

Navigating Illness, Finding Place: Enhancing the Experience of Place for People Living with Chronic Illness

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ABSTRACT

When chronic illness, such as Lyme disease, is viewed through a disability lens, equitable access to public spaces becomes an important area for consideration. Yet chronic illness is often viewed solely through an individualistic, medical model lens. We contribute to this field of study in four consecutive steps using Lyme disease as a case study: (1) we highlight urban design and planning literature to make the case for its relevance to chronic illness; (2) we explore the place-related impacts of living with chronic illness through an analysis of interviews with fourteen individuals living with Lyme disease; (3) we derive a set of design guidelines from our literature review and interviews that serve to support populations living with chronic illness; and (4) we present an interactive mapping prototype that applies our design guidelines to support individuals living with chronic illness in experiencing and navigating public and outdoor spaces.

CCS CONCEPTS

• **Human-centered computing** → Accessibility; Accessibility technologies; Accessibility; Accessibility design and evaluation methods; Accessibility; Empirical studies in accessibility.

KEYWORDS

Chronic illness, Lyme disease, public space, urban design, interactive mapping

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1 INTRODUCTION

Research shows that the experience of a place with certain qualities can enhance our physical and emotional wellbeing [14, 29, 48, 51, 56]. For people living with chronic illness, third places (social

settings away from the home and workplace) have the potential to reduce isolation, provide healing, and a welcome change in routine [10, 40]. Public and outdoor spaces have been shown to be therapeutic and empowering [10, 50], yet chronic illness is mostly absent from the dialogue about creation of accessible social spaces [21]. While certain chronic conditions, most notably cognitive impairments, have received some attention in the realm of spatial design [e.g. 10,45], chronic conditions are typically not included when planning for accessible public spaces [7], and are also not prominent in accessibility research [34]. If we can better understand the impact of illness on the experience of public spaces, and the role of third places in supporting accessibility, we can envision technologies that might help with identification and design of accessible third spaces. This in turn can support effective use of such spaces by people with chronic illness.

However, accessible design features for everyday public spaces, if present, has mostly focused on sensory and mobility disabilities [7, 18], while the more complex and wide-ranging needs of people living with chronic illnesses (primarily been a concern only in places intended for healing, such as healing gardens at hospitals [7]. As a result, public spaces often present many accessibility challenges for people with chronic conditions. Conversely, the accessibility literature published in HCI venues to date has essentially no overlap with the literature on built environments [52]. As a result, the built environments literature has largely been overlooked by accessibility researchers.

This paper contributes to our understanding of the use of third places by people with disabilities involving chronic illness and introduces a tool that prototypes our research findings. Chronic illness represents many different conditions and needs; we use Lyme disease as a case study since Lyme disease symptoms are wide-ranging and significantly impacts patient quality of life [4, 28]. Our contributions include: 1) A review of literature relating urban design to health, specifically to the management of chronic illness, demonstrating a lack of attention to the needs of people with chronic illness in design guidelines, even those specifically focused on accessibility 2) semi-structured interviews with 14 individuals living with Lyme disease, demonstrating that concrete changes to urban public spaces and the information available about them can increase their accessibility 3) a set of design guidelines that synthesizes literature and interview findings to provide better support for individuals with chronic illness, and 4) an interactive mapping tool that helps people with different environmental needs to experience and navigate public and outdoor spaces with greater comfort and ease.

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2 RELATED WORK: BUILT ENVIRONMENT, HEALTH, AND INTERACTIVE TECHNOLOGY

Environmental impacts on health and accessibility can take many forms, such as exposures to sensory stimuli, spatial affordances that support certain behaviors, and urban forms that impact social capital or disease transmission [27]. As the built environment and digital technology are becoming increasingly interwoven, digital tools have made information related to physical spaces readily available, presenting many opportunities to increase health and accessibility for people with different needs. Web-based mapping platforms not only increase access to spatial information, they also filter and cater spatial data in a way that transforms how people perceive and experience their environments, influencing where people go and how they get there [20].

2.1 Sharing Experiences through Interactive Mapping

Interactive mapping technologies can engage users in bridging digital and built spaces. Crowdsourced mapping tools such as WAZE provide dynamic real time information that allows users to plan around changing spatial conditions. Different participatory mapping projects have allowed for qualitative visualizations of spatial data, creating different ways to understand individual experiences of place [11]. One example is Streetwyze, an app that uses mapping to promote racial and spatial justice by allowing users to document their lived experiences on the ground, creating a database of rich experiential local knowledge [1]. Another example is Cityflock, a mobile system that utilizes geo-tagging to allow urban residents to leave ratings or recommendations for urban spaces, enabling visitors to access local knowledge [6]. These tools demonstrate the impact of knowledge-sharing and the power of having access to the right information. They also highlight the potential of digital tools in providing meaningful place-related qualitative information that can benefit people with different needs.

A few applications have been designed to achieve similar goals specifically for people with chronic conditions. The location based reviewing app called Care and Connect was built to identify and rate dementia-friendliness of public spaces [38]. The app allows users to review different aspects of a public space that incorporates both the physical and emotional needs of a dementia patient. However, while Care and Connect allows for the mapping and rating of public spaces, it does not allow users to search for spaces with specific qualities.

2.2 Apps supporting people with disabilities

A second group of apps provide crucial information for people with disabilities moving around a city. Open Sidewalks has created comprehensive spatial data for pedestrian environments [41]; AccessMaps provides route planning support based on individual characteristics such as ability to walk hills or need for elevator access [8]; and project sidewalk uses crowdsourcing to collect information about accessibility issues with sidewalks [46]. This body of work demonstrates the importance of capturing specific physical qualities of space to support people with different needs. However,

these apps mostly support route planning, and do not focus on spatial qualities of destinations.

Outside of this group of apps, much existing interaction research relating to chronic illness focuses on the use of computing technology for illness management. For example, many studies have examined systems for symptom tracking [30, 35, 43], while others have examined how patients use technology to navigate their condition [5, 36], as a communication tool [42], and for social support [32]. This trend is reflected in a review of self-care technologies for chronic illness patients, which found that existing technologies largely cater to increasing patient awareness of their conditions, supporting communication with care teams, and connecting patients with each other [39]. While these tools are valuable, the concept of place as a facet of care is still lacking.

Some issues that interactive technologies for chronic illness might add to this body of work include information about how a place can provide physical comfort, emotional support, and social interaction. The design of the built environment and development of accessible technology are interconnected, and should work together to create more inclusive experiences. Guidelines for built spaces are important for the development of HCI tools, as physical spaces intermingle with how technology is used. Williams et al. demonstrated the importance of new technologies to be designed alongside accessible built environments through a study with visually impaired individuals [55], demonstrating that while spatial accessibility can be enhanced through digital technology, experience is strongly shaped by the design of the physical environment itself. Goodspeed further suggests the potential of “IT-enabled collaborative planning” in which technology can be used to include more diverse voices in design and decision-making processes that contribute to the way our environment is shaped [23]. These ideas are relevant to designing for chronic illness.

2.3 Current Research in Designing Built Environments for Health

The creation of healthy built environments is a well-established topic that is present in multiple textbooks (e.g. [17, 33]) covering a wide range of topics, including spatial strategies for community-building, enhancing mental health in urban settings, and incorporating active design measures to reduce lifestyle-induced chronic conditions, to name a few. However, spatial design and planning strategies specific to supporting individuals living with chronic illnesses are rarely addressed in built environment research.

Using the search words ‘chronic disease,’ ‘chronic illness,’ ‘illness,’ and ‘disability’ we conducted keyword searches in highly ranked urban design and planning journals including *Journal of Landscape Architecture*, *Journal of Urban Planning*, *Landscape and Environmental Design*, *Journal of Planning*, and the *Journal of Landscape and Urban Planning*, as well as index searches in various textbooks for built environment and public health courses [15, 17, 33, 48]. This analysis revealed that chronic illnesses are rarely addressed in built environment research beyond the context of prevention, that disability is largely limited to discussions on mobility and sensory disorders, and that applications of healing design are mostly present in the context of medical facilities, and not in everyday public spaces. For example, in the *Journal of Landscape and Urban*

Planning, a keyword search of the word “illness” in the title, abstract, or author key words yielded only 3 results, all relating to the prevention of illness rather than the condition of living with illness. In contrast, in the same journal, a similar search using the keyword “exercise” yielded 27 results, and “physical activity” yielded 54 results.

This indicates that public health efforts in the design and planning of our everyday environments are not concerned with improving the quality of life for those already living with illness. Though aspects of topics like mobility and psychological wellbeing are important and relevant, there is a lack of understanding in how the current practices in environmental design and planning might pose accessibility challenges to people living with chronic illnesses and how the built environment may have potential to support this population.

Despite this, our literature survey did uncover many studies that explore different qualities of a healing environment more generally. The World Health Organization defines health as a state of complete physical, mental and social wellbeing [57]. Using this definition, we explored different therapeutic design theories that contribute to the design of healthy environments, which could also benefit people living with chronic illnesses.

2.3.1 Emotional Restoration and Stress Reduction. In 1991, Ulrich put forth the Stress Reduction Theory, suggesting that four elements in an environment are key to alleviating stress: a sense of control, social support, physical movement and exercise, and positive natural distractions. [14, 51]. Kaplan & Kaplan further pioneered the idea of nature’s restorative effects, leading to the conception of the Attention Restorative Theory, suggesting four qualities that make up a restorative setting: being away, extent, fascination, and compatibility, and deriving four key principles in designing restorative places: coherence, complexity, legibility, and mystery [14, 29]. These theories laid the foundation for many related studies on therapeutic landscape design that followed [9, 22, 50], and have been widely applied to designing supportive environments in medical settings, including healing gardens [15]. In particular, studies have found that natural elements such as green spaces provide a form of psychological ecosystem services that helps improve mental clarity and reduction of stress levels [50], highlighting the importance of public open spaces in providing health benefits and implicating the detriment to populations that are excluded from experiencing outdoor spaces.

2.3.2 Physical Comfort & Accessibility. In recent years, accessible design guidelines have helped bring visibility to the spatial needs of people with disabilities and established requirements for urban design, such as through ADA standards [18]. The idea of inclusion in built spaces has also been explored through the concept of universal design, which highlights seven principles that can allow environments to be maximally accessible to people with different conditions beyond disabilities related to mobility and sensory impairments. Universal design principles include equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and use [49]. Beyond accessibility, environments can also contain sensory stimuli that influence one’s physical wellbeing by bringing comfort or triggering discomfort. Comfort studies encapsulate four sensory

dimensions, thermal, respiratory, visual, and acoustic, that create our physical experience in an environment [2]. Related research has shown that specific ranges and levels of each sensory dimension can create maximal comfort in indoor environments [2]. Creating comfort in physical spaces is particularly important to people living with illness, who often already experience discomfort from symptoms of illness and are more sensitive to stimulation. However, external spaces present greater technical difficulties in controlling some sensory triggers, and the idea of comfort can vary greatly among different individuals and cultures [13].

2.3.3 Social Health. The study of third places further illustrates the critical role of the physical environment in building community, an important facet of our overall wellbeing [40]. Third places are social destinations distinct from the home (first place), and workplace (second place), and are often regarded as anchors of community [40]. A study by Rosenbaum and Scott demonstrates the restorative benefits of third places such as arcades or coffee shops in relieving attention fatigue in individuals with ADHD [45]. This work signifies that spaces that facilitate social interactions, can serve to increase our overall wellbeing. In his book the Social Life of Small Urban Places, Whyte suggests certain spatial elements that can attract social activity to a place, for example, seating, particularly flexible and movable seating, and strong connections to the street, such as through visual axes or sightlines [54]. Hertzberger further suggests ways to turn people’s attention to one another and increase social interaction in a space through design elements such as sociopetal seating arrangements, crossing paths, and intersecting views, as documented in his book, Space and the Architect [26].

These existing studies offer a wide range of overarching design considerations that can be applied to creating supportive places for people living with different conditions. However, currently, in public spaces, they are largely applied only in medical environments such as healing gardens [7]. Though healing gardens can provide valuable support to people dealing with chronic illness, they are limited in geographical coverage and create “segregated spaces that reinforce exclusion from ‘ordinary’ environments” [7]. Furthermore, the broad-stroked approaches of many of these design theories do not provide sufficient information in addressing the needs of people living with complex chronic illnesses. Chronic illness experiences, marked by the invisibility of symptoms and fluctuations in ability level, represent a dynamic form of disability that changes from day to day [16]. Thus barrier-removal approaches of accessible design can prove to be too reductionist and rigid.

To design more effectively for people living with illness, we must know about the accessibility challenges they face in the existing environment. A more thorough understanding of the experience of illness as it pertains to place and a different approach to design and planning therapeutic landscapes could help urban design to more effectively provide a form of support to populations living with chronic illness.

Our study focuses on understanding the experience of place in the everyday lives of chronic illness patients and the significant environmental factors related to illness management (Section 3). Following, we propose physical spatial design guidelines that serve to support populations living with chronic illness (Section 4). Lastly, we employ our design guidelines to develop a digital mapping

Table 1: Interview participants' demographics

P#	Age	Gen.	Years Sick	Years w/ diagnosis
1	27	F	5 years	2 years
2	41	F	10 years	3 years
3	18	F	4 years	1 year
4	64	F	32 years	3 years
5	60	M	27 years	8 years
6	28	F	9 years	6 years
7	30	F	12 years	5 years
8	44	F	17 years	2 years
9	38	F	10 years	6 years
10	29	M	5 years	3 years
11	36	F	6 years	4 years
12	40	F	6 years	1 year
13	38	F	13 years	5 years
14	39	F	10 years	5 years

prototype that can help cater relevant environmental information to individuals with different needs (Section 5).

3 INTERVIEW STUDY: PHYSICAL & VIRTUAL SPACE IN EXPERIENCES OF CHRONIC ILLNESS

To understand how living with a chronic illness can impact the experience of place, a qualitative study was conducted using in-depth, semi-structured interviews with fourteen individuals living with chronic Lyme disease.

Lyme disease represents a common and growing condition in the United States that is associated with a wide range of symptoms and causes significant impacts on patients' quality of life. Caused by a tick-borne bacterial infection of the spirochete bacteria, *Borrelia burgdorferi*, Lyme disease accounts for 95% of all reported cases of vector-borne illnesses in the U.S., with over 470,000 new cases each year [12]. Though Lyme disease is widely considered as a curable condition if caught early, proper and early diagnosis can be challenging [3]. Even with treatment, up to 36% of diagnosed individuals go on to develop chronic, debilitating symptoms that can last for years [4], resulting in long-term complications that can affect multiple body systems, including the skin, nervous system, heart, and joints [28, 44, 47]. In many cases, the condition can also result in psychological distress [19, 24]. An estimated 1.5 million people in the U.S. live with chronic Lyme disease [37]. A recent survey found that chronic Lyme disease patients experience a lower quality of life compared to individuals living with most other chronic diseases, including those with congestive heart failure, strokes, and multiple sclerosis [28]. The same survey also found that 75% of Lyme patients experience severe or very severe symptoms on a daily basis. As a chronic illness with limited medical treatment [31], environmental factors are crucial in supporting people who live with Lyme disease. Understanding the experience of this illness can help us recognize how to cater the built environment to better support populations living with it.

3.1 Method

Our interview protocol included questions that encouraged participants to express their physical, emotional and social experiences of place through the lens of illness. For example, they were asked to describe the types of places they spend time in, qualities of an environment they seek out when they feel unwell, environmental elements that can trigger their symptoms, and how they maintain a community through illness. Interviews were informal, allowing participants to share their experiences at their own pace and in a fluid narrative.

Prior to conducting interviews, an interview protocol and informed consent form were submitted to the Institutional Review Board (IRB). Upon approval, participants were recruited through postings on two online support group pages for Lyme disease, at a local clinic, and through snowball sampling. The interviews were all recorded and notes were taken for each interview.

Fourteen individuals with Lyme disease volunteered to take part in the study (Table 1). Participants ranged from ages 18 to 64; twelve of the fourteen participants were female. A previous study showed a significant preponderance of women (83%) among those diagnosed with chronic Lyme disease [28], which correlates with our sample. Participants reported having lived with chronic illness between 4 and 32 years. After each interview, the recording was reviewed and combined with additional notes from each session to generate an understanding of participants' illness experiences in relation to place. Each recording was replayed, transcribed, and analyzed using a combination of top down and bottom up coding, in which relevant or repeated concepts, words, or phrases across the interviews were identified in order to understand shared narratives of illness related to place and specific environmental preferences of participants.

We used iterative bottom up coding to identify common themes relating to how illness impacts participants' experience of place, combing through transcripts multiple times as themes emerged. This process revealed a shared narrative of isolation among participants. Subthemes included discomfort away from home, distrust in public spaces, loss of place-based community, and virtual community building. We used top down coding to identify different

supportive qualities of an environment described by participants, using the various therapeutic design theories discussed in our literature review (Section 2.2) as a framework. For example, we looked for types or characteristics of places that gave participants feelings of “being away” (Attention Restoration Theory), or a sense of control (Stress Reduction Theory). These findings are integrated into the design guidelines in Section 4.

While findings in this project reflect a relatively small sample, the semi-structured interview format allowed each participant to provide in depth and wide-ranging descriptions of their experiences.

3.2 Interview Results

Our interviews and bottom-up coding analysis revealed a shared experience of isolation among participants, attributed in part to a loss of third places. Specifically, participants experience aggravated discomfort away from home due to sensory triggers and unaccommodating environments. They feel distrust in public spaces and greater anxiety with leaving home. Lastly, they experience a loss in place-based communities from the diminishment of shared spaces and shared experiences with others due to the inaccessibility of third places that lead to a tendency to avoid outings. These findings indicate the importance of accessible places in supporting the physical, emotional and social wellbeing of those living with illness. Interviews also revealed that participants overcome some feelings of isolation through interactions in digital spaces with virtual communities, suggesting an opportunity to create a platform for building community by bridging digital and physical spaces.

Each participant reported experiencing numerous physical symptoms as a result of Lyme disease, including neurological abnormalities (n=14), such as headaches, dizziness, cognitive issues, and visual disturbances; digestive issues (n=7); musculoskeletal pain and inflammation (n=7); and nervous system dysfunction (n=10). All but one participant experience some level of post-exertion malaise, in which symptoms are aggravated through physical activity (n=13). Most participants experience increased environmental sensitivities, including discomfort when exposed to mold (n=10), synthetic scents (n=6), bright lights (n=8) and loud noises (n=11). The majority of participants also live with immune dysfunction (n=10), resulting in more frequent flu-like symptoms. Many participants described the frequent fluctuation of their symptoms (n=8) and having “good days and bad days” (participant 1).

3.2.1 Aggravated discomfort away from home. The debilitating and unpredictable physical symptoms of Lyme disease can be exacerbated in places away from home, where one has less control the environment. For example, places with loud noise, strong scents or bright lights may trigger those with increased environmental sensitivities; and places without universal access or comfortable and frequent seating may discourage those with exacerbated pain or fatigue. One participant described her sensitivity to sound: “I try to avoid over-stimulation or noise...[Even] music can be very stimulating” (participant 7). Another participant discussed needing places to sit down and rest when going on a walk: “It was difficult at times when there weren’t places to rest [along the trail]” (participant 5). While it may seem obvious, having places to sit down is a simple

but important form of support. Additionally, about half of the participants also described the importance of lying down when they experience an onset of symptoms. One participant described:

“Sometimes I would go out, and it would be too much, and I would start convulsing. . . I could avoid this if I could just lie down for ten minutes. . . because laying down resets me. . . but you’re not really allowed to do that” (participant 13).

There are very few public spaces that provide amenities that allow people to lie down. On the contrary, most public spaces discourage it. Other challenges emerge on the way to destinations away from home. Different means of transportation raise concerns specific to different symptoms of illness. Walking and biking can be difficult for those who suffer from post-exertion malaise or muscle and joint pain. Just walking to the nearest bus stop can be too exerting: “I would take the bus some places, but just to walk the block to the bus I would be seeing double, I would be totally out of breath” (participant 13). The unpredictability and severity of neurological symptoms also limit the ability of people to drive, affecting close to half of the participants: “I can’t drive with all my [neurological] symptoms...I would end up somewhere else” (participant 3). Moreover, nearly one third of participants reported discomfort with ride-sharing platforms due to chemical sensitivities because many drivers use artificially scented air fresheners. As a result of these uncontrollable triggers, many participants reported avoiding outings altogether. One participant provided an example of the third places she’s lost:

“I used to go to a lot of shows, and now I find that music can be very stimulating, and shows tend to happen in old houses, so they’re usually moldy, and have dusty moldy furniture” (participant 11).

3.2.2 Distrust in Public Space. The unpredictable symptoms and inability to control one’s own body can generate anxiety, resulting in growing distrust with unfamiliar environments. One participant described their increased sense of unease when leaving home: “There is a lot more fear and a sense that I’m the most comfortable if I can control my environment and if it is predictable” (participant 6). Because of uncertainties away from home, over half of the participants reported that they plan more and are more cautious about venturing away from safe and familiar settings. There is much less spontaneity with leaving home. For instance, one participant said: “I always just have to scope out my environment wherever I go. Make sure there’s ways to get out of it and a quiet safe space” (participant 2). The thought of going somewhere alone can be anxiety provoking with fear of sudden onset of symptoms. Deterrence from using public transit was reported by half of the participants for this reason: “I don’t take public transit, especially by myself. I’m afraid of collapsing” (participant 4). These limitations lead to a loss in mobility and results in spatial confinement. Participants reported that living with Lyme disease results in them spending most of their time at home, where they feel most at ease and are most able to control their immediate surroundings. One participant stated: “I don’t go anywhere out of pleasure anymore. I go to work and I come home” (participant 8).

3.2.3 Loss of Place-Based Community. Living with long-term illness like Lyme disease can lead to a loss of community. The combination of debilitating and unpredictable symptoms and inaccessible public spaces may limit access to travel, work, and play. As a result, many people with Lyme disease lose the “third places” in their lives, as well as the activities, interactions, and shared experiences that come with their place-based communities. As one participant explained:

“I’ve not done a lot of things in the last 27 years. You avoid going to events, crowded places and noisy places. You don’t interact with your friends and family as much” (participant 5).

Nearly all of the participants reported that they stopped going to places because they could no longer keep up with the activities that take place there: “My life has changed a lot. . . I live a really restrictive life now. I used to be able to eat out places. I can’t drink [now] either” (participant 7). Physical limitations, combined with inaccessibility, can make people feel excluded from being a part of a space or community. These forced changes in lifestyle and daily activities lead to further loss of relationships. “I feel like I’ve lost a lot of friends whose pace of life I just can’t keep up with anymore” (participant 1). Over time, living with Lyme disease can become isolating: from being more physically limited, spatially confined, and the resulting loss in social relationships. One person described losing community as their illness persisted from weeks to months, then from months to years:

“I moved back home to focus on getting better. I had the mentality like I’ll just wait until I get better [to focus on my social life]. . . I kept waiting to be ready to go back out. . . that cycle drove me deeper and deeper down the hole of being isolated” (participant 10).

The persistence of illness limits the capacity to build community: “It’s a big loss, [not being able to be] active and sharing that activity with people” (participant 4). In addition to losing social capital, half of the participants revealed that these losses in shared experiences and spaces can also result in a loss of meaning and identity.

3.2.4 Building Virtual Community. With the loss of physical “third places” and the ability to build community through shared spaces, many participants turned to digital environments to find support and community. All participants discussed using online platforms as a tool for sharing and discovering resources related to their chronic illness, including different events such as targeted yoga classes, meet-ups, and lectures, which in turn encourage face-to-face interaction and community building. In addition, a few participants reported using online groups and forums to share place-related information, such as hotels that are mold or scent-free.

Many participants also reported that connecting with others who share similar experiences through social media and online support groups helped to reduce the feelings of isolation that come with a chronic illness. Around two thirds of the participants described having built virtual relationships through social media:

“I have a whole new group of friends that share a mutual understanding. . . We mostly keep in touch online. . . We’ve created some group chats and personal messages that we keep” (participant 5).

Additionally, half of the participants also use social media platforms to share their own experiences of living with a complex chronic illness. Individuals who have lived with an illness for longer periods of time serve as valuable resources to those who are starting their journey. “I engage with people online. I’m supporting other people [through online platforms]” (participant 12). This quote references the value of providing a source of comfort for others going through a difficult time.

Digital platforms provide a space for dialogue and knowledge exchange that fosters connections among those sharing illness experiences. They help connect people who have similar needs, allow for resource sharing, and provide a sense of control and empowerment. We found that people living with chronic illness heavily utilize and even rely on these resources. While virtual environments and relationships cannot replace face-to-face contact and the experience of a physical space, it has great potential to help facilitate physical interactions with others and with the environment.

3.3 Discussion

Our study found that those living with Lyme disease experience exacerbated physical and emotional symptoms when they leave their homes and go to public or unfamiliar places, which often deters them from doing so. Participants also reduce their outings because they can no longer keep up with activities programmed for a given space. This results in increased isolation not only from the loss in everyday places but also from the loss of community and shared experiences that come with different places (“third places”). As a substitute, some participants turn online for social engagement and support “outside the home.”

This phenomenon represents a failure of accessible design to properly situate the responsibility for making third places accessible to people with chronic illness in the public sphere. In other words, from a social model perspective, it is immediately apparent that what is viewed medically as being caused by illness can be addressed by social change in expectations around third place design. This in turn can contribute to improved physical and mental health as well as more equitable access to shared resources by people with chronic illness. In the next section we propose design guidelines and applications (both physical and digital) focused on creating supportive destinations outside of the home and helping people find them by addressing issues we identified in this section. If physical spaces can be designed to allow someone with a chronic illness feel at ease, regain control and trust of their environment, and encompass spatial affordances to support activities they can take part in, they would be able to expand their everyday environment, rebuild community, and increase their quality of life. Digital technology can help with identifying and locating supportive spaces and cater relevant spatial information to individuals with unique sets of needs.

4 DESIGN RECOMMENDATIONS

To situate our interview results in the context of existing design theories and guidelines, we present a set of tables (Tables 2, 3 and 4) that summarize our interview findings related to physical amenities, environmental preferences, and spatial affordances combined with various existing therapeutic design theories discussed in Section

Table 2: Guidelines for Physical Comfort include equitable use, low physical exertion, minimizing stimulation, tolerance for error, and the possibility of gentle exercise.

Principles	Quality	Design Elements	ADA	HG
Equitable use ⁴	Mobility access	Wheelchair Access	X	X
		Smooth ground surfaces	X	X
	Access to essential facilities	Access to restrooms	X	
Access to easy transportation				
Access to food/water				
Low physical exertion ⁴	Resting spots	Comfortable seating		X
		Frequent seating		X
		Seating along paths		X
		Places to lie down		
	Easy routs	Flat paths	X	X
		No steps	X	X
		Seating along paths		X
Minimize stimulation/ Maximize comfort ¹	Control of lighting ¹	Shade structure		X
		Tree canopy		X
	Temperature regulation ¹	Heating source		
		Wind break		
		Shade structure		X
		Tree canopy		X
		Indoor nature connection		X
	Elimination of olfactory triggers ¹	Mold-free		
		No chemical scents		
		No smoking		
		Quiet space		X
	Low noise ¹	Sound barriers		
		Low traffic		
Tolerance for error ⁴	Minimal hazards ⁴	Traffic calming		
		Smooth ground surfaces	X	X
		Avoid harmful materials	X	X
	Places to walk	Protection from bugs		
		Flat paths	X	X
Allow for gentle exercise ²	Places for flexible movement	Seating along path		X
		Open flexible space		X
		Open lawn		X
		Flat surface	X	X

¹Comfort Studies

²Stress Reduction Theory

³Attention Restoration Theory

⁴Universal Design

⁵Social Life (Whyte)

⁶Space and the Architect (Herzberger)

HG – healing garden literature

ADA – ADA standards for accessible design

2.3, including Stress Reduction Theory [51], Attention Restoration Theory [29], Universal Design Principles [49], Comfort Studies [2], as well as foundational studies on social spaces by Whyte [54] and Hertzberger [26]. The three tables correspond to the first three themes we identified from the last section, respectively. Each table consists of five columns. The first three columns are organized as a nested series of design attributes that relate to the quality of a

space. The column furthest to the left represents overarching Principles that would support populations living with chronic illness. Each principle is then broken into specific spatial qualities (Quality column), which represent more specific characteristics of a space. Each quality includes several Design Elements, which are tangible and measurable features or amenities or specific affordances of a physical space. Each principle and some qualities listed in the table

are marked with a superscript that refers them to the respective study/theory from which they were derived. The design elements are a combination of relevant features from healing garden design recommendations [15, 56] and important amenities mentioned by participants in the interview study. Design elements that came out of interviews are highlighted in light grey. In the right two columns of the table, we indicate which design elements are present in the ADA standards for accessible design (ADA) [18] (representing everyday public spaces) and Healing Garden design guidelines (HG) [15, 56]. We also highlight in dark grey which design elements derived from our interviews are currently not included in ADA design standards or the healing garden design literature we examined. This helps to highlight how well current accessible design practices reflect the needs of people living with chronic illness. Lastly, we discuss how these physical spatial design guidelines might inform interaction design.

4.1 Physical Comfort

Physical comfort, shown in Table 2, refers to environmental conditions that minimize pain or constraint, and reflects issues identified in the previous theme of physical discomfort away from home (section 3.2.1). Design principles in this section were derived from themes in our interviews relating to physical symptoms, physical abilities and environmental sensitivities. This set of guidelines is focused on aspects of the physical space that are primarily about hazards, access, and basic needs (such as bathroom facilities). For example, one design principle for enhancing physical comfort for people with chronic illness is to design spaces that require low physical exertion (column 1 row 2 in Table 2); this principle can be supported by providing resting spots, such as frequent and comfortable seating, seating along a path, and places to lie down. Another example to support physical comfort for people with chronic illnesses is to minimize exposure to sensory stimulation (column 1 row 3); this can be achieved by providing control over the lighting, temperature, noise, and olfactory triggers.

4.2 Emotional Restoration

Emotional Restoration, illustrated in Table 3, refers to how a physical space can minimize or alleviate feelings of psychological distress that come with chronic illnesses. It was derived from our interview results relating to anxieties associated with being in unfamiliar environments and reflects issues identified in the previous theme of distrust in public spaces (section 3.2.2). It also relates to feelings of loss and despair that stem from the physical constraints imposed by the combination of illness and inaccessible environments. These guidelines focus on helping individuals feel at ease in their environment, improving access, minimizing uncertainties and distracting from negative experiences that are not addressed solely by making environments more accessible.

An example of a design principle that encourages emotional well-being for people with chronic illnesses is to create a sense of control (column 1 row 2 in Table 3), which can be facilitated by providing flexibility or choices in a space, such as through movable furniture, different seating options, and access to both open and private settings. A sense of control can also be enhanced by ensuring easy access to essential provisions. For instance, knowing

that there are bathrooms, food, and water nearby and having easy access to transportation home can help one feel less anxious in the event of symptom onset. Another design principle is to create environments that allow for the sense of “being away” (column 1 row 1), bringing people out of their routine and temporarily away from the experience of illness; this could be facilitated by providing positive distractions such as views of nature, soothing sounds, interactive elements, or people-watching spaces.

4.3 Social Support

Social Support, illustrated in Table 4, refers to spatial elements or configurations that encourage community building. This list of guidelines was derived from themes in our interview results relating to the loss of place-based community (section 3.2.3). These design principles focus on ways to facilitate social interaction and encourage expression. We include programmable elements and spaces that encompass spatial affordances to facilitate supportive, interactive activities. An example of using site-level design measures to promote social capital is to facilitate social interaction (column 1 row 1 in Table 4) through informal gathering spaces, which can include physical amenities such as open flexible spaces, movable tables and chairs, and sociopetal seating. Another way to support social wellbeing is to encourage expression and dialogue by providing spaces for events or interactive installations.

While acknowledging that the design of a space is more complex than the sum of its parts, the presence (or absence) of certain physical elements, amenities or qualities, along with programming opportunities, can still serve as the basic building blocks for creating an accessible space that better supports the needs of people living with chronic illness.

4.4 Discussion

The development of these guidelines and our analysis comparing them to existing guidelines show that even though the accessibility needs of people living with chronic illnesses are not surprising, they are largely absent in the design of everyday places. Moreover, while many supportive design elements are included in healing garden design literature, some needs related to Lyme disease are still missing. Therefore, there is urgent need to improve the design of our public spaces to increase accessibility for populations living with chronic illnesses like Lyme disease. However, even with an understanding of how the physical environment can be supportive, modifying public spaces to be accessible and accommodating of everyone’s needs is impractical because individual needs and preferences are widely variable and sometimes contradictory. In addition, physical infrastructure can take time and money to improve and upgrade, meaning that a widespread change in accessibility of third places is likely to take time.

Thus, in our final section, we suggest an interactive mapping app that can complement therapeutic place design by helping to improve access to supportive places: an interactive tool that can allow for customized searches of relevant spatial/environmental elements to help find therapeutic third places with specific qualities that meet different needs.

Table 3: Guidelines for Emotional Restoration include feeling of being away, sense of control and legibility and coherence.

Principles	Quality	Design Elements	ADA	HG		
Feeling of being away ³	Positive distractions ²	Views of nature		X		
		People-watching space		X		
		Wildlife habitat		X		
		Soothing natural sounds		X		
		Playful colors		X		
	Spaces with complexity ³	Interactive objects	Presence of water		X	
			Variety of views		X	
		Places for reflection	Variety of textures		X	
			Variety of sounds		X	
			Variety of activities		X	
		Spaces with mystery ²	Views of nature		X	
			Memorial space		X	
	Sense of control ²	Having choices/ flexibility ⁴	Quiet space		X	
			Private/enclosed space		X	
			Presence of water		X	
Curving paths				X		
Framing of views				X		
Perceived safety		Seating options	Private or open space		X	
			Well maintained	X	X	
		Access to essential facilities	Visual access		X	
			Protection from bugs			
			Lighting at night		X	
		Legibility & coherence ³	Perceptible Information ⁴	Access to medical help		
				Access to restrooms	X	
Access to transportation						
Access to food and water						
Visual Access					X	
Simple & intuitive use ⁴	Simple & intuitive use ⁴	Landmarks		X		
		Signage/signaling	X	X		
		Spatial delineation		X		
		Clear/simple layout		X		
		Appropriate destination		X		
		Circular paths		X		

¹Comfort Studies

²Stress Reduction Theory

³Attention Restoration Theory

⁴Universal Design

⁵Social Life (Whyte)

⁶Space and the Architect (Herzberger)

HG – healing garden literature

ADA – ADA standards for accessible design

5 A PLACE-FINDING MAP PROTOTYPE

Our research shows that the presence or absence of specific physical elements can influence the experience of place. However, relevant information about places is hard to find; people commonly have to

scour the Internet to know if a place is accessible to them. While there are many different online applications for finding third places (such as Google Maps or Yelp), they lack features to easily identify many qualities that improve the experience of someone with a chronic illness. The highly variable experience of people with

Table 4: Guidelines for Social Support include invites social activity, and facilitates interaction.

Principles	Quality	Design Elements	ADA	HG	
Invites social activity ^{2,5}	Event programming Spaces that attract crowds ⁵	Flexible space		X	
		Water feature		X	
	Seating spaces ^{5,6}	Access to food			
		Focal point			X
		Variety of seating			X
		Large sharable table ⁶			
		Movable seating			X
		Seating options			X
	Connection to street ^{5,6}	Sightlines ^{5,6}			X
		Gathering spaces	Sociopetal seating ⁵		
	Activity Space ⁵	Open flexible space			X
		Movable tables & chairs			X
		Intimate spaces			X
		Gardening area			X
		Recreational amenities			X
		Open flexible space			X
		Playgrounds			X
Facilitates interaction ⁶	Event programming Design for chance encounters ⁶	Flexible space		X	
		Intersection of paths ⁶			
	Space for art or exhibits	Framing of views Sightlines ^{5,6}			X
		Display space			
		Framing of views/ focal point			X
	Perceptible Information ⁴	Dedicated memorial space			X
		Spatial delineation			X
	Meeting spaces ⁶	Visual access			X
		Signage/signaling		X	X
		Private/enclosed space			X
Seating options				X	
Seating with tables				X	

¹Comfort Studies²Stress Reduction Theory³Attention Restoration Theory⁴Universal Design⁵Social Life (Whyte)⁶Space and the Architect (Herzberger)

HG – healing garden literature

ADA – ADA standards for accessible design

chronic illnesses also creates challenges for presenting useful information to each individual user.

Using design elements we derived in our guidelines in the previous section as qualitative filters for existing public and outdoor spaces, we introduce a platform that can complement therapeutic place design and increase access to public space by allowing people with different abilities to find physical places with specific qualities that are accessible for them.

5.1 Prototype Construction

To explore ways that users could potentially interact with accessibility information for public places, we developed a prototype that lets users browse and filter places on a map (Figure 1). The purpose of the prototype was to probe the value of the information that arose from our design guidelines, thus the interface design was intentionally generic. We envision the information could be integrated into a modified version of other mapping interfaces (e.g. Google Maps) with the addition of searching and filtering by categories from the guidelines. We began by developing a coding scheme based on the design principles in Tables 2, 3, and 4, and

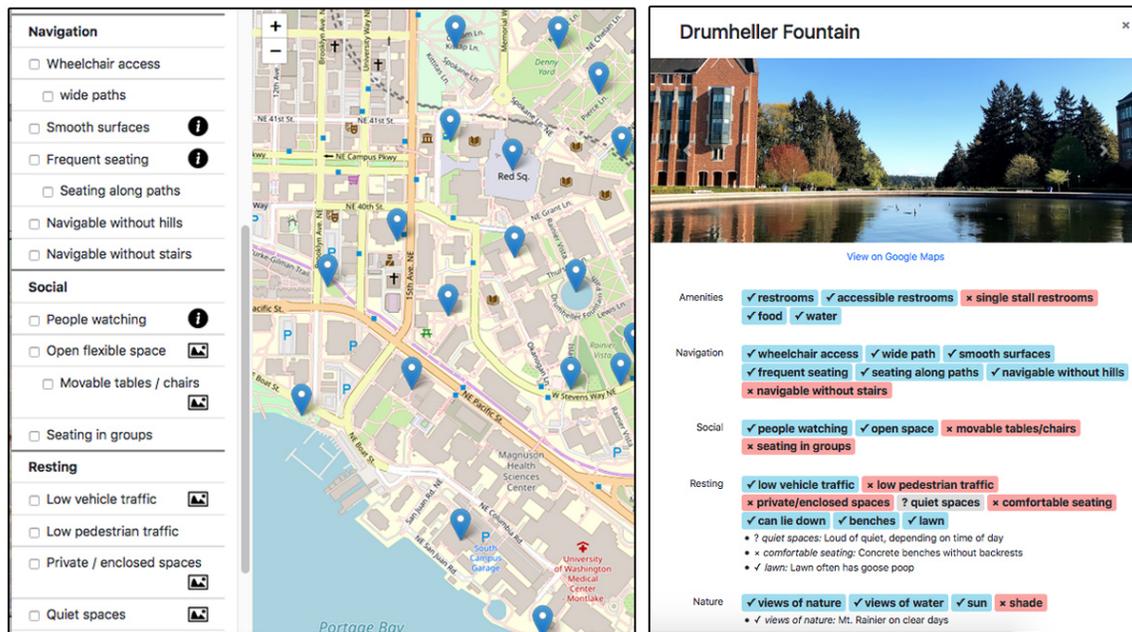


Figure 1: Screens from the prototype. (Left) Users can select accessibility qualities to filter the places shown on the map. (Right) Clicking on a place opens a popup window to see all of that place’s coded accessibility qualities, pictures, reviews, and additional textual descriptions.

an author visited and coded places around the University campus. Some elements presented in the tables were omitted to allow for the prioritization of other elements in order for us to cover a wider range of different needs (for example, we did not include types of lighting for indoor spaces but included option for sun/shade for outdoor spaces).

Some challenges emerged from the first attempt at coding places: many of the characteristics are subjective or hard to specifically define (e.g. private enclosed spaces); some qualities are difficult to identify for an inexperienced coder (e.g. identifying triggering chemical scents), and some vary over time (e.g. noise levels). We revised our codebook to include more specific definitions when possible, and included example pictures for qualities that were too subjective. In the user interface, we added buttons to show details about each criterion in the codebook (Figure 1, left), and freehand text comments (Figure 1, right). For the user study, we made two versions of the map prototype: one for outdoor places on the university campus, and a second for indoor businesses on a nearby popular commercial street.

5.2 User Study

Once the prototype was completed, we conducted a user study to understand whether the information presented in our prototype was helpful to individuals living with Lyme disease in navigating public and outdoor spaces, and whether such an app would encourage them to increase outings and experience public and/or outdoor spaces with greater comfort and confidence. We invited the fourteen original interview participants who contributed to the formulation of the design guidelines, and eight volunteered to take

part in the study (participants 2, 3, 4, 6, 7, 9, 13, 14). Five of the fourteen did not respond to the invitation and one declined.

In the study, we first asked participants about their existing technology use for place-finding and navigation purposes, then we asked them to complete three place-finding tasks under different scenarios, first using Google maps then using the prototype. Participants were asked to complete the tasks in hypothetical situations from home. The study was conducted virtually via zoom when stay at home orders were in place, and the participants’ use of Google maps and the prototype were captured through screen share. Following the tasks, there were semi-structured interviews and a survey questionnaire with Likert scale questions comparing the two different maps. We used Google maps for direct comparison with our prototype, but also as a way to probe the users’ existing technology use practices. In the first task, we asked participants to find a place to rest and recover in the event of a sudden flare-up. In the second task, participants used the maps to plan a walking route with safe stopping spots. In the third task, participants were asked to find destinations for socializing on a “good health day”. Together, the three scenarios covered a range in likely health fluctuations and a range of uses in “third places”.

5.2.1 Use of Currently Available Technology. In the pre-task interview, we asked participants about their current use of technology. All participants reported using digital tools to search for and navigate different places. Most reported using Google Maps (n=8) and Yelp (n=6) to find destinations for leisure and daily needs, browsing reviews and images for specific qualitative information, amenities, and accessibility. Participants also checked places’ official websites

(n=6), as well as purpose-specific tools like All Trails and AirBnB (n=6). However, all participants reported that many important characteristics and features for accessibility and comfort are difficult to find, and certain qualities of a space can be particularly hard to discern if they are not visible from pictures (such as presence of mold or noise). Participants described having to “*read between the lines*” (participant 6) to make judgments about whether a place will be safe and comfortable, or frequently using a combination of different resources to “*piece together information*” (participant 2). Some participants used Facebook to crowdsourcing accessibility-related information, asking friends for recommendations (participants 7 and 9). Some used Google street view to check for certain outdoor amenities, like places to rest or sit down (participant 2 and 4), or whether there are steps (participant 13). However, with the currently available forms of information, they often still are unable to find correct information: “*I’ve had difficulty finding information about a place and had to change where I’m going based on accessibility issues [after getting there]*” (participant 13). As a result, participants tend also to rely on other forms of information in addition to digitally available data, such as word of mouth, prior experience, or familiarity with certain types of places from which they infer likely spatial qualities.

This is evident in observing participants’ use of Google maps as a tool to find places with specific qualities in the tasks conducted in our user study. For example, because one cannot easily search for a quality or amenity of a place on Google maps, people tended to look for types of places that they associate with specific qualities based on prior experience (i.e. Starbucks usually has comfortable seating (participant 9), and libraries are usually quiet and have places to sit (participant 3)), then try to confirm their assumptions through pictures or reviews. For example, one participant said, “*You can search for coffee shops [on Google], but the amenities you can’t really look up, like where there are comfy benches...or where can I sit down or lie down in a public space*” (participant 6). Sometimes people had a hard time knowing where to start to find a safe and comfortable destination using Google Maps in an area they were unfamiliar with. “*Gosh I don’t even know where I would start. . .I’m thinking about there are all these things that I would maybe consider but I have no idea how to find*” (participant 6).

5.2.2 Response to Prototype. In contrast to Google maps, the prototype presents a way to search for destinations based on qualities of a space in a given area, as opposed to type (e.g. restaurant or bookstore) or name. Most often, users browsed the prototype map by toggling on and off filters to narrow down choices, as a first screening for places they would consider visiting based on accessible features: “*It was nice to be able to narrow things down with the different selections. . .because if you see that there are thirty places you can go that’s kind of overwhelming*” (participant 7). Once they had essential features selected through the filters, participants would look through the details, photos, and reviews of individual places to verify their accessibility and decide if it was somewhere they actually wanted to go. These additional pieces of qualitative information conveyed more complex experiences of a place that were critical for the participants’ decision-making. For example, one participant said: “*I don’t see a picture of this [place]. . .so honestly I think a picture is worth a thousand words. It doesn’t look as compelling*” (participant

9). When specific accessibility characteristics are a priority, the filters allowed for quicker navigation. Participants could play around with different options, and easily try different combinations that met their needs:

“It’s definitely easier [to find places] on the prototype. It brought up more options. You can even play around with what you choose. What would happen if I press this? What if I did want food?” (participant 13)

Bringing these accessibility features as filters to the forefront presented an “*ease of information*” (participant 6) that was highly relevant to the participants and helped them find more options and discover supportive places not only in an easy and efficient manner, but also in an engaging fashion: “*It was also just fun! It felt really friendly, and it made me want to play with it more. Almost like a little game or something*” (participant 4).

In both task one and two, 7 out of 8 participants expressed that it was easier to use the prototype than Google Maps to find a safe and comfortable place, and in task three, 6 out of 8 participants said that the prototype was more helpful in finding a place for socializing even in the scenario of having a good health day, because it provided a safety net in case symptoms emerge, and certain accessibility features provided comfort and something enjoyable regardless of immediate health status (such as views of nature). Six of eight participants said that the prototype, in its current form, would encourage them to go out more. Other participants expressed that adding some additional filters that were more relevant to their specific symptoms (such as filters related to mold or scents) would make a more compelling case in encouraging outings. Compared to Google maps, using the prototype increased confidence levels for 5 out of 8 participants in finding a safe and comfortable destination during a flare, 6 out of 8 participants in planning a walking route with safe stopping spots, and 4 out of 8 participants in finding a desirable destination to socialize. As one participant expressed: “*[the prototype presented] more information and more relevant information to the things that I particularly need when I’m feeling [sick]*” (participant 4). The filters provided a legible way to visualize options and gave users the opportunity to prioritize their place-related needs based on their changing symptoms:

“Being able to see all those different options, like things that mattered a lot to people who have chronic illness... That was really nice. Depending on what I needed. . .[it] was really nice to have all those options” (participant 2).

Several participants expressed that the prototype presented options that they desired, but didn’t think of or know they could search for on Google: “*Having it all laid out – all the things that I would want – made me think about the things I could’ve searched*” (participant 6). While Google Maps can be helpful in finding the location of specific places, the prototype provided an exploratory platform that helped participants to discover destinations they wouldn’t have picked out or seen otherwise on Google Maps: “*That plaza was something that I never would have picked out from Google Maps. It was really nice to know that it had all those [amenities]*” (participant 3). Another participant expressed: “*It opened my ideas to things that would be along the path that I’d want to stop at that I wasn’t thinking about*” (participant 13).

The user study also revealed some shortcomings of the prototype that should be explored in future research. A major challenge that emerged was the difficulty in trying to quantify the subjectivity of qualitative sensory information. For example, the level of noise and whether seating is comfortable vary to some degree from person to person, as previously identified in our literature review in Section 2.3.2 [2]. One participant who was familiar with places that we coded disagreed with some of the coding that was done regarding noise levels. Issues like these will need to be explored further in future interface designs to allow for a more accurate and agreed upon documentation. Furthermore, the prototype did not fully address the range of accessibility needs for all participants. Some additional filters that participants expressed desire to see in a future iteration included information on scents or mold, type/intensity of lighting in indoor spaces, and parking locations. These types of feedback again illustrate importance of knowledge sharing.

Several participants (2, 4, 6, 9, 13) imagined using this tool in moments of urgency with a sudden onset of symptoms, in which a mobile version of the app would be important. For example, participant 9 reported that: *“I can tell you that I’m not going to want to walk a whole block because if I’m experiencing symptoms I would be close to passing out and I’m going to want to sit down really quickly.”* In this situation, having a tool on hand that can quickly inform the user of nearby places with comfortable seating or places to lie down would be important. Similarly, participant 4 described sudden flare-ups as having “this panicky component to it,” in which case a mobile version of the app would be able to provide a sense of control for users so they feel more able to react when symptoms occur. Lastly, having the app handy can allow users to be more spontaneous when they are away from home. During task 2, in planning a route, participant 13 stated:

“It gave me more options. So I can kind of walk a little bit and see how I’m doing and see what’s close to me, then make decisions [based on that]...Which is so much less stressful than planning something out.”

5.3 Future Work

Our prototyping experiment and user study serve as a proof of concept, demonstrating that increasing the availability and ease of information can make it easier for people with Lyme disease to find accessible third places, encourage them to leave their home more often and occupy social spaces. These findings have strong implications for improving the quality of life and overall wellbeing for populations living with chronic illness.

Much more work is needed to explore interface designs and coding approaches for interacting with this information in more useful and efficient ways. Accessibility information could be better integrated into commonly-used features and workflows in platforms like Yelp and Google Maps; such as searching for certain types of places (e.g. cafes or bookstores), information on opening hours, and options for multi-modal routing. Additionally, a key challenge is to source accessibility data for different third places. One possible approach is crowdsourcing, which is often used to gather qualitative information in apps related to experiences of place and accessibility such as Care and Connect [39] and Streetwyze [1] that were previously mentioned in section 2.3.1. However, crowdsourcing

is challenging for this application because the necessary data is big, complex, and specific. Many of the important characteristics would be difficult for inexperienced coders to identify without prior training. Without a critical mass of users to contribute data, the accessibility information we could provide would likely not be more accurate or useful than what is already available. Future work could investigate the potential use of machine learning techniques to extract accessibility information from reviews and images on sites like Google Maps [25, 53] and Yelp [58].

5.4 A Tool for Designers and Planners

If successfully populated, the same spatial database collected through the app could also help planners identify areas that lack supportive public spaces by presenting geographical and qualitative patterns of existing accessible environments. It could also inform designers of design elements that may be lacking in certain sites or neighborhoods, and serve to prioritize opportunities for implementing therapeutic design in everyday places.

In summary, digital tools can structure design work and directly benefit people with chronic illness. In addition, tools for designers and users of physical spaces are complementary. For example, a connected system could provide a more complete picture of spatial patterns to designers and researchers, and inform more comprehensive strategies to support people with different disabilities.

6 CONCLUSION

Through this project, we highlighted a gap in the existing built environment literature regarding accessibility for people with chronic illness, documented the experience of place by people living with chronic Lyme disease, demonstrated the possibility of creating places accessible to those living with illness, and began to explore how digital applications can serve as a tool to help enhance the experience of place for this population. Our analysis shows that the needs of people living with chronic illnesses are not well reflected in the design of everyday places, making such places inaccessible. Our contributions can serve as a guide and reminder for policy makers, spatial designers, and those living with a chronic illness or their advocates to apply in their own homes or community. Bringing healing environments beyond medical facilities and into the everyday environment – sidewalks, parks, gardens, parking lots, coffee shops, grocery stores – can have a profound positive impact on people living with chronic illnesses, as well as creating a public sphere that supports health and wellness for us all.

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