevator. So, I just have to say no, that's all. [….] I could do it, but I'd be puffing and panting, and I get a bit stressed when that happens. I don't like it. […] just imagine, you're visiting a friend, your friend opens the door and they're confronted with a sight of a guy standing there, puffing and panting, not being able to breathe until he regains his breath. I feel a bit uncomfortable about that sort of thing. […] It's just that I like to be relaxed and I like to be calm. And I don't want to be under any stress when I'm talking to people. (Michael, lung transplant)

Nicola, a young woman recently diagnosed with multiple sclerosis, discusses her choice not to disclose her condition as a means to take back control of how others see her (e.g., as capable, normal, healthy) and resist being diminished by them.

Because [when you do disclose] then you start to subtract more from your identity. Losing my job was more than enough. That's 90% of me, so there's not much more to subtract. So, when you start to risk, I don't know, losing more, it's very confronting. You lose, I don't know, the choice over how people can see you a bit, and your ability, basically. (Nicola, multiple sclerosis)

Astrid, with severe asthma, similarly discusses her choice to not use her asthma puffer in front of friends as promoting personal agency and upholding social dignity. Through concealing her asthma, Astrid indirectly reconstructs her condition as taboo and socially unacceptable, contributing to feelings of shame, embarrassment, and estrangement (e.g., not being seen or understood by friends).

I definitely never, ever use a puffer in front of other people pretty much. I still am very much, this identifies me as different or that there's something wrong with me or it's embarrassing or something like that. So yeah, very conscious of always - I have a preventer and puffer almost in every bag. So, for any situation, if I happen to forget or run out of time, I've got one I can sneak away to a bathroom to have. It's still quite effective. I feel like I do have that control and autonomy and choice and stuff. (Astrid, severe asthma and anxiety)

However, attempts to preserve dignity came at the expense of relational authenticity. Many participants talked about their sadness of being unable to share hidden pain and suffering of living with chronic illness with friends, and the loneliness this evoked. They frequently rationalised their non-disclosure as necessary to maintain friendships. Nicola, for example, discussed how disclosing her diagnosis to friends had led to noticeable changes in the dynamic of friendships.

I've noticed that when I do disclose it, perceptions instantly change. Yeah, it's just like it's an instant thing. It's not like, "Oh, okay." It's like a "Oh shit." And then you've got to go into this reassurance to someone that you're not going to die in the next five seconds. (Nicola, multiple sclerosis)

Others described noticing friends acting 'unnaturally' or being visibly uncomfortable in their interactions. This discomfort created distance in the friendship. Sensing friends' discomfort, participants, like Rob who was diagnosed with multiple sclerosis, adjusted how they engaged with friends, seeking to 'normalise' or bring back familiarity by emphasising their commonality with friends, and minimising changes imposed by their health condition. Rob discusses not talking about his illness with friends, but in doing so silencing parts of his identity. This strategy ensured continued social inclusion within his friendship group, but leaves Rob emotionally isolated, and unable to secure the support he needs from his friends.

But there's a few mates that I catch up with every now and then, I remember telling a couple of those and I don't know that they've really said anything about it since then, and it always feels a little bit kind of awkward sometimes when I'm talking to them. So, I just try and ignore it and don't talk about it. I think it's because maybe they feel a little bit awkward. Maybe that bloke thing, right? Males have different relationships with their friends. (Rob, multiple sclerosis)

Luke described showing caution, carefully weighing up which friends he felt safe to share his experiences of poor health with and which friends he concealed these experiences from to maintain the friendship:

I'm careful now who I speak [about] that to, because there are friends who find it difficult and I don't want to put them in that awkward position. It's not fair. I would rather have them as friends. Come over, have a cup of coffee, biscuit, chit-chat, that's fine. So, I'm very, I don't know if "selective" is the right word, but I'm careful. (Luke, multiple conditions including kidney disease and chronic pain)

For many, friendships became a series of compromises, performances, and episodes of misrecognition which eroded participants' sense of worth, esteem and self-respect. Many described episodes of embarrassment, where they perceived that their capabilities did not match the requirement of a social situation or their condition drew attention to their imperfections in ways that made them feel ashamed. As Ida describes:

When you have to go somewhere new and you have to go into a social occasion. I've got weakness on my left side, I have a lot of footfall, it drags a bit and you sort of have to stagger in and get to the - And especially if you go to someone's house. My friend's place, that I see a lot of, she's got uneven ground in her backyard and it's really scary going on uneven ground when you can't walk properly. So, you're just really concentrating on getting to the seat and sitting down. That's really embarrassing when you have to go somewhere, because you're just sort of a pathetic mess that staggers in and sits down. That's sort of my worst fears. (Ida, multiple sclerosis)

Ida's account of 'staggering' into her friend's house, and her corresponding perceived social unacceptability highlights some of the complexities around taking care of self and the difficultly of weighing up the desire to preserve dignity versus the desire to maintain friendships and continue to participate in social activities. The act of attending a social event brought with it *both* great social risk as well as potential social rewards that had to be weighed up.

4.4. "I walk away from people who aren't willing to see me": demands for recognition and authentic relating

Being a significant part of a friend's life was described by all participants as important to experiencing a sense of meaning and belonging in

daily life. Yet, as the first two themes highlighted, staying connected with friends, frequently required participants to forgo important parts of their identity and personhood such as feeling important, feeling understood, feeling valued, and feeling equal. Thus, attempts to maintain friendships could ultimately contribute to feelings of loneliness and misrecognition. Few participants contested this situation or sought to push-back against the boundaries of their friendships and/or voice their unmet needs. Those who did, made demands to be seen and recognised for their humanity and value beyond their limitations and insisted on higher levels of authenticity in their connections. This is exemplified in the case of Tina, a young woman living with multiple chronic conditions who discussed the long process of finding friends willing to accommodate her as she was, and the numerous times she had been let down. As Tina's mobility changed daily, she was often unable to walk or required walking aids to do so. Additionally, she needed to continuously monitor her energy level and adhere to a restricted diet. She described herself as having a small handful of friends, most of whom were 'online-only' friendships. Many acquaintances never developed into friendships as people were either uninterested in getting to know her fully, or unable to be flexible around how they socialised with her. Instead of making compromises to maintain social ties, Tina described a heightened sense of caution and risk associated with allowing new people into their life.

> That's why I've become a lot more selective with people, over time, who I become friends with, and I walk away from the people who aren't willing to see me for my ability, for my humanity, my feelings, and who are just going to define me by my disability. I'm not interested in people like that. I want people to be aware of and compassionate towards that in times where I need it, but that's not a form of compassion, completely just cutting someone out of your life because it's an inconvenience for you to have to think about their needs. (Tina, multiple chronic conditions)

Rather than being overwhelmed by her limitations, Tina emphasised what she had retained, highlighting that despite her bodily limitations she was still 'herself'. For Tina, the social trade-off did not justify the cost. On the contrary, she described the dignity-evoking, emancipatory potential of friendship when she was able to be herself:

> One of my dear friends, she actually works as a carer for people who are elderly, and she is brilliant. When she comes to my house she knows all the things to do and help me with without overstepping the mark. She is trained in it. She knows exactly how to read me and what I need and when to ask, when not to ask. [...] So, I'm so relaxed around her. I can be completely myself. If I'm in a grouchy mood she knows how to look after me. So, that's really nice to be able to let your guard down and be yourself in whatever state you're in that day. (…) Around my in-laws, around my colleagues, and all of that. Just putting up a front to please other people. I'm not doing that and I haven't done that in the last two years and I feel a lot better for it. I found out who my real friends were. And I did lose some people, but I gained others, and I'm perfectly at peace with that. (Tina, multiple chronic conditions)

For Tina, the awareness of increased bodily and emotional vulnerability created a heightened sense of boundaries, of needing to exercise discernment when it came to when to socialise and who to let into her life. Demands for social recognition had both increased her sense of worth and deepened her friendships but had also reduced the number of friends in her network. Similarly, Ida, talked about the importance of reframing her identity away from a primary focus on disability toward her whole and complex personhood in helping to feel better in herself and in participating more fully in social life.

> You still do feel a bit lonely because you do have a disability and you are aware that you're different when you go out and everything, but it's not that real pressing, sort of, I want to kill yourself loneliness sort of thing. It's like you realise that I'm still a person. I've got a disability, but I'm still a person. Whereas before, I used to see the disability as the main thing. (Ida, multiple sclerosis)

Changes in the ways participants felt about themselves and their abilities also influenced their experiences of friendships. May reported trying to gain a better understanding of herself and how her identity as a person living with chronic illness shaped social interactions with friends in order to identify changes that she could make in building new friendships:

> I think just because the disease really changed my sense of self, understanding how I relate with other people was warped and I am just trying to regain a sense of that so I can interact with people a bit better. (May, inflammatory disorder)

Others, like Tammy, forged new friendships with people whose lifestyles aligned with their changed identity, that were willing and accepting of their different abilities in socialising with others, and/or could empathise and understand their experiences of chronic illness without feeling pitied.

> … new friends I meet now don't know me as any different. […] They only know me as I am now. So, the friendships I'm making now are this version of me and they see this version of me. They're not hyperactive, kind of, "Let's go on a four hour bushwalk or something." They're people that accept my limitations because they don't know me any differently. (Tammy, multiple sclerosis)

However, demands for recognition and authentic relationships came with challenges for participants, who had little control over how friends viewed and interacted with them. Illustrative of the complexities of being authentic and vulnerable with friends about lived experience of chronic illness, Nelly, in her seventies with chronic obstructive pulmonary disease talked about how sharing her experience of illness had changed the nature of her one close friendship. She talked about the noticeable changes in her friendship since becoming less mobile and needing to use portable oxygen. Her friend frequently offered practical support (e.g., help with housework and other practical tasks) but did not provide her with the emotional closeness she wanted. Evident in her extract is that the relationship, from Nelly's perspective, had become more unequal and unfulfilling. Nelly's friend appeared to be taking on the role of carer or helper, when what Nelly wanted was emotional intimacy. In articulating how emotional closeness is desired but not received, her fears of being a burden to her friend, and the loss of past work friends who understood her, Nelly's account points to some of the subtle differences between connection and friendship.

> [My girlfriend] she's very helpful. She'll come in and say, "Is there anything I can do for you? Do you want anything?" And I feel like saying, "No, I want you to talk to me. I don't want you to go and fix my hose or change a light globe or whatever. I just want you to talk to me." […] She's got a really full life. And yeah, and I feel like I'm whingeing if I say something to her. […] I don't want to burden them. (Nelly, chronic obstructive pulmonary disease)

Nelly went on to discuss her longing for a close friend to share emotional intimacy with when her brother died. During this difficult time, she had no one with whom to share her feelings of grief. But beyond the lack of emotional intimacy, she described missing someone to share the everyday of her life with. As she says:

> It was horrible and I just needed somebody to talk to about my brother, and there's nobody around, really, to talk to. […] people who are there a bit more […]. Maybe just coming around, playing a game of cards or spending more than an hour here, just talking and having coffee or a wine or whatever. Having some lunch with me." (Nelly, chronic obstructive pulmonary disease)

Her account shows how being dependent on others for care (and being seen by others as in need of care), can be an obstacle to meaningful connectedness. Nelly does not ask for emotional intimacy because she does not want to be treated as lesser (needy, dependent, burdensome) by

her friend. Bruno shares a similar sentiment when reflecting on how he copes with feelings of loneliness. He describes his reluctance to be dependent on others but also his unspoken desire for his friends to show him care:

> I don't want to burden others with problems that I feel they may not be equipped to give advice on. [...] I want to deal with such issues in my own way, and I want to be self-sufficient and capable of dealing with anything. It is only on rare occasions that friends will ask how I'm going. I'm sceptical as to whether they would be able to give me advice anyway, but perhaps that's not the point; just showing that they care is more important to me, I think. But as I have stated before, I push back on any bitter feelings or expectations on them. (Bruno, chronic fatigue syndrome)

5. Discussion

Friendships involve a set of discourses and practices that have developed in tandem with contemporary economic, cultural and social trends such as those related to independence and reciprocity (Blatterer, 2015). As such, friendship norms are embedded within a larger social and cultural context, reflecting existing hierarchies and divisions based on race, class, gender, sexual orientation and able-bodiedness. From a sociological perspective, the exploration of friendship and friendship patterns reveals much about the structure of society, especially when focusing on people with chronic illness. The stories told by people who endure chronic conditions and loneliness provide rich accounts of friendship encounters and the meaning of friendship within a context of precarious forms of relating. Similar to Charmaz (1983), we suggest that living with chronic illness can be a potential threat to friendships through the subsequent alterations in anticipated and established ways of being together. The experience of emotional and health-related pain was sometimes seen to contest the boundaries of what could be recognised and accommodated within the field of friendships. For those experiencing chronic illness, we found that the process of cultivating friendships requires a certain calculus of risk. The participants in this study actively weighed the expenditure of emotional work needed to reveal (or not) the ways in which illness has impacted one's identity, against the potential gains or needs (emotional, physical, social) being sought from the friendship, tempered by the very real hazards of rejection, disappointment, and loss of dignity. Hence, participants found themselves in a bit of a quandary: wanting to be seen and accepted as one's authentic self yet feeling it necessary to hide part of the self in order to be seen and accepted by others.

For those with enduring physical and mental health conditions, connecting with others can be difficult and complicated relational work due to fear of stigma, self-censorship and caution in showing vulnerabilities (Brooks, Bee, Lovell, & Rogers, 2020). In this study, friendship was often narrated as an ambivalent experience for participants. On the one hand, participants described friendships as fostering a sense of dignity, worth and belonging through sharing their life with others. Yet, participants also used tactical concealment and/or social withdrawal to uphold social dignity within their interactions with friends. While friendships were articulated as vital in limiting the social pain of loneliness, many participants described corresponding loss of meaningful, authentic relating and sense of self-worth. Similar to findings of research on university students with chronic health conditions (see Spencer et al., 2021), our findings detail the numerous social trade-offs that people with chronic conditions make. For some, loneliness and social isolation meant trading on important personal values such as authenticity and social dignity to maintain valued connections with friends. Others lost friendships due to the importance of maintaining an authentic self.

Our findings extend work on the relational dynamics of living with a chronic condition. First, our findings show how chronic conditions and the threat of loneliness gradually introduce unevenness in friendships with the person with a chronic condition undertaking significant personal labour and performative identity work to maintain connectedness within friendships. Second, our findings highlight the numerous compromises people with chronic conditions make to maintain social connections and friendships, from enduring pain and discomfort, enacting complex self-management and/or fighting against their bodies to maintain friendship; to trading authentic self and social dignity; to weighing up the need to take care of self, but in doing so, losing opportunities for socialising with friends; and finally upholding social dignity and valuing meaningful connectedness but in the process losing friends or needing to form new friendships.

Our findings illustrate that friendships are in part driven by dominant social norms, such as positivity and physical activity and may limit opportunities for the recognition of diverse life experiences; adding explanatory value to the observations made by Cacioppo et al. (2009) of the spread of loneliness within a network. Where friendship can at times reinforce a sense of dignity, respect and esteem in forms of relating through mutual care and receptivity (Honneth, 1995), our findings highlight the complexity of friendship experiences for people who are living with chronic health conditions and report experiences of loneliness. For these participants, friendships involved navigating interpersonal mechanisms such as belonging/loneliness, authenticity/concealment, difference/sameness, and exclusion/inclusion. Where Honneth (1995) highlights the emancipatory potential of friendship, seeing friendships as a source for personal and societal change, the participants in this study often did not have the social resources required to demand recognition for their unique experiences and unique requirements concerning types of social activities and interactions. Few were able to change the social expectations and conformity on which recognition was granted in the context of friendships, by demanding to be recognised for their humanity, contribution and person beyond the illness.

It is important to acknowledge that participants in this study self-reported experiences of loneliness and/or social isolation (many tracing experiences of loneliness to the onset of their chronic condition, but some describing feelings of loneliness that preceded their illness). It is thus possible, that these participants had more to lose compared to individuals who may be more socially connected. An increased susceptibility to the threat or loss of friendship may mean demands for dependency, authentic relating and/or recognition from friends could come with greater risk. It is also important to recognise that the findings reported here are from the perspective of the person with the chronic health condition, and how they experienced friendships. It is thus important not to make any assumptions about how the other party experienced and perceived the friendship. Nonetheless, the dynamics shown in this paper, where expectations of how to perform friendship at times work against meaningful and fulfilling connections with others, is likely more widely applicable.

6. Conclusion

This paper illuminates the contextual conditions that contribute to friendship, connectedness and loneliness for people with chronic conditions, revealing some of the taken-for-granted and cultural assumptions of friendship, and what it means to be a friend. Taking conceptual work on social dignity and recognition we have examined how normative expectations about able-bodiedness and positivity are implicated in the lived experience of loneliness for people with chronic conditions. These normative expectations can distance people with chronic conditions from their communities, and limit opportunities for belonging, social valuing and inclusion. Such contemporary economic, cultural and social norms regarding independence and reciprocity interplay with the everyday experience of living with a long-term condition to increase vulnerability to loneliness. While much scholarship describes friendship as a reciprocal, interdependency of mutual recognition, these participants' narratives of friendship describe a continued negotiation between the need for connection and belonging against the need to be understood and

recognised for who they are. Two concepts emerged as central to friendship for these participants: authenticity and social dignity. Participants' accounts detail their experiences of pressures to align with social norms about the ideal healthy body, friendship and socialising. Grappling with the, at times incompatible, demands of friendships and chronic health conditions produced strategies, to uphold a position of dignity, normality and social connections. Being included often involved trading in personal dignity and authenticity in relating, and many deemed it necessary to hide aspects of themselves or their illness experience to sustain connections. In this sense, participants trade-off one social gain for another.

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Authors' contributions

SL, KW, LS, LD and AR designed the study; MM and SL collected data. MM, SL, LD, KW, LS were involved in the analysis of data. MM and SL drafted the paper, and LD, KW, LS and AR iterated and commented on drafts. All authors read and finalised the manuscript.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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