From Chronic Health Condition to Disability Identity: Opportunities for Health Informatics Engagement

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Abstract

Of the millions of Americans with chronic health conditions (CHCs), a growing number are coming to identify as disabled due to their CHCs. Their definition of disability differs substantially from how health informatics has traditionally thought about disability and CHCs. Rather than seeing disability as worsening CHCs that ought to be prevented, disability community definitions see disability as a form of social difference, akin to race and gender. To understand the impact of this perspective on disability on people with CHCs, we interviewed 15 participants who identify as disabled due to their CHCs. We found that it was often difficult to develop a disability identity, but doing so had significant benefits: greater self-acceptance, accessibility, and community. We conclude by identifying opportunities for health informatics to enable more people with CHCs to develop and benefit from a disability identity.

Introduction

Hundreds of millions of Americans have been diagnosed with at least one chronic health condition (CHC),[1] such as diabetes, arthritis, and migraines. Diagnosing, managing, and preventing CHCs is a major concern for health informatics. Current informatics approaches emphasize improving uptake and adherence with medical treatment, viewing CHCs through a lens of medical management.[2–4] However, some individuals with CHCs have begun to identify their CHCs as disabilities, not solely ill health.

When health informaticists have researched CHCs as a type of disability, they have identified individuals as disabled by a CHC if they face barriers across a range of activities of daily living.[5] The goal of that research is often to understand which CHCs may progress into disability in order to prevent such progression in the future[6]—disability is framed as an entirely negative outcome.

In contrast, rather than seeing disability as a range of undesirable losses of physical and mental function, disability scholars define disability as a type of social difference, akin to race and gender.[7] This reframing has animated decades of activism, resulting in landmark legislation such as the Americans with Disabilities Act,[8] as well as social transformations that, for instance, lead many to celebrate disability pride month each July.[9] Though CHCs were not well-represented in early disability activism, the contemporary disability justice movement is led by many people who identify as disabled due to a range of CHCs.[10]

Understanding how people with CHCs have come to identify with disability and the impact that has on their day-to-day lives has the potential to open new frontiers in health informatics research that could enable greater support for the growing and under-served population of people with CHCs. To understand what causes people with CHCs to identify their health experiences as a disability and the impact that identification has on their daily life, we interviewed 15 people who identify as disabled due to CHCs.

We found that people came to identify their experiences of life with CHCs as disability through myriad sources, often through the process of setting up accommodations or connecting with online or in-person disability communities. Participants identified substantive benefits that followed developing a disability identity—affirmative narratives about disability replaced deficit narratives around illness, they became skilled at seeking accommodations, and they found community. Having identified the value of a disability identity for people with CHCs, we describe opportunities and provocations for health informatics to facilitate this identification process across many domains of healthcare.

Methods

This paper's findings are drawn from semi-structured interviews conducted with people who identify as disabled due to chronic health conditions. We recruited participants via university accessibility affinity groups, snowball sampling, and authors' existing research recruiting pools. Participants joined researchers for a 90-minute study session via Zoom and were compensated $75 for their participation. Study protocols were deemed exempt by the University of Washington's Institutional Review Board. When expressing interest in participating, individuals also shared access needs, which we met during the study session—common requests included using automatic captioning, sharing questions in advance, and taking breaks.

The data reported upon in this paper was gathered in the first half hour of study sessions, guided by a semi-structured interview protocol. The interviewer asked participants about their experiences with chronic health conditions, their path toward developing a disability identity, contexts where it is more or less comfortable to identify as disabled, experiences seeking accommodations, and what a disability identity means to them. The interviewer identifies as disabled due to CHCs, an identity disclosed to participants at the beginning of the study.

All data was transcribed using Zoom's automatic transcription tool and reviewed by the first author. Data was analyzed using reflexive thematic analysis.[11] Specifically, the first author read through each transcript, taking notes about what could be of interest in an eventual codebook. Upon development, that codebook was shared with the last author and colleagues for review and discussion. The first author then coded all data using the updated codebook. The last author reviewed the final transcript coded and authors discussed and implemented any needed updates to coded data. Data was then organized into themes which comprise the major findings subsections.

Results

To understand how disability identity benefited our participants, we first (1) identify the negative ways CHCs reshaped our participants' daily lives, then (2) explore how participants came to develop a disability identity, before finally (3) explicating the benefits participants found from disability identification. We describe the participants involved in this study before discussing findings.

Participants

Fifteen participants joined this study, with a wide range of CHCs. Participants disclosed 60 unique conditions, most commonly dysautonomia/POTS (5), asthma (4), chronic pain (3), migraines (3), hypermobility/hEDS (3), chronic fatigue (3), and autoimmune conditions (3). Ten participants disclosed multiple CHCs, and four of five participants who shared only one diagnosis had a multisystemic condition (fibromyalgia, muscular dystrophy, a rare genetic condition, a yet-undiagnosed autoimmune condition). Though we did not solicit this data, seven participants disclosed cooccurring mental health diagnoses or neurodivergence. All CHC data was self-reported, and we did not require participants have formal diagnoses to participate in this research, as access to diagnosis is a barrier for this community.

We collected data on participants' age, gender, and race. Three participants were 18-25, seven were 26-35, four were 36-45 and one was between 66 and 75. Overall, nine participants identified as white, four identified as Asian, four identified as Latin/x or Hispanic, one identified as Middle Eastern, one identified as Indigenous, one identified as Black, and one participant reported only 'mixed'. Several participants indicated multiple racial identities - only six participants solely identified themselves as white. Regarding gender, six participants reported being women/female, six reported being non-binary/gender queer/agender, and three participants reported being men/male.

Participants' Experiences with Day-To-Day Access Needs

Our participants described the ways their lives changed due to their CHCs, highlighting barriers to activities of daily living, the need to plan around bodily limitations, and obstacles to relationships with others. Overall, CHCs operated to mark our participants' lives as different from those living without health concerns or other disabilities.

Our participants found that CHCs either limited or substantially altered their daily activities, reshaping their lives. Many of these changes impacted the minutiae of everyday life and were most pronounced at the beginning of people's experiences with CHCs—for P2*"it was so painful to lift a fork,"* for P3 *"it was hard just to walk to the mailbox sometimes, after I got really sick,"* and for P9 *"I stopped being able to hold [my daughter] on one side as a baby."* Changes in their ability meant that participants often had to stop doing the things that had previously been central to who they were. P4, who had been a lifelong athlete, found that *"I got to a point in my life where people were like, surprised. They're like 'oh, you played sports?' It was shocking to me and it hurt my soul deeply, … no one ever didn't know that I was this fantastic athlete."* P12's condition progressed to a point where she had to go on disability and stop working, and she reflected that, now, *"I don't do anything. I was a professional photographer, I used to work with kids, I'm good at teaching, but I don't do it anymore."* Even when activities remained possible with modification, these modifications were often a marker of difference. P14 shared his experiences of being *"17 years old and I already have to use a cane to get around school … visually I was different than all of the other kids."* CHCs often had a profound and pervasive impact on how participants conducted their daily lives, producing a sense of otherness.

For many of our participants, their CHCs determined how they could schedule and plan their lives, on both small and large scales. For people with conditions that cause intermittent symptoms, planning their work around the possibility that symptoms may arise is a key tactic. P1 described learning to *"mak[e] sure I do my homework really early, so that if I were to get a migraine later on, then my homework is already done."* This skill was not always easy to develop—P2 reflected that *"my work-life balance is almost nonexistent ... because there might be a day where I just can't get out of bed until like 10 AM."* For many participants, the need to plan for and accommodate their CHC limited how they could navigate the world. While P14 had access to the elevator when in high school, he would often *"have to walk halfway across the school and halfway back"* to use it, and found that the stairs, while painful and difficult to manage with his cane, were "*more energy efficient."* P3's heat intolerance means they try to *"take advantage"* of cooler winter weather, as they struggle to exercise outside when summer highs often exceed 100°F. P5's diabetes medication means he must use the bathroom frequently, and it is the *"kind of uncertainty that makes [him] think twice about going out or traveling."* For others, their energy limitations and fluctuating abilities mean they are not able to work consistently. P4 found that *"the three days I rested up for that one hour and the three days it took to recover for that hour"* made it impossible to hold a job, as "*no one's gonna hire you for one hour's productivity that takes a week."* P12 had been working as a substitute teacher in 2020, but eventually she found that *"say I had four days full time sub teaching work – by the fifth day I wasn't able to function anymore."* She chose to apply for disability benefits rather than return to work after schools reopened following COVID. To manage their CHCs, participants often required non-normative schedules and plans, which they often struggled to secure.

Participants also found that their relationships changed in response to their CHCs, often losing support and community. P7, who has had a CHC from birth, reflected on how her relationships changed while growing up. While she found that *"kids don't really care unless they're taught to care about people's differences,"* by high school, her friends were all *"walking to get Wendy's or walking at the mall or playing manhunt."* With limited mobility and severe digestive symptoms, P7 could no longer join in. P8 *"always felt guilty saying 'I can't go out to do something with friends,'"* eventually falling out of touch with many pre-diagnosis friends. Both P2 and P15 found that their necessarily early bedtimes meant they could not join in with peers who *"would start hanging out at 10 PM"* (P15). P11's marriage could not endure her higher support needs—her ex-husband *"didn't know what to do. It made him extremely anxious. And that made his behavior horrible, just horrible."* CHCs were often isolating, particularly when participants' primarily nondisabled communities lacked the skill to support them in navigating new support needs.

Paths To Developing a Disability Identity

We specifically recruited participants who identified as disabled due to their CHCs, and they described the paths that led them to a disability identity. Myriad sources brought people to disability identity, namely accommodations processes, disability affinity communities, and, rarely, clinicians and therapists.

Accommodations As Formative to Disability Identity

Many of our participants first came to understand themselves as disabled when seeking accommodations. Several participants' disability journeys overlapped with their time in college, where they first learned they could use accommodations through student disability resource offices. P1 received an email from her academic advisor that explained *"we have this office of disability and some people have test anxiety accommodations. And before that I didn't even know that was something that existed."* Though P1 experienced migraines, not test anxiety, this incidental exposure caused her to seek disability services, which led her to get a long-missing diagnosis and understand herself as disabled for the first time. P15 found that *"even though I was, what, six years post injury, I was basically newly disabled as far as the world of accessible accommodations is concerned"* when he finally returned to school following severe traumatic brain injuries. His community college disability services professional *"realized that faster than I did, and she helped my transition a lot"* (P15). When people developed CHCs while still in school, formal student support infrastructure meant they got identified as disabled and received needed services.

Others found this structure at work. For P10 *"the place I feel most disabled"* is when interacting with *"bureaucratic legal systems,"* and fighting for access to a bathroom in their workplace led them to understand their needs as a *"legally protected right."* When working as a nurse, P11 grappled with how her use of accommodations impacted how she identified and was perceived, reflecting: *"I do what I do, and I am who I am, and I do the best I can. And if that indicates to folks that I am disabled, then that is who I am."* While P13 built her career, *"as time went on I kind of looked at things and I was like, you know, I do I have a disability, I do need accommodations."* Being in workplaces where their access needs were not met served as a catalyst for participants' disability identity development.

Many participants struggled to first reach out for accommodations, but the process of receiving access for the first time often led people toward a disability identity. Both P4 and P11 began to develop a disability identity after acknowledging their need for an accessible parking permit. After receiving a permanent disability parking placard, P4 *"was like, 'you know, this is making such a difference'… that kind of helped me step into other ways of accepting the rest of—that I'm disabled and changing that mindset."* Experiencing the benefits of access in this one arena helped bring P4 into a place where disability identity was something P4 could accept. When P9 was first introduced to the idea of accommodations in their undergraduate education *"I rejected that pretty emphatically, because I was like … I can't accept that I need special treatment. There was so much shame."* However, they realized that *"being aware at least that [access] was an option and that I was choosing suffering would later inform"* their development of a disability identity. Moving from shame toward access often helped participants begin to form a disability identity.

Disability Identity Facilitated by Interactions with Others

Meeting other disabled people and realizing they shared experiences was another common path to disability identity for our participants. Participants found disability community via groups they interacted with in person, online groups, and, rarely, through their medical providers. For some participants, family histories of disability shaped their own ability to contextualize their experiences of CHCs.

In-person connection with disabled people led some participants toward identity transformation. For instance, P15 spent several years homebound, and while, at the time, *"had I heard of the word disabled I probably would have identified with it,"* it took until he was using *"all these disability resources at school, [that] I now identify as disabled, having met people with very different disabilities."* For many, it was specific individuals or groups that enabled them to first claim a disability identity. P10 had a professor who was *"very vocal about her disability identity"* and discussing disability scholarship during that professor's office hours *"awakened my understanding of disability."* For P2, a support group gave her *"other people to talk to—that was a big change in terms of … recognizing that like, 'oh, disability is a term I can use to describe what I'm going through.'"* These recognitions of solidarity were crucial to allowing participants to claim disability identity. When attending a conference for marginalized scholars in her field, P1 met others who identified as disabled due to their chronic health conditions and felt that *"that's the first time that I really felt seen by other people."* Meeting other disabled people and connecting over shared experiences was formative for participants' ability to claim disability identities for themselves.

These interactions were not limited to in-person connections—in fact, online communities were a crucial part of developing disability identity for many of our participants. Before participants could come to identify as disabled, they often had to first learn about disability. P3 reflected that, prior to joining online chronic health forums, *"I just didn't really know a lot about the disability community because there's a lot of stuff that is just not really readily available."* P6 joined a Facebook group for others with autism and it was through that group that they *"met a lot of people who were also dealing with chronic disability. And we started talking … I learned about, like, comorbid disorders, and how a lot of people who have autism also have A, B, and C, … and then it was very much like Alice in the rabbit hole."* Online affinity groups often gave people the chance to meet others they would not be likely to connect with, particularly when their CHCs limited their ability to regularly engage with in person communities. For P8, being able to build disability community was revelatory: *"there's different friends that I've had that … have really shaped how I view, I guess not even just disability but myself."* Online communities could also provide people the opportunity to reframe past understandings of disability. Though she has had CHCs since birth, P7 didn't *"really interact with part of the community until like my mid-twenties"* but *"now I've been creating content about disability education online, so that's kind of been a lot more full force in the disability community than historically I ever was."* Health informatics has long studied online communities as a source of solidarity and health information[12–14], and we find this trend continues within the domain of disability.

Medical providers were uncommon paths toward disability identity for our participants. P2 found a therapist who ran a chronic health and disability support group after her primary care provider recommended that mental health therapy could be useful. Her therapist's education on disability history and community changed P2's perspective on disability, from a thing that has *"always kind of been looked down on, and it wouldn't be something that I'd want to associate myself with"* to seeing that *"oh I do fit into that. And it's ok, here's all these other people … in their mid-twenties to mid-thirties just like me"* (P2). P8 also had a therapist who was a key ally in advocating for her to apply for disability benefits as she *"had a clearer picture of how difficult things were for me."* Notably, though diagnosing clinicians could be a pathway to therapy, mental health therapists were the most transformative providers for our participants.

For some participants, their first introduction to CHCs and disability was at home, where family histories of disability informed their own disability identity. P11 and P12 have genetic disorders that they share with other members of their family. P11 inherited her condition, but in her experience *“it’s very classic for my mom and her family that you don’t talk about these things.”* P11 took a very different approach when raising kids who inherited her condition, taking them to the activist events she organized around their diagnosis. P12 also shares her CHC with her mom, who chose to delay genetic testing *“because she felt like she wanted me to be able to live my life and if my symptoms weren’t that bad to be able to ignore it.”* However, her mom was the first to *“point out that it’s not normal to get home and not be able to function after work”* when P12 developed symptoms in her twenties. Though not inherited, P10 contextualized their new disability identity with the fact that they *“come from a very disabled family”* but drew distinctions between their more privileged experiences and the greater obstacles their disabled family members faced. On the other hand, P14’s dad used a cane intermittently, meaning *“using a cane was not really a taboo for me to this day.”* Familial approaches to disability shaped how participants reckoned with disability identities for themselves.

Benefits of Disability Identity

Coming to identify their experiences with CHCs as disability experiences had immense benefits for our participants. First, affirmative narratives around disability replaced deficit narratives about illness. Second, as participants came to identify as disabled, they gained skills at seeking accommodations to expand the range of daily activities they could engage in. Finally, participants found community via their disability identity.

Replacing Deficit Narratives with Affirming Ones

A key function of disability identity for our participants was providing a source of affirming narratives to replace problematic narratives around CHCs. Many of the narratives participants encountered about their health were dominated by doubt and avoidance. A key step to moving toward disability identity for participants was grappling with ableist[*] narratives they had internalized. Participants developed less ableist views of the world and themselves through education and often-difficult life experiences. Disability identity gave participants access to narratives of mismatch, self-acceptance, and survival to positively reframe their experiences of CHCs.

Especially at the beginning of their journeys with CHCs, participants’ experiences were frequently questioned and they, their medical providers, and their communities often avoided frankly reckoning with their changing health. Many participants’ medical providers doubted and dismissed their experiences. Participants described providers who *“didn’t really believe me as much”* (P2), *“assume people of a certain age could not be disabled”* (P7), and were *“very dismissive”* (P3). When P3 struggled to comply with a difficult treatment plan, their provider responded *“like, ‘oh, well, you just don’t want to get better.’”* Developing positive relationships with providers was made more difficult for participants due to the prevalence of providers who did not take their experiences seriously. This doubt extended to participants’ everyday networks. P6 recounted that *“I have been telling the adults in my life that I’ve had pain in my bones for as long as I can remember”* but were not taken seriously, feeling like they were met with *“a bazillion excuses”* (P6). P1 also found that *“growing up it was kind of just like, ‘oh, well you have a headache, just stop complaining,’”* despite experiencing a serious migraine condition. This tendency to not believe people’s accounts of their health delayed treatment and isolated our participants from potential supporters. Especially in periods of undiagnosis, uncertainty also dominated participants’ interior experiences. P2 found that she and her loved ones struggled with the fact that *“it’s not like, ‘Oh, I got pregnant!” It’s like, ‘Oh, my body is failing on me, and I have no idea why.’”* P9 also needed time to arrive at a place where they were able to seek care— *“I just kept running away from how my body—what my body was feeling.”* The narratives participants faced when developing or first acknowledging CHCs were dominated by a desire to not believe or honestly discuss the realities of their health.

For our participants, grappling with their own internalized ableism was a necessary step on the way toward an affirming disability identity. Participants reflected on the impact of a culture where disability has *“just always kind of been looked down on”* (P2), where information about the disability community is *“not really readily available”* (P3), and where, without substantial engagement with disability activism, *“we all have some ableist ideas, right?”* (P4). P9 highlighted the impact of ableist culture on their experiences as a disabled person: *“I’m butting up against this tension where I’m judging myself or, yeah, like, trying to be something that doesn’t fit for me, and looking at it as like something that I’m doing wrong.”* P7 found that ableism went unchecked in her rare disease-oriented communities.

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[*] Disability studies scholar TL Lewis defines ableism as *“a system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness.”*[15]

While she had tried to lead discussions of *"why someone doesn't, like, love the word cure,"* P7 eventually chose to spend more time in disability communities instead, where *"there's more room for nuance."*

Participants were able to overcome ableist narratives through a combination of lived experiences and education. P4 reflected on the process of accepting disability, describing *"having to then look at myself as I was able to do less things and be like, 'oh, I really do need a shower chair' … I was just so resistant to it, because that was like admitting like I might be disabled."* For P2, it took *"having the educational aspect"* of a chronic health support group alongside *"literally going through it and losing the ability—like, for a while it was hard to eat"* to arrive at a point where she could challenge societally-engrained ableist beliefs. While these processes were often painful, the lived experience of accepting that they needed help was transformative for participants. When graduating college, P11 experienced needing help to walk onto the stage as *"extremely traumatic,"* but told herself *"are you gonna let your pride inhibit you from receiving, you know, the diploma that you worked really hard to get?"* Later in life, when a colleague pitied her use of a mobility scooter, P11 had reached a point where her response was *"life, it could be so much worse! This gives me more freedom."*

Internalizing affirming disability narratives reoriented participants' lives, allowing for self-acceptance and resilience. First, participants drew from the disability design concept of 'mismatch'[16] to understand their experiences as not personal failures, but societal ones. P3 valued *"just knowing that the society was not, like, built for people like me in mind"* and to P14, disability meant *"the world doesn't really think about what it takes for some people to live their lives."* This reframing allowed participants to identify the root of their struggles in an inaccessible built environment and ableist culture, rather than in personal failings. Disability perspectives also gave participants the ability to build or rebuild a positive sense of self in changed bodies. P4 realized *"admitting I'm disabled does not mean that I'm less than or worse than, or anything, like I'm still me. But it's just a different me."* P8's adoption of a disability identity let them find relationships that *"made it feel more okay that I really don't have that much energy to do much stuff, because I always felt, like, guilty."* A final affirming narrative participants highlighted was a compassionate reframing of their experiences as survival against stacked odds, rather than of bodily failure. P4 found narratives of survival useful in the face of the numerous changes COVID wrought: *"I am the heaviest I've ever been. But, like, this is the body that survived, you know? That body that did all those other things was great … but like this is the body that survived a global pandemic, like, I'm still here."* P6 echoed similar sentiments: *"I found inherent strength in my acknowledgement of my disability, it's like I've went through all of this shit while, like my body and my brain have actively been trying to kill me so like I'm strong as fuck, even if I like, can't open a fucking soda."* Many aspects of illness experiences are framed as weakness, failure, or suffering, and it was through reflecting on all they survived that participants were able to recontextualize their abilities in a positive light.

Disability Identity Enables Accessibility

Coming to identify as disabled also gave participants new perspectives on accessibility—instead of perceiving a task as impossible and something to be embarrassed by, it became simply a task that was not yet accessible to them. This paradigm shift transformed participants' daily worlds, their future planning, and their relationship to medical care.

For some, coming to identify as disabled and seek out access was the point where their world started to expand. When she first got sick, P2 experienced her world getting smaller, and excluding many things she loved to do. After identifying as disabled she started *"having that conversation about what accessible alternatives there might be … I think part of that comes with, like, accepting and identifying … [as disabled] so that you can start to adopt those practices."* A key part of finding more balance post diagnosis for P9 is to respond to times where they berate themselves for not being able to do something by interrupting that thinking and asking *"okay, but what if I look at it as like, I need to make modifications to be able to participate or be able to do this thing?"* P15's approach to the world changed when accessibility, rather than treatment, became his dominant framework: *"I thought that, like, I needed my headache to go away before I could start school again. As opposed to seeing … if I can make school more accessible in other ways then I can manage a headache."* A focus on medical treatment did not prepare participants to figure out how they could continue doing the things they enjoyed while symptomatic, but disability identity enabled that shift.

For some participants, disability identity was not always central to their self-conception but was particularly useful as a path to access. P7 tries to make disability *"like a neutral term, you know, just so I can live my life, but it's also important to acknowledge because then, if you don't, you won't get the accessibility you need."* P10 found that understanding themselves as disabled has helped them see that *"lists, notes, like visual cues for me are things that I* *can do to make like my home or work or life more accessible and that doesn't have to come from a medication perspective"* For these participants, a pragmatic approach to disability still conferred substantial accessibility benefits.

With an accessibility focused mindset, participants also were able to plan for their future. When buying a house, P12 prioritized the fact that *"right now I can do a few stairs no problem, but if my disability continues to progress in the way that it has been, that may not be true in 5-10 years from now, so we better look for a house that has level entry."* Disability identity also enabled hard conversations about accessibility. P14 reflected: *"My disability is getting worse. And I was hiding that from [my family] for a while, because like ... honestly it was a little bit of I didn't want to acknowledge it, like, I didn't want to make them sad, but also like I think I finally hit a point in like my deteriorating health where I am just like, over this. New thing is, you know, like a way to better help me live my life."* Rather than hoping for a future where CHCs are cured or eliminated, disability community perspectives on accessibility enabled participants to plan realistically for their future abilities.

Medical care did not preclude the value participants found in seeking access—often, medical care raised participants' health baseline to a point where they could better utilize accommodations. Long COVID majorly reshaped P4's world, but eventually an infusion-based therapy allowed P4 *"not to be bed bound, and to return to some kind of life of doing stuff outside of the house ... I still pace, still need a lot of recovery days, but it's a lot better than it was."* For P14, a combination of occupational therapy and university accommodations enabled his training as a scientist. He *"[got] like splints and exercises and sort of relearn[ed] how to write"* through occupational therapy and then worked with his university's office of disability accommodations to get double time on *"science tests where you have to write and do all this drawing."* After developing pain in her hands, P2 stopped many of her favorite hobbies, such as knitting. She and her occupation therapist have recently reached a point of "*trying to find resources online about people using larger knitting needles, for example, or different styles"* (P2). For our participants, medical care augmented, rather than replaced, the need for accommodation when managing CHCs.

Disability Identity Creates Community

An additional function of disability identity is that it provided our participants with new disability community. This community gave people a sense of belonging, the ability to share vital information, and let them help others.

For several participants, disability community was instrumental because it made them feel like they had a place to belong. P1 found that, while she had a lot of skills at managing her disability, the piece she was missing prior to identifying as disabled was *"the comfort of knowing that other people are experiencing the same thing."* P3 experienced that, in her daily life *"people just aren't really the most understanding sometimes."* and was craving *"a community that, like, really understood."* After finding online disability community groups, she felt *"it was very helpful for me just to find ... people who might understand like [I] might [not] always have the energy to talk or just talking about some of the issues that we've faced in our lives."* For P8, her disability community is a group that both understands her daily limitations and shares her values: *"disability justice like made me more grounded in other principled things too, that I'd rather focus my energy on than just like going out whenever my [nondisabled] friends want me to go out, not considering if I can go out or not"* P15 articulated why it was so useful to have a place to belong while navigating CHCs: *"when someone says they're disabled because they have a health condition, it's, it's not something you celebrate. But the fact that we're here in this community–that is something to celebrate."* The existence of a community worth celebrating is particularly impactful, given the ways that CHCs often isolate people from their preexisting communities.

For others, being in community with other disabled people helped them access vital information. For P13, being in a disability community has *"honestly been kind of incredible for me ... not necessarily even because of, like, camaraderie"* but because she was able to get a life-changing diagnosis thanks to information she learned in online disability groups. Similarly, P7 learned through social media that there was a foundation relevant to her type of CHC, which connected her to researchers who could investigate her unidentified genetic condition. In addition to specific information, others valued the sensemaking disability community afforded. P14 reflected that *"without the disability community I would probably, wouldn't still understand why my body is so weird"* For P6, making disabled friends online *"helped me do better, and then talking to them about what I do to manage my symptoms like I noticed that a lot of us do, like, the same stuff."* Especially for conditions where there is not bountiful available information, disability community serves as an important information resource.

Finally, some participants valued the opportunity to support others in their community. Living with chronic conditions produces considerable expertise, and P5 was excited to *"translate my experience to other people, so they can do better on their ends."* P7 has also supported people experiencing similar CHCs: *"I've talked to a lot of people about the undiagnosed thing. And they've shared some experiences and resources and asked me questions as well. So it's been nice to kind of share resources. and it's a nice community thing"* Participants also focused on providing others a sense of belonging. P13 recounted a time when a young girl came up to her to show her that they both wore continuous glucose monitors, an experience that validated her choice make her health condition visible as *"it's kind of a solidarity thing, it made people feel safer."* P11 has dedicated her retirement to working with community groups for her CHC, as well as community and state level accessibility and disability advocacy groups. Her experience of this community engagement has been *"life altering, it's been life changing. I've met so many wonderfully … fun, very kind and caring and gracious, smart, smart, smart people that are doing wonderful things."*

Discussion

Prior work in health informatics views disability as a loss of function, rather than an affirming identity, when discussing CHCs[6]—most efforts focus on preventing disability in this population. The disability perspectives our participants found show us a different path forward, one where health informatics could support people with CHCs in developing a disability identity that becomes a positive source of change in people's self-perception, fosters an ability to access the world, and builds a sense of community. This change in perspective provides new opportunities for health informatics research to investigate as-yet-unexplored research areas. It also requires that health informaticists shift perspectives to work with people with CHCs as disability community members, rather than solely as patients. We offer preliminary provocations to explore both these open areas of development.

Specifically, we articulate directions for future health informatics work around identifying who could benefit from a disability identity, integrating accommodations into treatment plans, and connecting people diagnosed with CHCs to disability community and support. We also identify necessary perspective changes around providing access to people with CHCs and engaging them as experts.

AI Interventions to Identify Who Could Benefit from Disability Identity Supports

Health informatics could provide necessary support in identifying who could benefit from a disability identity. CHCs are often characterized by variable presentations, and not all individuals diagnosed with the same condition have the same support needs. For instance, some people with type II diabetes require only blood sugar monitoring while others develop progressive blindness. Health informaticists could use AI and other data science techniques to analyze clinical data, such as provider notes and patient-reported outcomes, to identify who would be best supported by developing a disability identity. Determining the threshold at which an individual's experiences would benefit from disability identity is an open question in this space. Furthermore, our data suggests that disability identity could be useful to people experiencing a very wide range of CHCs—our 15 participants reported 60 unique conditions. Having one intervention that could serve people across a wide range of diagnoses presents unique problems of scale and delivery. Health informaticists are uniquely well-suited to developing interventions in this space, as we are positioned outside any one medical specialty and have expertise in AI and other techniques suited to working with data at-scale.

Making Accommodations Part of The Treatment Plan

Our participants benefited greatly from accommodations and accessible tools throughout their daily lives. However, it is often challenging to identify who could benefit from tools and policies, such as accessible parking placards, extra time on testing, mobility devices, and assistive technologies. Health informaticists could create mappings between common symptom presentations and appropriate accommodations, facilitating greater awareness and use of potentially life-changing resources. Some tools, particularly wheelchairs and other durable medical equipment, are financially inaccessible if not covered by insurance, and standards should be updated to ensure that a wider range of people with CHCs can access tools that bring them considerable benefit. Key areas of accommodation to consider include how CHCs could be supported by mobility devices, digital assistive technologies, and policies.

Connecting People with CHCs to Disability Communities And Information

Health informatics could play a major role in connecting people with CHCs to disability communities and in curating relevant information. Our participants described diverse, undirected paths to the information they needed to develop a disability identity, and consumer health informatics interventions could provide more direct pathways. Educational resources and connections to existing relevant disability communities could be provided to individuals diagnosed with CHCs, enabling disability identity development. Furthermore, health informaticists have extensively researched online health communities,[12–14] which many of our participants reported finding great value in. Future health informatics research into online health communities could investigate the ways those communities discuss disability and the role they play in disability identity formation.

Making Healthcare for CHCs Accessible

Understanding that people with CHCs benefit from accommodations reveals the need to ensure that healthcare is accessible to this population. Recent work[17–19] has focused on ways that health informatics can make healthcare more accessible to people with disabilities broadly, without considering the unique access needs of people with CHCs. Accessibility research within the human-computer interaction community has indicated that chronic health disabilities produce unique access considerations, beyond traditional accessibility approaches.[20] Namely, established accessibility approaches do not consider fluctuating symptoms, the consequences of any given action on health baselines, and the importance of making physical sensations (e.g., pain, dizziness, fatigue) more bearable. CHCs must be included in efforts to use health informatics to make healthcare more accessible, both to ensure that appropriate accommodations are not overlooked and to aid providers in extending the range of people they think of as needing access. While the NIH has focused on people with disabilities as a population that may not receive frequent health care due to pervasive bias,[21] people disabled by CHCs are disproportionately likely to interact with healthcare systems. Therefore, it is crucial to consider this group when working to make healthcare more accessible.

Reframing Expertise Around CHCs

Recent work has stressed to health informatics communities the importance of viewing patients as experts on their lived experiences and treating patients as important partners in healthcare.[22] Reframing CHCs as disabilities further disrupts power dynamics around health management. The disability community has long argued that it is disabled people who are the experts on disability, not support professionals, researchers, family members, or medical providers.[23] Therefore, when working with disabled people with CHCs, health informatics researchers must learn to see this community as expert collaborators, rather than patients in need of help.

Limitations and Conclusions

In this study, we interviewed only people who already identified as disabled; thus, we cannot report on the impact of not having a disability identity on CHC experiences. Next, our sample skewed young, with 10 participants 35 and under. While we are excited to report on perspectives underrepresented in CHC research, where it is assumed that older adults dominate this population, we cannot speak to whether this identity process changes with age.

This research highlights the experiences of people with CHCs who have come to adopt a disability identity. CHCs operate as a form of difference in people's everyday lives, and when our participants came to recognize that difference as disability, they saw numerous benefits. Adopting the definition of disability that has been pioneered by disability activists and scholars, rather than a definition centered on functional limitations, could enable health informaticists to better serve the large and growing number of people with CHCs. We envision a future where health informatics identifies individuals who could benefit from a disability identity and facilitates education and connection, fostering self-acceptance, accessibility, and community for this under-served group.

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