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An occupational perspective of individuals living with Lyme disease: a qualitative descriptive survey

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Abstract

Purpose – This study aims to explore the changes in occupations experienced by individuals with Lyme Disease, their strategies to re-engage in their meaningful occupations and future aspirations to better understand their occupational participation and engagement.

Design/methodology/approach – This is a qualitative descriptive survey. A form with four questions was distributed online on three social media platforms, achieving 27 full responses. Data were analysed using Reflexive Thematic Analysis.

Findings – Three main themes were generated: 1) Living with the effects of the unknown, 2) Experiencing occupational losses and changes and 3) "I know my limits": adapting lives.

Originality/value – To the best of the authors knowledge, this is the first study conducted with individuals with Lyme Disease from an occupational perspective. Their study is a pioneer in identifying how the condition impacts individuals' occupations, revealing their strategies to re-engage in meaningful occupations. Therefore, this study contributes to producing evidence for occupational science and future occupational therapy interventions.

Keywords Lyme disease, Occupational participation, Lived experience, Qualitative research

Paper type Research paper

Introduction

Lyme Disease (LD) is a zoonotic and vector-borne disease spread through the bite of an Ixodes tick infected with *Borrelia burgdorferi sensu lato* bacteria (IGeneX, 2020). The *Borrelia burgdorferu sensu stricto* strain accounts for most cases of LD within the USA, and the *borrelia afzelii* and *borrelia garinii* strain accounts for most cases within Europe and Asia (Beard *et al.*, 2016; Conant *et al.*, 2018).

In recent years, there has been a consistent increase in cases around the world, a pooled data analysis estimated a global seroprevalence of 14.5% of the *Borrelia burgdorferi sensu lato bacteria* (Dong *et al.*, 2022). It has been suggested climatic changes creating more favourable conditions for tick and tick host habitats, as well as increased human activity in these areas, have contributed to the rise in LD (Chomel, 2015). Early symptoms of LD can include; a high temperature, headache, muscle and joint pain, fatigue (Centers for Disease Control-CDC, 2024; National Health Service- NHS, 2017) and in 70%–80% of cases, an erythema migrans rash (Snydman and Hu, 2021).

Testing accuracy, however, faces much scrutiny as each method produces a significant rate of false negatives (Sotsky, 2022). When antibodies are still developing in the first few weeks following infection, sensitivity to serology tests is low, thus generating an inaccurate result (Conant *et al.*, 2018; Moore *et al.*, 2016; Sotsky, 2022). Additionally, incorrect interpretation of results by medical professionals also contributes to the number of misdiagnoses (Boyce *et al.*, 2020; Conant *et al.*, 2018; Moore *et al.*, 2016). These occurrences therefore indicate a central problem within the diagnostic process of LD, and whilst these issues remain, the true figure of cases remains unknown (Schutzer *et al.*, 2019).

When LD is successfully diagnosed, the current recommended treatment plan is a course of 2–4-week antibiotics (National Institute of Allergy and Infectious Diseases- NIAID, 2018; National Institute for Health and Care Excellence-NICE, 2018), however for approximately 10%–20% of recipients this treatment is ineffective and leads to new recurring symptoms (National Institute of Allergy and Infectious Diseases- NIAID, 2018; National Institute for Health and Care Excellence-NICE, 2018; Sotsky, 2022). For these individuals, those unaware of infection, or those misdiagnosed, later onset symptoms of LD can include: arthritis, heart palpitations/irregular heartbeat, dizziness, shortness of breath and nerve pain (Centers for Disease Control-CDC, 2024; Maksimyan *et al.*, 2021). Current literature reports

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that those experiencing re-occurring symptoms of LD face significant changes to their occupational participation (MacInnes, 2023; Ciotti, 2023; Baarsma *et al.*, 2022). Occupational participation in this paper is defined as the broad doing of occupations in various social and cultural contexts, such as activities of daily living, work and play (Kielhofner, 2008), while occupational engagement is the cognitive and affective subject experience of involvement with an occupation (Cruz *et al.*, 2023). Baarsma *et al.* (2022) found huge differentiations in occupational participation before and after the onset of LD. Participants similarly described changing occupations, such as exercising, attending social events and working, because of their symptoms, similar to the findings of MacInnes's (2023), a study that included household tasks and leisure occupations due to fatigue, pain and cognitive or physical impairments. Moreover, Ciotti (2023) also described within her autoethnography that the unpredictability of chronic illness and managing symptoms can be disruptive to daily life, for example, spending days focused on coping with pain.

The condition's' invisibility' is another theme throughout the literature. The invisibility of symptoms and lack of understanding towards chronic illness were presented by Baarsma *et al.* (2022), a study in which participants expressed attempts to make their symptoms "invisible" to avoid exposure to unhelpful attitudes, aligning with Rebman *et al.* (2017) findings documented the frustration amongst participants when communicating the seriousness of their symptoms, receiving labels such as "whiny" or "exaggerating". Likewise, invisibility was also recognised to affect occupations through negative experiences with the healthcare system. As such, Fagen *et al.* (2023, p. 8) explain that "interactions with doctors who doubt the lived experiences of patients with Lyme Disease have health implications (e.g. delayed treatment can lead to chronicity) and psychological ramifications" which has long-term effects on participants such as anxiety, depression and trauma, exacerbating physical symptoms (Fagen *et al.*, 2023).

Although Rebman *et al.* (2017) and Ali *et al.* (2014) offer insights into how individuals with LD strive to regain control over their occupations, their findings provide limited perspectives on the perceived effectiveness of these strategies or alternative modes of adapting occupations employed by this population. This illuminates a gap in the literature, allowing us to explore the experiences of individuals with LD through an occupational perspective. Therefore, our aim is to explore the changes in occupations experienced by individuals with LD, the strategies they employ to re-engage in their meaningful occupations and future aspirations to better understand their occupational participation and the factors influencing their engagement.

Methodology

According to Yerxa (2009), occupations are a complex phenomenon that require understanding individuals' unique subjective experiences. Therefore, our research is aligned with a naturalistic paradigm since the world is "made up of multiple, overlapping realities that are subjectively experienced" by individuals (Polatajko, 2010, p. 39). Having said that, a qualitative approach was suitable for gathering information from participants' experiences, perceptions and behaviours concerning the phenomenon of interest (Tenny *et al.*, 2022).

Our study adopted a qualitative survey to gather information through social media. Braun *et al.* (2021) argue that qualitative surveys are extremely underutilised despite having great potential to harness rich qualitative data. The advantages of online surveys comprise how long respondents can spend with the survey, as well as when, where and how they can complete it (Braun *et al.*, 2021). Moreover, due to the severity of symptoms, some participants may experience (Centers for Disease Control-CDC, 2024; Maksimyan *et al.*, 2021; National Health Service- NHS, 2021), the flexibility of qualitative surveys felt appropriate in accommodating their needs and encouraging them to contribute to the survey. Braun *et al.* (2021), also highlight the benefits of qualitative surveys in capturing diverse experiences by hearing different voices, which can be applied to unexplored subjects as it is the example of an occupational perspective of individuals with LD.

Participants

Participants were recruited through a sampling frame of LD-related social media groups on the Facebook platform. This included: "Chronic LYME: It"s a thing', "Chronic Lyme Disease" and "Lyme Disease Support and Wellness". The inclusion criteria required participants to be aged 18 or over and have either a confirmed LD diagnosis or be in the process of obtaining one. Due to the difficulties with current diagnostic accuracy (Boyce *et al.*, 2020; Conant *et al.*, 2018; Moore *et al.*, 2016; Sotsky, 2022), participants with ongoing investigations did not wish to be excluded as their insight could still offer valuable information on the day-to-day experiences of this group.

Survey questions

Survey questions were designed by both researchers through discussions, including the need for easy language, for example, instead of occupations that would lead to associations with only work, the need to not overwhelm respondents with too many questions and avoid low rates of responses and to emphasise response in-depth, for example, including prompts such as "Please provide as many examples as possible". A pilot of the questions was applied to one participant with Lyme Disease. Since changes did not affect the content of the question but were more focused on paraphrasing, the participant was included in the data analysis (see Table 1).

Data generation and analysis

Data were generated using a survey on the software Qualtrics (Qualtrics XM, 2024). After the permission of the administrators of the aforementioned social media pages, the first author circulated a poster with the following information:

> We are looking for participants with Lyme Disease to take part in an anonymous online survey. We want to know if your life has changed and what those changes look like. If you are interested in participating, please follow the link below for further information

Before taking part, the participant was informed about the study's aims, purpose and what their involvement would require. The researcher and their supervisor continuously dialogued regarding the quality of the data generated; the

Table 1 Changes in the interview questions after piloting

Survey questions before piloting	Changes after piloting
1 Could you please tell the story of when you discovered you had Lyme Disease?	1 Could you please explain how and when you discovered that you had Lyme disease? [Prompt: When did you receive your diagnosis, or are you still in the process of seeking a diagnosis? / are any of your other chronic conditions caused by lyme disease co-infections?]
2 Have the activities you used to do prior to your condition changed? If yes, how so? Please provide as many examples as possible	2 Have the activities you used to do prior to your condition changed? If yes, how so? Please provide as many examples as possible
3 Have you had to make any adjustments to take part in any activities you want, need, or are expected to do? If yes, please explain the adaptation and if it helped	3a Have you had to make any adjustments to take part in any activities you want, need, or are expected to do? 3b. Have the adaptations that you have made helped and if yes, how so?
4 Are there any activities from the past that you are not currently taking part in but would love to do so in the future? For example, this could be related to your work, leisure, self-care, quality of sleep etc. [Prompt: What are the activities that are most meaningful to you? Are you completing them at the moment?]	4 Are there any activities from the past that you are not currently taking part in but would love to do so in the future? For example, this could be related to your work, leisure, self-care, quality of sleep etc. [Prompt: What are the activities that are most meaningful to you and why? Are you completing them at the moment?]

Source(s): Table created by authors

survey was only taken offline once a satisfactory response rate had been achieved.

We follow the six stages of Reflexive Thematic Analysis (Braun and Clarke, 2022), and we did not use any software for data analysis. JP (first author) re-read the data several times and recorded analytical insights of each data item and the entire data set to familiarise themselves with the data. JP shared the first annotations with DC (research supervisor). Semantic and latent codes were identified during data analysis; however, latent codes were predominately used to extract interpretation (meaning) from the discourse. JP conducted initial theme generation. Codes with similar meanings were grouped to generate initial themes. JP reviewed the initial themes by re-reading the entire data set and ensuring all themes were consistently represented. Finally, JP and DC refined the themes' titles, created a synopsis of each theme and wrote the data analysis presentation into three themes. Table 2 exemplifies the coding process.

Semantic and latent codes were used during data analysis; however, latent codes were predominately used to extract interpretation (meaning) from the discourse. JP conducted initial theme generation. Phase three included grouping the codes to generate initial themes. Within this data analysis, the researcher placed all codes onto one sheet of paper, contrasted them and compared them. Similar meanings were identified between different codes; for example, the experience of chronic symptoms, worsening of symptoms, feeling at their lowest point and faking being okay were grouped. This included the use of direct quotes such as "zombie", "surviving", "shell of how I used to be" and "cancer comparison", all of which generated

Table 2 Generating initial codes

Participant	Extract	Initial codes
P3	"Just in a zombie state [C1] all the time or if I'm able to sleep I sleep. I no longer do anything they I used to love to do, I can't even video game or watch sports and def can no longer run or play soccer"[C2]	[C1] Perception of self [C2] Occupational disruptions [C3] Strategies to adapt [C4] Physical changes [C5] long term impact [C6] Social relationships [C7] Barriers to sustain participation levels [C8] Being misunderstood
P8	"Yes. I have to take lots of breaks [C3] when doing anything. Including normal activities like laundry"	
P15	"Being tired and in pain [C4] all the time really limits social activity [C2]. Diet has changed [C3]. No Sugar/ Gluten/ processed foods"	
P17	"Constantly. Only low-level exercise [C4]. It was near fatal Lyme, and I was in a coma, and my parents told me I wouldn't survive. I went in as an elite athlete and came out barely able to walk and have never recovered [C2]. And told I am a time waster and lazy [C8]. My weight dropped to 6 stone" [C4]	
P27	"For a long time, I just couldn't do things, so I avoided things [C2]. Lost a lot of my community and became very isolated [C6]. All my relationships have suffered. My symptoms meant that a lot of things weren't available to me anymore and there aren't really adjustments [C7] that would enable me to maintain those things to the same level"	

Source(s): Table created by authors

the initial theme of "The debilitating nature of the condition and its impact upon occupational participation". In phase four, JP reviewed the initial themes by re-reading the entire data set and ensuring all themes were consistently represented with DC supervision. The analysis was predominantly deductive. In phase 5, JP and DC refined each theme title, created a synopsis of each theme and wrote the data analysis presentation into three themes. Finally, JP and DC wrote the final report at stage six, revising the theme's name and participants' quotations.

Ethical considerations

The Leeds Beckett University Research Ethics Coordinator granted ethical approval for both the pilot and current study prior to the commencement of data generation.

Ethical considerations were applied at every planning stage and mitigated potential risks. This included obtaining gatekeeper consent from the Facebook group admin leads before ethical submission. Survey questions were designed to be non-intrusive to minimise the risk of harm to participants' well-being, recognising that topics surrounding participants' illness and experiences may be upsetting (National Health Service- NHS, 2024). The survey was entirely voluntary; informed consent was obtained through participants' requirements to read the participant information sheet and accept the consent form before participating in our research. The consent form also detailed the participant's right to withdraw, and a participant debrief sheet was provided following the completion of the survey.

Participant data at every stage was safeguarded. The survey was entirely anonymous; therefore, no identifiable information was collected or used in this study. The names of participants outlined within the findings section were randomly assigned to participants with pseudonyms and in no way represent the identities of the participants they relate to. Survey responses were recorded and stored on Qualtrics before being transferred to the OneDrive account at the University that hosted the research. The password was encrypted, and only the first author accessed the drive.

Trustworthiness

Trustworthiness was achieved by researcher triangulation (JP and DC) in the data analysis process. Researcher triangulation refers to more than one researcher involved in the data analysis (Denzin, 1970). JP carried on Stages 1, 2 and 3 with the supervision of DC, while DC revised Stages 4, 5 and 6 in discussions with JP. These supervisions occurred at the university library using MS Teams, where JP shared her screen to show the data analysis. JP discussed the coding process with DC and showed the initial themes addressed, and both researchers agreed. Although it is recommended not to fragment results and discussion because it can be interpreted as positivistic (Braun and Clarke, 2024), in our research, to facilitate the reflexive process on the data, we decided to keep the analysis section separated from the discussion would be a strategy to focus on participants experiences and illuminating their voice to guide the analysis.

Reflexivity was addressed by discussions between JP and DC so that there was always an opportunity to revise and go back to each stage of the analysis, which is expected in this type of analysis (Morrison *et al.*, 2021). Moreover, DC and JP reflected on the importance of positionality for transparency (Braun and Clarke, 2024). JP is a female who was studying in the MSc Occupational Therapy (Pre-registration) Programme in the UK. JP was familiar with LD and had a friend with the condition. In contrast, DC, male, had no familiarity with the disease or lived experience related to the research subject. We used the Reflexive Thematic Analysis Reporting Guidelines (Braun and Clarke, 2024) to increase the quality of our report. A careful revision of terminology included the words "analysis" instead of "findings", "data generation" instead of "data collection", "methodology" instead of "methods" to avoid a positivistic approach in qualitative research.

Analysis

Participants demographics

Our research included 27 complete responses. All participants had received an LD diagnosis. Most participants were white (96.67%), female (90%), aged between 35 and 44 (33.33%) and declared "other" as their employment status (53.33%), including self-employed, being a mother or working flexibly, for example 15 h.

The mean time participants lived with LD was 16.3 years, and the mean time since participants had received an LD diagnosis was 6.96 years. The percentage of participants who stated they had other chronic conditions was 77.78%, and of this, 66.67% said that LD co-infections caused their chronic conditions. Table 3 specifies the time individuals have been living with LD and their pseudonymous:

Table 3 Time living with Lyme disease ($n = 27$)

Participant	Pseudonym	Time living with Lyme disease
P1	Hayley	12 years
P2	Jermaine	50 years
P3	Hannah	3 years
P4	Fatima	19 years
P5	Gabriel	15 years
P6	Eric	2 years
P7	Diya	3 years
P8	Charles	7 years
P9	Sabrina	8 years
P10	Charlie	28 years
P11	Aysha	1 year
P12	Robin	30 years
P13	Jamie	5 years
P14	Eve	30 years
P15	Sam	1 year
P16	Tanisha	30 years
P17	Rita	10 years
P18	Jasmine	30 years
P19	Laila	5 years
P20	Billie	4 years
P21	Rachel	60 years
P22	Bailey	10 years
P23	Dakota	10 years
P24	Ash	30 years
P25	Cameron	18 years
P26	Ellis	1 year
P27	River	18 years

Source(s): Table created by authors

It is important to note, as shown in Table 3, that the time since diagnosis and duration of living with LD varied significantly among participants, ranging from 1 to 60 years. This variation likely influences how individuals respond emotionally, physically and occupationally to living with the condition. As such, interpretations of the findings should be made with caution, considering how duration may shape how participants perceive and engage in their occupations, including coping strategies.

Theme 1: Living with the effects of the unknown

All participants expressed in some form the extent to which their symptoms affected them daily. Therefore, symptom severity and variance were described to be a significant reason participants had experienced a severe drop in their engagement in occupations. When asked which symptoms had changed the activities participants take part in, a variety of answers included fatigue, pain and joint problems. Fatigue, sleep issues and pain were most cited in the written responses as reasons participants could no longer participate in their meaningful occupations, which tended to be physical, and outdoor activities. Hannah compared their current presentation to being in a constant "zombie state", whilst Gabriel and Tanisha compared it to having cancer. Tanisha, who suffered from the condition, shared that overcoming cancer was the easy part for them in comparison to living with LD. Similarly, Billie illustrates the impact LD and its symptoms had on his occupations:

> Before I was doing long hiking and camping trips, a competitive gymnast and super strong. After my tick bite, I woke up and couldn't move. I was in the worst pain of my life and lost all of my strength and mobility. Now, I can't even get water or food without help and am bedridden (Billie).

This quote above demonstrates how Billie lost the ability to participate in meaningful occupations. Additionally, it shows the changes that have occurred in how he engages in self-care occupations, such as eating and drinking, as he was unable to complete these tasks independently.

Other participants also highlighted the need for assistance in completing daily occupations. For instance, Tanisha described her previous ability to cook daily, which has been reduced to five times or less a month, as well as her complete dependence upon her partner. The tone of responses also indicates dissatisfaction or sadness amongst individuals regarding their current participation levels.

Symptoms of LD were also referred to by participants in influencing their occupational choices. For example, Dakota described her need to seek out wheelchair-accessible occupations or occupations compatible with their current ability level. Dakota states:

> My symptoms meant that a lot of things weren't available to me anymore and there aren't really adjustments that would enable me to maintain those things to the same level [...] being in social situations or busy environments is totally overwhelming. I freak out and end up shaking and soaked with sweat. Loud noises and bright lights physically hurt. It would be nice to feel normal again (Dakota).

Indeed, being out in public and social occupations was mentioned on multiple occasions as difficult to complete and maintain due to sensory issues, disassociation, derealisation, fatigue, pain and the requirement of assistance. Furthermore, the lack of knowledge and stigma surrounding LD and chronic illness was also attributed as another reason for respondents' reduction in participation in occupations. Many respondents recalled doctors being unable to diagnose their symptoms for many years, Jermaine and Ash stated it was over 20 years before LD was even considered as a possibility. In addition to being "brushed off" by medical professionals, receiving false negatives or inconclusive test results was also noted. Robin, Ash and Eve recall being dismissed with mental health issues, told it was all in their head or that they were lazy and a time waster. Laila described her journey to receiving a diagnosis:

> I ended up hospitalised because my legs and arms seized up, and I couldn't walk or use my arms. When I was able to move them again, I am just so unstable, have bad muscle spasms and tremors. Spent 5 days in the hospital, they said it was psychological. Me and my family knew this was wrong as I was having other symptoms doctors were having a hard time diagnosing for years. My mom did a lot of research and did a PCR test for Lyme through DNA connexions, and I came back positive for 4 strains and a babesia co-infector. Finally, an answer (Laila).

These experiences, therefore, resulted in delays in treatment, which participants attribute to impacting their current ability levels to participate in meaningful occupations. The lack of knowledge and stigma surrounding the condition was accompanied by feelings of frustration and isolation in coping with LD and its impact, with Jasmine stating: "fake that you are fine even when fatigue is debilitating".

Theme 2: Experiencing occupational losses and changes

Participants referred to being unable to complete any of the occupations once inherent to their identity and the feeling of loss they experienced. The occupations mentioned by participants were outdoor sports and activities such as hiking, running, biking and camping, which is a stark contrast to their current lives, which many described as being bound to their home environment. Robin and Billie noted they had athletic careers that ended since contracting LD. Referring to their time in hospital upon discovering they had the condition, Robin stated:

> I went in as an elite athlete and came out barely able to walk and have never recovered (Robin).

Additionally, Hannah also stated the impact on her being and repercussions on mental health:

> I do not even recognise myself anymore I can no longer do anything that I used to do before. I'm so exhausted and mentally unstable with constant anxiety and disassociation (Hannah).

Changes within occupational roles were also reported among participants. For example, parents Aysha, Eve, Eric, Fatima and Gabriel reflected on not being as involved in their children's lives as they would like. This was expressed as being unable to attend their children's events, play or generally spend time together. When referring to what occupations were most meaningful to them, Fatima said:

> Just taking care of myself and family in basic ways like cooking large meals or deep cleaning the home or yardwork etc (Fatima).

Other typical occupational roles referenced included friend and employee. Moreover, nine participants declared they had either left their employment due to illness or had made considerable changes to maintain their work roles. Dakota revealed how mental health issues impacted her work:

> Anxiety and depression skyrocketed, reducing my resilience and causing me to bomb out of my career. I couldn't manage the demands of it anymore. I went on long term sick and now work remotely in a low-key role (Dakota).

The inability to work cited by participants, therefore, comes with an associated financial impact, with some participants referring to high stress and the further restriction this placed on accessing occupations they would like to engage with, such as travel. Additionally, being an active friend and maintaining friendship groups was described by participants as something complicated to retain whilst living with the condition. Consequently, the changes within participants' occupational roles led many to describe either changes or breakdowns within their role's associated relationships. For example, there was an underlying sense of "missing out" from parents regarding their children growing up, and many stated that they rarely or no longer see those they used to call friends. Indeed, Dakota described human connection as most meaningful to her; however, due to the severity of symptoms, she avoided these situations. As a result, they stated that all relationships have changed, and she has lost much of her community relationships, becoming isolated.

The considerable changes to participants' being and associated roles were accompanied by a mourning of one's old life. Hannah stated:

> My whole life is just a shell of what and who I used to be. Everything has changed [. . .] I am no longer who I used to be (Hannah).

Thus, a strong desire to return to "normal" was present throughout the responses. This was in the form of wanting to return to participating in previous hobbies, rebuilding relationships and engaging in essential self-care occupations that would allow them to regain active participation.

Theme 3: "I know my limits": adapting lives

Awareness and knowledge about their limitations appear to allow participants to create coping strategies and adaptations to engage in occupations. Participants had implemented pacing as a technique to enhance their participation in everyday occupations. This included managing their energy levels throughout the day by taking regular breaks or napping, planning all occupations, including tasks such as laundry, not to overexert themselves and maintain their already limited choice of occupations and avoidance/reduction in participation of occupations that require a tremendous amount of energy, such as exercise or social events. These examples indicate the extent to which LD affects participants both physically and mentally in terms of their energy levels and how the occupations they choose to participate in have changed because of this. Ash stated:

> I have to be extra careful with energy consumption. I can have Chronic Fatigue for months on end (longest spell was 18 months) so when I am feeling better, I have to not overuse my reserves, or I will suffer (Ash).

The word "suffer," in particular, suggests the impact and extent to which not implementing pacing as a technique can have on health and well-being. Additionally, participants noted adapting occupations and the environment as one way to increase their participation. Indeed, River stated:

> We have had to buy a wheelchair adapted vehicle (WAV) as I struggled transferring into the car which made it even harder and more exhausting to go out. This saves my energy and helps me not feel as isolated. I have to do little of any activity and often struggle to make it to the end, e.g. leaving early, but usually, this is too late, and I am already immensely struggling. We have had to adapt the bathroom so it is a wet room that I can use by sitting in a shower chair and having assistance to get washed (River).

Other modifications made by participants included taking part in adapted exercise classes to reduce pain, the need to write a shopping list if buying more than two items due to memory issues, as well as learning new ways to spend time with loved ones whilst resting simultaneously. In a broad sense, lifestyle changes were also noted as attempts to increase overall health and enhance participants' abilities to participate in meaningful occupations, such as changing their relationship with industrialised products. Dakota stated:

> I started working from home. I also changed my diet and home environment significantly. AIP diet at first. Now no gluten dairy sugar, low carb, drinking only water and herbal tea, and nothing processed. I was vegan for about a decade, but since changing back to eating animals and focusing on eating only meat and plants, I am a lot better. No fragrances. No make-up. No hair dye. Natural toothpaste. Avoidance of chemicals in soaps and detergents (Dakota).

Charlie, Eve, Robin, Jasmine and Diya also reported changing habits related to their diet, taking supplements, cutting out alcohol and uptake meditation and other complementary health approaches and integrative modalities. Likewise, it suggests the extent to which LD has impacted their life and their determination to return to their previous health and included in this, previous occupations. There was a mixture of attitudes amongst participants regarding whether the techniques and methods they had implemented had helped. Dakota stated:

> I don't think you can do much about fatigue and mental health issues. But being very careful about diet and environment has made a significant difference to me (Dakota).

Most noted that the adaptive approach had helped increase their engagement in occupations but also stated the effect was minimal and that they were still very limited in what they could do. Ash described themselves as accepting of where their current abilities lie, whilst Rachel noted that just completing housework was enough for them presently. Of the participants who said that the adaptive approach had not helped improve their occupational participation, Jermaine stated: "*Helped? I'm just surviving*". As well, River implied that adaptations do not always equate to improved well-being from increased occupational participation, stating:

> Sitting in a shower chair and having assistance to get washed which helped by saving my energy though it compromises my dignity (River).

Discussion

Our research aimed to describe the lived experiences of people with LD, including changes that occur within their occupational participation and the methods used by those with the condition to regain, maintain or enhance their occupational participation. Our analysis presented that participants experienced occupational disruption and deprivation that possibly affected their dimensions of occupation: doing, being, belonging and *becoming*. These analysis will be discussed in light of the literature.

The varying symptoms individuals can experience after contracting LD and its impact on occupational skills appeared to be a clear contributor to individuals' decline in their occupational participation. This mirrors the analysis of various studies focused on LD consequences (Ali *et al.*, 2014; Baarsma *et al.*, 2022; Ciotti, 2023; MacInnes, 2023; Rebman *et al.*, 2017). Previous research frequently identifies fatigue and pain as the most significant factors affecting social occupations, a finding that aligns with the responses from participants in our study. This suggests that pain and fatigue are common symptoms in individuals with LD that impact their level of occupational participation.

In terms of strategies to deal with difficulties with occupational participation, up-taking pacing to overcome fatigue was generally adopted by participants to engage in self-care occupations, household tasks and leisure occupations, echoing the current understanding of the lived experience of this population (Baarsma *et al.*, 2022; Ciotti, 2023; Eliassen *et al.*, 2017; MacInnes, 2023). Rebman *et al.* (2017), for example, described this incidence as a coping strategy to reassert predictability and power over the condition. Reasserting the predictability of symptoms by using pacing was an emergent concept from the current study's analysis; however, it was inferred that this was not accompanied by a sense of power over the condition. Contrastingly, it appeared the limited choice of occupations individuals could participate in was continuously at the forefront of participants' minds, instead generating an impression of powerlessness.

From an occupational perspective, our analysis suggest the multidimensional nature of occupation in participants' lives (Eastman and Twinley, 2024). For example, let's consider occupation a synthesis of doing, being, belonging and becoming, as proposed by Wilcock (1999) and Wilcock and Hocking (2015). We can identify that in our research, the lack of understanding from others and stigma reported in participant responses suggests that these problems can affect their *belonging* dimension of occupation since it comprises a sense of being part of spaces, culture and relationships with others (Wilcock and Hocking, 2015). This is also connected with disruptions in their *doing* dimensions that connect them with others, evidenced by participants reporting a lack of leisure, work and other outdoor occupations.

Our data also proposes that *being* appeared to change from different perspectives, with participants viewing themselves as disabled, ill, or like a "Zombie" described by Hannah. On the other hand, the occupational needs of *being* were defined in terms of occupational roles such as worker, parent and friend, and they struggled to enact these roles routinely as before the LD. The analysis of our study also exhibited changes amongst occupational roles, including friend, employee and parent, described in previous studies (Ali *et al.*, 2014; Baarsma *et al.*, 2022; Ciotti, 2023; MacInnes, 2023; Rebman *et al.*, 2017). In particular, Ciotti's (2023) Reflection on the changes she encountered in maintaining her role as mother, mirror the emotions inferred from parents within our study. The author describes feelings of self-doubt, sadness, guilt and shame about her inability to be as involved in this role, thus demonstrating the effects LD can have on parenting roles. However, this appears to not be exclusive to those living with LD but may be a common trend or pattern experienced by those living with chronic conditions. A recent scoping review into motherhood for those with a lifetime chronic illness found considerable evidence that mothers unable to balance the role's required occupations alongside their illness experienced guilt, anxiety, depressed mood and feelings of helplessness (Haines *et al.*, 2023).

It is essential to discuss the connection betwee*n being* and *doing* since being is partially related to the identity generated by the history of occupational participation while *doing* is associated with enacting the role identity (Kielhofner, 2008). As such, in our analysis, changes within the dimension of *doing* were present throughout responses where participants noted they couldn't no longer participate in outdoor occupations that conflicted with their being or who they really were (Wilcock and Hocking, 2015).

Interestingly, it is unsurprising to note the association of the nature of their *doing* in such occupations (e.g. sports, gymnastics, camping, hiking, cycling) within environments that are favourable tick habitats (University of Maine, 2024). Indeed, using data from "The Tick App", a research tool developed to understand better human behaviours affecting tick exposure across the USA, Ozdenerol *et al.* (2021) found that those who engaged more often with outdoor occupations were more likely to be app users. Furthermore, this could be explored in future studies to identify relationships between those who possess an occupational identity affiliated with outdoor occupations with an increased risk of contraction LD, which would be helpful for future preventative actions.

In addition, *becoming* in terms of goals and aspirations (Wilcock and Hocking, 2015) appeared to be related to returning to routines and being active in previous occupations such as cooking, cleaning and gardening, as referred by Fatima. In our analysis, *becoming* can also be interpreted through the challenges faced by participants that elicited attitudes and strategies focused on returning to their meaningful occupations. Indeed, it appears that facing scrutiny over one's condition is a trend that those who contract LD are expected to endure. They are placed in a position in which they must advocate for themselves – for instance, Morrison *et al.* (2021) found mistreatment from doctors ranged from dismissive to bullying; participants called names such as "idiot," "weak," or "crazy". This parallels our study's analysis of participants being dismissed by medical professionals told their illness was all in their head, or that they were "lazy" and a "time waster". Described by Nesgos *et al.* (2021) as due to "betrayal" from mainstream healthcare, these negative medical encounters could link to the high usage of complementary health approaches or Complementary or Alternative Medical (CAM) therapies amongst this population, ranging from acupuncture to reiki (Ali *et al.*, 2014; Baarsma *et al.*, 2022; Ciotti, 2023; MacInnes, 2023; Nesgos *et al.*, 2021), something which resonates with the analysis of our study, with participants *becoming* focused on lifestyle changes and adopting complementary health approaches to improve their health, for example, food habits, thus illustrating transitions in their occupational participation to future regain participation in previous daily occupations.

Limitations

Several limitations must be acknowledged in this study. The survey was accessible only to individuals with internet access, thus limiting the population to those who are internet literate.

The time since diagnosis and living with LD varied and possibly influenced different experiences of coping and occupational adaptation. While this was not the primary focus of our analysis, this variety of experiences influencing their occupational participation warrant further investigation in future research.

Given the qualitative nature of the study, responses could have more exploration if both the researcher and participants had an opportunity to interact with each other. For example, particular answers could be exemplified or explored more in-depth in participants' lived experiences. Future qualitative studies should provide clear instructions to encourage more detailed responses. Moreover, due to data protection protocols, researchers did not consider participants' email addresses, which prevented member checking. This process could have enhanced the trustworthiness of the analysis and mitigated the risk of poor-quality responses.

Implications for occupational therapy and occupational science

An essential aspect of the current study is that it adds evidence of the lived experience of people living with LD from an occupational perspective. Our study is the first to identify how the condition impacts occupations and how participants developed strategies to engage in occupations. Therefore, our study is worth contributing new knowledge to the fields of occupational therapy and occupational science in relation to this population.

From the occupational therapy perspective, occupational therapists could work collaboratively with individuals experiencing the consequences of LD to participate and engage in occupations. This could be achieved by identifying compensatory, restorative, educational and skills training approaches (Fisher and Marterella, 2019). It is hoped our research will benefit occupational therapists in providing person and occupation-centred care and developing services for people with LD, as its insight into the occupational challenges of this population demonstrates the potential for occupational therapy input.

From an Occupational Science perspective, further research could explore the dimensions of doing, being, belonging and becoming in greater depth, thereby contributing additional evidence to occupational therapy practice. Given that our research highlighted the connection between LD, occupational participation and identity, investigating the meaning, form and function of occupations within this population would offer a deeper understanding of individuals' lived experiences.

Conclusion

The analysis from our study emphasise the experiences of living with LD in participants' daily lives and occupations. Participants described significant disruptions in their ability to engage in meaningful occupations, with symptoms such as fatigue, pain and mobility issues playing a role. The loss of previously valued occupations, such as outdoor activities and physical pursuits, was often accompanied by feelings of frustration, sadness and isolation, reflecting or views of themselves (being) and relationships with others (belonging). Delays in diagnosis compounded these challenges, as participants frequently encountered stigma and misdiagnosis from healthcare professionals, which led to a sense of being misunderstood and unsupported. The participants' experiences suggest that living with LD is not only physically limiting but also emotionally and socially isolating, with many describing a sense of loss of their doing, particularly in terms of relationships and personal identity.

Despite these challenges, participants demonstrated resilience and adaptability in managing their condition. Many reported adopting coping strategies, such as pacing and lifestyle modifications, to maintain some level of occupational participation. However, while these adaptations helped to reduce the strain of occupations, their effectiveness was limited, and many participants acknowledged that they were merely "surviving" rather than fully thriving. The importance of ongoing support, understanding and tailored interventions is evident, particularly as participants expressed a strong desire to regain their previous levels of participation and connection (becoming). Future research should explore the complexities of occupation in individuals with LD, including the potential for additional interventions that can enhance both the physical and emotional aspects of occupational engagement.

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