Centering Accessibility for Person-Centered Care Planning for MCC

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1 Overview

This response to the Request for Information on Person-centered Care Planning for Multiple Chronic Conditions (RFI) **emphasizes the importance of centering the experiences of the individual with multiple chronic conditions (MCC), who has valuable expertise in their own condition and who has both medical and non-medical access needs.** Our RFI response primarily focuses on challenges and open research areas associated with improving access for people with MCC both in and outside the hospital setting. Multiple chronic conditions (MCC) are highly prevalent, with four in ten adults in the US having MCC [24]. Many individuals with MCC experience *"uncertain, unpredictable, [and potentially] progressively deteriorating illness"* [2] that affects their health [43] and access to activities of daily living [29, 55].

Disability is a useful perspective to adopt in analyzing MCC, because individuals with MCC may have accessibility challenges in daily life [29] or identify as being disabled in addition to having MCC. Additionally, MCC individuals can have other disabilities unrelated to their chronic condition, such as being an amputee or being blind or low-vision. Thus, a disability perspective has important roles to play in understanding someone's experience with MCC [2, 42].

As such, people with MCC may encounter the same access problems as anyone with a disability, both those created by an ableist society and those relating to physical differences in bodies. Adopting the perspective that the sole goal of care networks is to alleviate symptoms and/or cure a person rests on a harmful and problematic set of assumptions. Adopting a disability perspective can empower a person with MCC by giving them new strategies for independence, control, and access to activities of daily living. This perspective highlights the importance of *accessibility technologies* that are often frowned upon by medical professionals, and the *right to access*.

In examining the lived experience of people with MCC, it is first important to examine how we define disability and impairments. Two of the most prevalent models of disability – the social and the medical model – have limitations that do not fully address the experiences of people with disabilities. The former is focused on access devices that support and accommodate individuals (*i.e.* a prosthesis or screen reader), while the latter is focused on improving access through social laws, architecture, and practices (*i.e.* a curb cut or accessible website) [9, 47, 48, 54]. Other models of disability address interpersonal relationships, as in the case of the *interdependence* model [6]; and the importance of an individual's disability experience and culture as something to be valued rather than fixed, as in the post-modern model [31].

The tight relation between disability, society, life experience, and the body, especially for people with MCC [8], must be considered in supporting people with MCC. Wendell argues *"some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate"* [53]. We call for an approach to MCC that gives individuals the tools, and control, to live with their MCC, treat it, and access assistive devices and services and disability perspectives according to their overall, and momentary, needs.

2 Delivering Care for the Whole Person

The RFI asks: *What terms, strategies, and models of care are used to describe and deliver care planning for the whole person (not just for individual health conditions) that records: (1) roles and tasks among care team members, including the individual, their family, and caregivers; (2) plans for coordinating care within and across organizations and settings; (3) strategies for supporting and empowering patients to manage their own health; (4) plans for engaging in shared decision making?* We address **(1),(3) & (4)** in this section.

To answer these questions, we must **view MCC people as having access needs, and valuable expertise to identify challenges and shape solutions**. This view challenges existing assumptions about roles and tasks for medical providers, including the assumption that medical providers should always be consulted as subject matter experts, while firmly centering MCC people as the relevant, necessary experts that can guide the identification of challenges and solutions to social determinants of health for people with MCC.

(1) Rethinking Roles and Tasks among Clinicians and people with MCC A medical, patient-centric approach often obscures the deeply contentious relationship many people with MCC have with the medical field. While medical treatments, testing, and guidance can be critical to chronically ill people's quality of life, the medical field is often simultaneously hostile to chronically ill people [4, 16, 17]. For example, it frequently takes years to get formal diagnoses for many people with MCC [13], patients are routinely not believed by medical professionals [26, 33, 35, 41], and complex medical care is often prohibitively expensive [15, 18]. These experiences are exacerbated when people with MCC are otherwise marginalized because of medical racism, sexism, anti-queerness, ableism, classism, fatphobia, and other biases that harm people's ability to access care and be treated with dignity [11, 22, 37, 52].

One consequence of this history is that, while medical care and assessment are crucial for many chronically ill people, they can also be a primary site of trauma, ableism, discrimination, and disbelief. Discussion of and engagement with medical systems must be done with caution and recognition of this fraught history. Longstanding critique by feminist [10, 27], and queer [36] activists calls attention to the ways that labeling people as "patients" takes away their agency and imposes a set of assumptions around what patients ought to want, do, and need. The label "patient" also establishes a clear power hierarchy, implying a subordinate relationship to a more knowledgeable and powerful clinician [13]. Viewing people with MCC primarily as patients suggests that they should only be understood in a medical context and situates them as recipients and dependents of medical practitioners' expertise.

Recommendation 1: Account for medical trauma Discussion of and engagement with medical systems must be done with caution and recognize the fraught history that many patients have with the medical system. Person-centered care takes on a new meaning in the context of the medical trauma that many individuals with MCC have experienced.

(3) Strategies for supporting and empowering patients to manage their own health: Rethinking MCC Through an Accessibility Lens A disability framing of MCC can help both patients and care providers to move past this history. Approaching people with MCC with an accessibility lens views them as people with access needs and creates room to center individuals' agency and knowledge, countering epistemic violence [56]. However, this requires working to change the basic assumptions and practices of medical care, which is inherently inaccessible [12, 20, 25, 41], both structurally and due to physician bias towards patients with disabilities [20]. These ableist biases raise significant concerns about people with MCC's equitable access to healthcare. For example, a patient with high fatigue, a common symptom of MCC, may find it physically difficult to get to a doctor's office. However, in-person appointments, including long waits in spaces that may cause sensory overload or further fatigue, may be required to access care. Access can be even more difficult for those who also have additional disabilities (e.g., blind or low-vision, wheelchair user). For example, websites might be inaccessible to screen readers or doctors' offices might lack accommodations for wheelchairs and assisted transfers to the examination table [12, 25]. Future work on identifying social determinants of health with regard to medical care provision should consider that individual patients with MCC may need accessibility accommodations to receive equitable care.

Recommendation 2: Meet Basic Standards for Accessibility Materials created for the care of MCC need to meet accessibility best practices. For websites, this involves meeting WCAG standards [7], which includes tasks like making sure the site can be used without a mouse and captioning videos. Apps also have best accessibility practices such as including labeling buttons and ensuring click targets are large enough. Even materials like slideshows and text documents have best standards to follow, like putting alt text with photos and following proper color contrast. Similarly, buildings should meet basic ADA standards [1] and ideally go beyond them as well. Staff should also receive accessibility-relevant training. These principles should be followed as best as possible in applicable contexts.

(4) Plans for engaging in shared decision making People with MCC may have managed their condition themselves long before they encounter supportive medical care. Knowledge shared outside of medical contexts makes clear that, individually and in community, chronically ill people hold vast expertise derived from both their embodied experiences and navigating the world with a chronic illness. Diagnosis-specific and general chronic illness social media communities are abundant (e.g., [5, 14, 46]), and they provide a place to share in-depth knowledge about living with a chronic illness. While much discussion centers on how to live with and acquire care for illness (e.g., symptom and flare identification and management, possible diagnoses, how to navigate the medical system), people also share information and advice to meet non-medical access needs (e.g., developing horizontal workstations, suggesting how to disclose access needs on a date, preparing meals that don't trigger dietary restrictions) [5]. Indeed, there are myriad individual and group examples that demonstrate the sophistication of this expertise, including a recent reconsideration of graded exercise therapy as a standard of care for myalgic encephalitis/chronic fatigue syndrome (ME/CFS) after ME/CFS advocacy groups demonstrated that it is a harmful practice [3, 49].

Recommendation 3: Value individual and community knowledge about MCC This individual and community-based knowledge should be valued and incorporated into care planning and research. For example, if a clinical trial finds radically different results than people with MCC share in community settings, do not dismiss the community knowledge. Instead, consider whether the study design may have, in controlling for variation, accidentally eliminated the complex experiences so commonly associated with MCC and thus fail to adequately describe, or apply to, the experience of MCC.

3 What are suggested strategies for effective implementation of person-centered care planning at multiple levels?

The RFI asks about strategies for effective implementation of person-centered care, including *(1) What kinds of information, tools, resources, or support are most needed to address barriers and challenges to implementation? (2) Which payment models might enable and sustain person-centered care planning?* We address both below.

We argue that to support and empower patients to manage their own health, we must take an approach that attends to both embodied and sociopolitical aspects of chronic illness. In 2003, the World Health Organization (WHO) stated that adherence to long-term therapy averages about 50%, and that "*increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments*" [38]. Crucially, this report highlights that, although interventions tend to focus on the individual receiving treatment, the medical professional and the health system also have a major effect on adherence [38, 50, 57]. With respect to MCC, we argue that when a person with MCC has difficulty with adherence to a prescribed medical plan, this may represent an accessibility issue arising from multiple types of barriers. People with MCC inherently face physiologically-based barriers to health access, such as symptoms of the chronic condition that they are obtaining care for such as nausea or fatigue) [55], as well as sociopolitical barriers (e.g., lack of insurance or access to clinics). We highlight these barriers in terms of the factors raised in the RFI and quoted above through a case study of physical therapy (PT) for MCC. [55]

Through a twelve-person interview study, we examined how people's access to PT for their MCC is hampered by social (e.g., physically visiting a PT clinic) and physiological (e.g., chronic pain) barriers, and how technology could improve PT access. Our study examined the interaction of disability with their PT. The study identified three design recommendations that highlight the kinds of *information, tools, resources and support* that can improve support for people with MCC, as well as the *impact of payment models* on success with PT. These data highlight the nuanced interplay between social and physiological access barriers and how technology solutions to PT access barriers can be reconsidered to take into account the lived experience of people with MCC [55].

(1a) Accessibility as a resource for support Physiological barriers can create pervasive and complex issues in completing assigned medical tasks, such as completing a physical therapy (PT) exercise. These barriers could include feeling too symptomatic to perform exercises, exercises triggering symptoms that persist throughout the day, fluctuating symptoms, and complex interactions with multi-faceted and/or multiple conditions. For example, someone who is doing PT for a physical chronic condition can find it challenging to do PT due to another chronic condition (depression): *"if you're really depressed, getting into the whole, 'what's the point of [doing PT], why bother"'*[55]. Such barriers are traditionally considered "adherence issues", both externalized by physical therapists who encourage adherence by encouraging the individual doing PT to remember their larger goals for doing PT [19] and internalized by the individuals themselves, who can have feelings of guilt when they do not adhere to the exercise routines.

However, if we adopt an accessibility lens for this example of doing PT for MCC, we can view the lack of adherence as not an physiological issue, but one that arises from a mismatch between the prescribed PT exercises and how the individual is feeling on that day, or even what their general goals are. For example, a person may prefer to shower in a chair, even if their body *could* learn to acclimate to "normal" showering with practice, so as to conserve their energy for other activities: A goal or exercise that alleviates one impairment or symptom may exacerbate another. One participant in our study discussed how they were *"just piled on with more and more exercises, it is getting harder to stay on track...it's a challenge being motivated, it's a challenge dealing with the fatigue [one of their MCC symptoms], I've been feeling overwhelmed by it all. I just feel like it's an endless list of things to do"*.

Recommendation 4: Treat accessibility as a first-class component of patient care The complex, contradictory health needs could be alleviated with attentive care and guidance from a clinician that considers not only outcomes but also access. When a person with MCC prefers an accessibility technology over a therapeutic approach, honor this choice. When selecting a therapeutic approach, ensure that barriers to care are not compounded by social barriers like ableism or medical bias [20, 23], and that the approach that is selected is itself accessible [44]. Doing this properly requires designing therapeutic approaches iteratively and collaboratively, as this has previously been shown to be critical to support individuals with chronic pain and other disabilities [34, 39, 51].

(1b) Community as a resource for support Being accountable to a community, whether it be with other people doing PT or with a physical therapist, is helpful for staying motivated to complete their exercises. In one study of a community-building PT application, participants found that the community was helpful for improving motivation and for comparing their PT exercises to other people who had similar conditions so they could experiment with new PT exercises [30]. Information sharing can also be a useful work-around for when people are unable to see a physical therapist to get updated exercises.

Recommendation 5: Prioritize Community Prioritize community as a form of accessibility through interdependence and support [6]. Communities can support important values such as independence, community living and engagement, and so on alongside symptom management. This requires accessible public spaces, something that is often overlooked [21]. Additionally, virtual communities can facilitate encouragement and engagement between users, especially those who have rare or multiple conditions [30].

Recommendation 6: Look beyond "care" People with MCC live full lives. It is important to support people with MCCs in all areas of life, not just medical. These priorities are demonstrated by chronic illness discussion forums and online communities. While much discussion centers on how to live with and acquire care for illness (e.g., symptom and fare identification and management, possible diagnoses, how to navigate the medical system), people also share information and advice to meet non-medical access needs (e.g., developing horizontal workstations, suggesting how to disclose access needs on a date, preparing meals that don't trigger dietary restrictions) [5].

(2) Challenges with Payment Models for Effective implementation of person-centered care planning Insurance is a major barrier to access to healthcare for many individuals with MCC. Generally, one needs to be employed to receive healthcare benefits in the US, which already excludes a considerable number of MCC people from receiving PT. Even if someone with a MCC wants more flexible work hours or fewer working hours to better manage their symptoms, that is often not feasible because benefits are directly tied to the job. While health insurance is available in the US for unemployed individuals, navigating that infrastructure with a MCC can be challenging, and the coverage can be insufficient [40, 45]

Recommendation 7: Remove financial barriers where possible. These barriers prevent people from accessing care, evaluation and documentation. There is a need for accessible technology to help navigate finding and obtaining insurance that provides sufficient coverage for people's needs. We should also reduce additional requirements such as meeting surveillance goals for compliance in order to have access to care. AI and data bias is a serious concern with such systems [32]. Finally, it is important to protect private patient data from being misused by the healthcare system, including insurance companies, to deny access to care. Insurance politics indubitably need to change before such access challenges are fully removed.

4 Best practices for supporting people with MCC

The RFI asks *Which personnel or roles within systems or practice settings would know most about person-centered care planning efforts, challenges, and successes (IT directors, c-suite, care coordinators, etc.)?* We wish to highlight the notable lack of people with MCC in that list. People with MCC can and should be included in person-centered care planning efforts.

Recommendation 8: Include MCC People in the Planning, not just as Participants To fully provide person-centered care, we must ensure that people with MCC are engaged in decisions about healthcare system design, not just as patients. This can be true at the level of national policy decisions as well as how individual clinics run themselves. We must trust the patient and their lived experience and choices and ask **why** friction occurs when it does, rather than blaming them. People with MCC should be given the opportunity to take advisory roles in clinic and healthcare system-level planning discussions.

When data is gathered from people with MCC through studies, focus groups, or other patient-centered methods, we must consider their access needs while remaining flexible and responsive to unexpected access barriers to successfully engage them [28]. This requires considering accessibility at all stages of the research process, from recruitment through payment and writing. Such research should considering how various needs intersecting and conflicting and power dynamics affect the accessibility of the research process.

Recommendation 9: Enable people with MCC to enter traditional clinical roles Further, we should reconsider the extent to which STEM and medical educational systems exclude people with MCC and other disabilities, and work to include clinicians with personal MCC experience in leadership groups wherever possible. It is often overlooked that clinicians, IT directors, c-suite and care coordinators may themselves have MCC or disabilities with access needs [28]. We should ensure that we successfully include people with MCC and/or disabilities at all levels of care for people with MCC.

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