Access to mental health services for people with complex chronic conditions: A qualitative study

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Abstract

Background

Mental health conditions are common among people living with complex chronic conditions (PLWCCC), yet recognition and treatment are low in medical settings.

Methods

To design appropriate mental health services for this population, a qualitative study was conducted to identify the factors affecting access to mental health care for PLWCCC. The study involved 13 PLWCCC enrolled in a heart failure management program, as well as 9 clinicians and researchers with expertise in mental health care and/or complex chronic conditions, recruited from a large academic hospital in Ontario, Canada between March 2021 and March 2022. Data collected from one-on-one semi-structured phone interviews were analyzed using inductive reflexive thematic analysis, and the resultant themes were mapped to the domains of Levesque's patient-centred access to care framework.

Results

A total of 14 themes were identified, revealing barriers to mental health care at the system and patient levels. System-level barriers included health care system and service approachability (difficulties detecting mental health concerns; unpreparedness for referral conversations), availability and accommodation (available mental health services were limited; services were poorly timed; pathways to care were inconsistent), and affordability (limited human resources; lack of options for choice or finding fit; insufficiency of generic mental health services). Patient-level barriers included limitations in the ability to perceive mental health needs (low mental health literacy; denial, stoicism, and self-reliant coping methods), as well as seek (stigma), reach (inconvenience of in-person delivery), and pay (lack of full insurance coverage and high cost of psychological services) for mental health care hindered access.

Conclusion

Given the multi-level factors identified that hinder access to mental health care services for this population, service pathways should seek to enhance the approachability, availability, and appropriateness of mental health services and promote the ability of PLWCCC to perceive their mental health needs.

Background

People living with complex chronic conditions (PLWCCC) are at heightened risk of poor mental health [1, 2] with the risk of conditions such as depression being three times higher in those with complex chronic conditions (CCC) compared to those without chronic conditions [3]. CCC encompasses the growing population living with one or more physical or mental health chronic conditions, wherein the complexity of care provision arises due to multimorbidity (two or more chronic conditions), high health care utilization, and/or adverse psychosocial circumstances [4, 5]. Mental health conditions, while chronic conditions in themselves, are considered mechanistically related to physical health conditions in a complex bidirectional pathway, wherein CCC may predispose the development of mental health conditions and vice versa [6]. Such a complex etiology poses challenges to identifying and treating mental health conditions among this population, risking undertreatment that can have cascading detriments to individual health (e.g., quality of life [1]) and the health system (e.g., costs [7]).

Amid the complex etiologies of, and interactions between, CCC, growing research recommends care that is person-centred rather than disease-specific [8]. Integral to the former approach is centring health care services around the needs and values of individuals receiving care instead of that of the healthcare system. Previous research exploring the mental health impacts of chronic conditions has done so with a focus on specific conditions, with minimal attention to the mental health experiences and needs of the growing number of PLWCCC, which may include, but does not necessitate multimorbidity [5]. Studies within the multimorbidity literature have explored how PLWCCC conceive mental health [9], the dialogues that promote their mental health [10], as well as the difficulties health care providers face to address these needs appropriately [11]. Yet, multi-level barriers prevent the identification and treatment of mental health conditions across CCC as mental health problems are often normalized (accepted as an expected response to chronic conditions), somatized (attributed to physical health), and/or deprioritized (delegated during care planning) [12, 13]. Designing and integrating mental health services into standard care for CCC can benefit from understanding the experiences accessing mental health care and remains a key research priority [14]. However, a theoretically-informed analysis of the factors affecting access to mental health care for this population has not yet been conducted.

To address this gap, we sought to design, implement, and evaluate a mental health service for PLWCCC. As part of a multi-phase investigation, the aim of the present study was to identify the mental health service needs of PLWCCC. The research question was: What do individuals living with CCC, clinicians, and researchers perceive as factors impacting access to mental health care for PLWCCC?

Methods

The COnsolidated criteria for REporting Qualitative research (COREQ) were used to guide the reporting of this study [see Additional File 1 for full checklist] [15].

Study design
A pragmatic qualitative study was conducted using reflexive thematic analysis, a methodology to acquire meaning within a dataset proposed by Braun and Clarke [16], to identify patterns in the data. Per the theoretical considerations of reflexive thematic analysis, the analysis was situated within a constructionist epistemology, with an experiential orientation to data to prioritize the ways in which participants experienced and ascribed meaning to various factors impacting access to mental health services for PLWCCC. An inductive approach was initially adopted followed by deductive analysis to allow for both data-based and theory-based meanings to be emphasized at different stages of the analysis. Both semantic and latent coding of data were also used.

**Sampling & recruitment**

PLWCCC were recruited from a heart failure management program (Medly Program) that includes smartphone-based telemonitoring, which is used as standard of care at the Toronto General Hospital, a large urban hospital in Ontario, Canada [17]. As enrollment into the Medly Program is based on the presence of complex heart failure and/or high healthcare utilization, all patients in the program have been identified as having CCC by their cardiologist. Individuals were recruited purposively across a range of demographic factors to gain representation of PLWCCC with respect to age, sex, ethnicity, place of birth, highest education received, place of residence, living arrangement, income (CAD $), and comfort with smartphone. All clinicians of the Medly Program were invited to participate in the study, with other potential clinicians and researchers identified through participants via snowball sampling. All PLWCCC were approached over the phone and clinician and researcher participants were approached via email. All 13 PLWCCC invited to participate enrolled in the study with no individuals refusing to participate or withdrawing from the study. Of the 10 clinician and researchers approached for the study, 9 agreed to participate, with one clinician declining to participate due to their high clinical workload at the time of the study.

**Data collection**

One-on-one semi-structured interviews lasting between 40 and 60 min were conducted in English by author A. Shah, a female-identifying PhD Candidate completing studies in Health Informatics Research at the time of the study. A. Shah has received formal training in qualitative research and has conducted qualitative research studies in the past. This author, separate from the clinical care team, had no previous relationships with participants prior to the study commencement, and participants were made aware of the researcher’s role (e.g., study coordinator and student). Due to the COVID-19 pandemic, all interviews were conducted over the phone, with the researcher calling from a private space at home and participants calling from a private space at home or at their workplace. No participants reported the presence of additional individuals during the interview.

As a public health professional with experience in the mental health sector, A. Shah was interested in the study topic due to employment experiences witnessing gaps in community mental health care sector and is interested in the use of digital mental health technologies to address some of these gaps. As a non-clinician, this researcher's interests in relation to the research topic may have introduced biases towards the experience of PLWCCC relative to the barriers identified by clinicians and may have led the researcher to look more favourably towards digital mental health technologies. To understand the ways in which the researcher's personal characteristics may have shaped the findings, A. Shah conducted memoing throughout the research process and engaged in ongoing discussions with other research team members with different experiences and backgrounds.

Separate interview guides with open-ended questions for each of the participant types (PLWCCC, clinician, and researcher) were developed and pilot tested. The interview guide for PLWCCC inquired about the mental health impacts of CCC experienced by participants, their current approaches to managing their mental health and associated challenges; experiences accessing mental health services (where applicable); and their needs and preferences related to mental health services. Clinician and researcher interviews inquired about participants’ perception of the mental health needs of the CCC population (based on clinical or research experience); experiences referring patients to mental health services (where applicable); current approaches and mental health services used to support the mental health of the CCC population; and the perceived gaps of existing mental health services.

While the concept of saturation, a point of informational redundancy in which no new codes or themes are identified from the data, is a commonly discussed concept in relation to qualitative research, Braun and Clarke [18] have argued that this concept is incongruous with the assumptions of reflexive thematic analysis. In alignment with Braun and Clarke’s proposition of sampling as a pragmatic practice [18], the inherently subjective considerations regarding the number of interviews and the amount of data collected were determined in advance with a provisional range of 15–20 participants and in situ to end data collection at 23 participants. This number of participants was determined based on the depth of data collected from each participant, the various demographic and experiential factors represented by the sample interviewed, and pragmatic constraints of the project (costs of transcription) limited further data collection [18].

The study was approved by the UHN Research Ethics Board (Protocol #16-5789 and #20-6329) and the University of Toronto Research Ethics Board (Protocol #40274 and #41477). Informed consent was obtained from all participants. Interviews were audio recorded, stripped of identifying information, and transcribed verbatim. No repeat interviews were conducted. Field notes were also made by author A. Shah both during and after each interview. Transcripts were not returned to participants for comments or corrections.

**Data analysis**

Two coders, A. Shah and A. Shahil, were involved in coding the data, to allow for a more nuanced analysis of the data. First, A. Shah and A. Shahil read the transcripts to familiarize themselves with the data. Second, the interviews were independently coded by the same two authors using NVivo 12 (QSR International) to organize the data. At this stage, initial themes derived from the data were created by each coder. Third, initial themes were discussed by both coders to inform the development of a final set of overarching themes and later discussed with the research team. Member checking processes to provide feedback on the findings were not conducted with participants.

Lastly, inductively developed themes were mapped to the domains of the patient-centred access to care framework by Levesque [19] to identify opportunities to improve access to mental health care for this population from both the patient perspective and health system perspective (Table 1). Per Levesque [19], access is an opportunity for a perceived need for care to be met through reaching and obtaining health care services. The framework outlines that access...
results from the interface of both supply (health care system, services, and providers) and demand-side factors (persons, households, social and physical environments). Such factors on the supply side include the approachability, acceptability, availability & accommodation, affordability, and appropriateness of health care services, and on the demand side, the ability of patients and their support network to perceive a need for care as well as to seek, reach, pay, and engage with health care services [19]. Dimensions on each side of this framework represent potential facilitators or barriers to access to health care during an episode of care [19]. Table 1 displays the paired patient and health system constructs outlined by Levesque [19] at each stage of accessing care (perceiving health needs and desire of care; seeking health care; reaching health care; using health care; health care consequences).

### Table 1: Domains of Access to Care Framework by Levesque.

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Perceiving Health Needs &amp; Desire for Care</td>
<td>1a. Approachability</td>
<td>A person in need of health services can identify that service(s) exist, can be reached, and have an impact on their health.</td>
<td>1b. Ability to perceive</td>
<td>Determined by health literacy, knowledge about health, and beliefs related to health and sickness.</td>
</tr>
<tr>
<td>2. Seeking Health Care</td>
<td>2a. Acceptability</td>
<td>Cultural and social factors that influence acceptance of aspects of the service (e.g., sex or social group of providers) as well as the judged appropriateness of those seeking care (e.g., societal or cultural beliefs).</td>
<td>2b. Ability to seek</td>
<td>An individual’s personal autonomy and capacity to choose whether to seek health care, knowledge about health care options, and rights that affect the expression of their intention to obtain health care.</td>
</tr>
<tr>
<td>3. Reaching Health Care</td>
<td>3a. Availability &amp; accommodation</td>
<td>Health services, including both the physical space and the associated health care roles, can be reached physically and in a timely manner. Availability involves the physical presence of sufficient health resources that can produce services and is dependent on the characteristics of the facilities, the urban context, individuals, providers, and the modes of delivery of health care.</td>
<td>3b. Ability to reach</td>
<td>Individual mobility, transportation availability, occupational flexibility, and knowledge of health care services that allow one to physically access health care service.</td>
</tr>
<tr>
<td>4. Using Health Care</td>
<td>4a. Affordability</td>
<td>The economic capacity of individuals to expend resources and time to use appropriate health care services. This capacity depends on the prices of services and the opportunity costs (e.g., loss of income associated with accessing care), and can vary based on the type of services of interest and the capacity to generate resources to pay for them.</td>
<td>4b. Ability to pay</td>
<td>A capacity to generate economic resources through savings, income, or loans by which health care services can be paid for without catastrophic expenditures of resources required for basic necessities.</td>
</tr>
<tr>
<td>5. Health Care Consequences</td>
<td>5a. Appropriateness</td>
<td>Service fit with an individual needs, timeliness, amount of care placed in identifying correct treatments, and quality of services received both technologically and interpersonally. Appropriateness considers both service adequacy (what services are provided) as well as quality (the way services are provided).</td>
<td>5b. Ability to engage</td>
<td>Individuals’ participation and involvement in treatment decision-making, which is determined by their capacity, motivation, and commitment to participate in care to its completion. Capacity to communicate, levels of health literacy, self-efficacy, self-management, as well as provision of care that is commensurate with the skills of the individual affect one’s ability to engage.</td>
</tr>
</tbody>
</table>

### Insert Table 1. Domains of Access to Care Framework by Levesque.

#### Trustworthiness

To strengthen the quality and trustworthiness of reflexive thematic analysis study findings, various measures were employed to promote reflective and thoughtful engagements with the data and analytic process [20]. Researchers engaged in repeated engagements with raw data and reflexive conversations among team members [21]. To promote the confirmability of the findings, a comprehensive audit trail was created from raw data to final themes by using NVivo for coding and memoing [21]. Both coders kept a reflexive journal throughout the research process to record their reflections; emerging insights on the data; as well as to interrogate their personal values (personal reflexivity), their disciplinary location (disciplinary reflexivity), and methodological choices (functional reflexivity) [22, 23].

### Results

In total, 22 participants were interviewed: 13 PLWCCC and 9 clinicians and researchers with experience in mental health care and/or CCC. Participants living with CCC were largely White (62%), urban-residing (46%), educated (61% with college, university, or postgraduate education), cohabitating with a family member (69%) (Table 2), and self-reported an average of 2.6 chronic conditions at the time of interview. Of the clinician participants, 3 were CCC clinicians (e.g., nurse, cardiologist) and 4 were mental health professionals (e.g., psychologist, psychiatrist). The 2 researchers had expertise in CCC. A total of 14 themes (Table 3) were identified that were mapped to the access to care domains outlined by Levesque [19].

### Table 2. Characteristics of patient interview participants (N=13).
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>21-30</td>
<td>2 (15)</td>
</tr>
<tr>
<td>31-40</td>
<td>1 (8)</td>
</tr>
<tr>
<td>41-50</td>
<td>0 (0)</td>
</tr>
<tr>
<td>51-60</td>
<td>2 (15)</td>
</tr>
<tr>
<td>61-70</td>
<td>4 (31)</td>
</tr>
<tr>
<td>71-80</td>
<td>2 (15)</td>
</tr>
<tr>
<td>81-90</td>
<td>2 (15)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (54)</td>
</tr>
<tr>
<td>Female</td>
<td>6 (46)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White (Caucasian)</td>
<td>8 (62)</td>
</tr>
<tr>
<td>Black</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Filipino</td>
<td>1 (8)</td>
</tr>
<tr>
<td>South Asian</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Arab/West Asian</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>8 (62)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (38)</td>
</tr>
<tr>
<td><strong>Highest education achieved</strong></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Trade or technical training</td>
<td>2 (15)</td>
</tr>
<tr>
<td>College or university</td>
<td>5 (38)</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>3 (23)</td>
</tr>
<tr>
<td><strong>Place of residence</strong></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>6 (46)</td>
</tr>
<tr>
<td>Suburban</td>
<td>4 (31)</td>
</tr>
<tr>
<td>Rural</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Not declared</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Living arrangement</strong></td>
<td></td>
</tr>
<tr>
<td>Living with family/partner</td>
<td>9 (69)</td>
</tr>
<tr>
<td>Living alone</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Living with friend(s) and/or roommate(s)</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Income in CAN $</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 15,000</td>
<td>1 (8)</td>
</tr>
<tr>
<td>$15,000-$49,999</td>
<td>3 (23)</td>
</tr>
<tr>
<td>$50,000-$74,999</td>
<td>7 (54)</td>
</tr>
<tr>
<td>&gt;75,000</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Not declared</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Comfort with smartphone</strong></td>
<td></td>
</tr>
<tr>
<td>Very comfortable</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>2 (15)</td>
</tr>
</tbody>
</table>
Table 3. Summary of Themes.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Characteristic of Health System</th>
<th>Theme</th>
<th>Characteristic of Patient</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceiving Health Needs &amp; Desire for Care</td>
<td>Approachability</td>
<td>Diculties detecting mental health concerns</td>
<td>Ability to perceive</td>
<td>Mental health literacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unpreparedness for referral conversations</td>
<td></td>
<td>Denial, stoicism, and self-reliant coping methods</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Attribution of causality</td>
</tr>
<tr>
<td>Seeking Health Care</td>
<td>Acceptability</td>
<td>*</td>
<td>Ability to seek</td>
<td>Stigma surrounding mental health care</td>
</tr>
<tr>
<td>Reaching Health Care</td>
<td>Availability &amp; accommodation</td>
<td>Limited types of mental health services available</td>
<td>Ability to reach</td>
<td>Inconvenience of in-person delivery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inconsistent pathways to mental health services</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Poorly timed mental health services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using Health Care</td>
<td>Affordability</td>
<td>Limited human resources due to underinsurance of mental health care</td>
<td>Ability to pay</td>
<td>Lack of full insurance coverage and high cost of psychological services</td>
</tr>
<tr>
<td>Health Care Consequences</td>
<td>Appropriateness</td>
<td>Underresourced system does not allow for choice or finding fit</td>
<td>Ability to engage</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Insufficiency of generic mental health services</td>
<td></td>
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</tr>
</tbody>
</table>

Table 2. Characteristics of patient interview participants (N = 13).

Table 3. Summary of Themes.

**Approachability**

**Difficulties detecting mental health concerns**

Recognizing the high prevalence of mental health concerns among the CCC population, clinicians expressed hesitancy in seeking to detect the mental health concerns of this population in fear of “opening the floodgates” and being liable for mental health conditions that they were not appropriately resourced to address. In addition to liability, clinicians worried that a higher level of sensitivity to the mental health needs of the CCC population could risk overtreating mental health deteriorations that may resolve on their own. As overtreatment could lead to unnecessary use of scarce mental health resources, clinicians grappled with finding the optimal level of responsiveness to the mental health trajectories of their patients.

“The tension working in this space is that you do not want to over-pathologize normal human experience, and we also need to recognize that mental health issues and disorders are under-recognized in physical medical populations. And so how do we hold that tension of not over-pathologizing and also knowing that we under-recognize...And then where on that spectrum from mental wellness to disorder [is the patient]?”  [Clinician 1]

Clinicians reported significant challenges in detecting mental health concerns among PLWCCC. Difficulties in detecting mental health concerns were attributed to time constraints during appointments, the absence of a standardized approach to detect mental health issues, and a medicalized care approach that often neglected the social and behavioural aspects of health. These challenges were further compounded by the bidirectional relationship between mental and physical health that gave rise to high patient complexity.

“...when you’re short of breath it’s very anxiety provoking...or you’re feeling anxious and you have a higher respiratory rate...Sometimes you don’t know if it’s heart failure that’s getting worse and you’ve got a real pending medical crisis on your hands or whether it’s your anxiety and sense of panic getting worse? And sometimes it’s both. So it can be hard to untangle just from a symptom perspective.”  [Clinician 2]

With no routine mental health screening conducted, clinicians relied upon verbal (e.g., individuals self-identifying and disclosing their mental health status) and non-verbal cues (e.g., facial expressions, body language) present during appointments to detect potential mental health concerns. As non-verbal cues were found to be easily lost during virtual care appointments, nurses reported using telemonitoring data to infer potential mental health concerns through various digital indicators (e.g., change in frequency entering a reading, change in physical health readings, etc.).
Unpreparedness for referral conversations

Nurses explained that the longitudinal relationships facilitated through telemonitoring not only allowed them to indirectly identify potential mental health concerns, but also offered opportunities to normalize mental health impacts as a common consequence of living with CCC through more frequent touchpoints with their patients. Despite this, nurses expressed discomfort in referring PLWCCC to mental health services, citing that their patients at times perceived a referral as the nurse “handing off” the burden of managing their mental health needs. One nurse reflected upon their challenges when referring PLWCCC to a digital mental health support.

“...it's actually really challenging to broach it in a way that's very formal...even though I know that a lot of patients would benefit from it. I find an intervention and when I bring it up in that way...I feel like it shuts down our relationship. Because they sort of feel like I’m trying to ship them out to something else...Which I find kind of counterproductive in a way. Because then they feel like “oh, I shouldn't be telling you these things because then you want to refer me to this other thing”.” [Clinician 4]

Psychiatrists posited that the minimal mental health training provided in clinical education contributed to a lack of preparedness of CCC clinicians in approaching mental health referral conversations effectively. As such, referral conversations often did not provide sufficient information about the reason for the referral nor did they engage the needs and preferences of the individual receiving care. Moreover, clinicians’ well-intentioned efforts to normalize the use of mental health services through framing them as universal supports (i.e., appropriate for everyone) would at times come at the cost of providing accurate information about the purpose of the mental health service.

“...sometimes people who really want to help and refer to other services say “oh you know this is a referral for mindfulness”. When it’s actually like a full psychiatric assessment...We [say we] refer everyone to this to try and normalize it when actually we don't refer everyone to this. We're just referring you, and I think people also know that.” [Clinician 5]

When referrals to psychiatry were made without engaging with their needs, values, and preferences, PLWCCC felt frustrated and unclear about why they were referred, as they did not perceive themselves as experiencing mental health challenges. For example, one individual who did not attribute their symptoms to their mental health experienced their referral to psychiatric services as unnecessary and dismissive.

“I just didn’t feel that I needed to go there. And so often in my journey—10 years ago, seeing doctors, they would look at me. I’m 130 pounds, I’m five foot three and I was really fit. So they would look at me going “I don’t think you have a problem, and when it gets worse, you know, give me a call. I think it’s just anxiety”. So I’ve been living that my whole life, saying it’s panic attacks, it’s anxiety, it’s this, it’s that. No it’s not, because I’m sitting at my kid’s baptism and I’m having an episode. Like I’m doing nothing. It’s not anxiety...So I was very frustrated going to those [psychiatrist] appointments and sitting there and saying “OK, your family life, explain that. Explain this. Explain that”. It was just revisiting a life that I didn’t really want to explain—like I’m fine. I’m fine.” [PLWCCC 1]

Ability to perceive

Mental health literacy

From the perspective of PLWCCC, the ability to perceive one's own mental health impacts was a central factor impacting access to mental health care. However, PLWCCC reported difficulties recognizing when their mental health deteriorated, as well as identifying the potentially effective mental health services available to them.

“I don’t know what my mental health needs are, there's the problem you know?” [PLWCCC 2]

Some PLWCCC noted that their understanding and perceptions of mental health and mental health care were shaped by having childhood experiences with a loved one with severe mental illness. At times, this contributed to a lack of readiness to engage in psychiatric care so as to not “dig up” painful experiences.

So I didn’t give it a fair chance...and [the psychiatrist] knew my childhood and when he said “Do you want to discuss this further?” I was like “Well no, I don’t see what that’s going to do for me now”. I’m very, very strong in not allowing that to weaken me. And maybe I’m fooling myself, I don’t know. Maybe I need a psychiatrist to tell me, you know, “I saw through what you were – “ ...we never discussed it...Not to the depth that maybe we needed to.” [PLWCCC 1]

Additionally, a lack of knowledge about mental health and different mental health professionals (e.g., difference between a psychologist and psychiatrist), as well as attitudes viewing mental health issues as a personal weakness posed as barriers for clinicians to be able to discuss the mental health impacts of their condition with their patients and offer referrals.

“My problem is that it’s not frequently labelled I think in [patients'] own mind as anxiety you know? It’s like they’re kind of like “well I just want to know about my disease”. Or “I just want to know about what's going to happen. Rather than like “I have anxiety about it”...Of course there’s also a lot of stigma which I think a lot of the population being older perhaps has to do with some of that...it’s so much easier for me to be like “oh I don’t have tons of information about getting more protein in your diet. So let me refer you to the dietician”. People are super open to that. That’s easy and then if I feel like saying “oh, let me refer you to this study about mental health”...Certainly the reception is different.” [Clinician 4]

Denial, stoicism, and self-reliant coping methods
In addition to limited mental health literacy, the coping strategies employed by individuals also affected recognition of mental health impacts of living with CCC. PLWCCC reported using coping methods such as denial and stoicism to cope with the mental health impacts of their CCC. Stoicism, as framed by PLWCCC, involved not recognizing or engaging with their feelings in order to live with their illness. This approach to coping, however, presented barriers to accessing mental health care as it denied recognition of the mental health impacts of the condition, and consequently, any need for mental health support.

“To be honest, I feel like I don’t want to reach out, because I know I’m just going to get in my emotions and just start bawling my eyes out and I’ve been stoic by myself and so, I’m like “why do I need to reach out?”. But I think stoicism does not necessarily mean there isn’t a problem, it just means you’re kind of shoving it down and suppressing it. So I think that it would be beneficial for me to reach out to [a mental health service]...it would take a little bit of a nudge.” [PLWCCC 3]

**Attribution of causality**

Individual beliefs about the cause of their mental health concerns further impacted the ability of PLWCCC to perceive their mental health needs and be ready to access mental health services. PLWCCC shared experiences of initially perceiving their mental health symptoms as physical health symptoms related to their chronic condition, which delayed diagnosis and connections to appropriate support.

“Panic attacks are very scary, they’re not heart related. It took me a very, very long time to understand it’s not heart related. I always used to think that it’s my heart. Even when I hyperventilated” [PLWCCC 4]

**Ability to seek**

**Stigma surrounding mental health care**

In cases where mental health concerns were identified, clinicians expressed finding it challenging to connect their patients with mental health services due to stigma. Use of medicalized language when discussing mental health services were found to exacerbate stigma and reduce the receptivity of PLWCCC to these types of referrals. Nurses expressed a need to normalize mental health impacts, potentially by framing them through common experiences such as the COVID-19 pandemic to reduce the stigma surrounding accessing mental health care services.

“...even though [we use] phrases like peer support counselling...I feel like they’re just like “oh sorry I didn’t mean to bother you about this” and it’s like “no, I don’t mean it that way”. It just might be nice and you know, even framing it within COVID...I think it’s just I don’t know, personal, ingrained stigmatization or something. Where they feel like “oh no, I don’t need that.”.” [Clinician 4]

**Availability and accommodation**

**Limited types of mental health services available**

Clinicians highlighted the overemphasis on psychiatric care in the Canadian health care system, which left publicly funded mental health services provided by other health care professionals (e.g., social workers, clinical psychologists) in short supply. Likewise, PLWCCC highlighted the few opportunities to access peer support through their CCC care. Support from peers was thought to be an invaluable source of hope and empathy, distinct from the care possible through medical professionals. As a result, this emphasis on psychiatric services was considered inappropriate for the bulk of the mental health concerns encountered by clinicians in their day-to-day practice, often requiring them to refer PLWCCC to a higher level of care (e.g., psychiatry) than required due to the limited availability or nonexistence of alternative publicly funded mental health services.

“...I don’t have tons of resources to refer to. Unless it’s quite severe. In which case, oftentimes people are referred to transplant psychiatry or something like that. But in kind of my day-to-day interactions—which are almost always feeling confused with anxiety and stress—then it’s mostly just like trying to untangle what maybe is driving some of that. And seeing how we can help, but it’s mostly like listening in an empathetic, or medically driven way.” [Clinician 4]

**Inconsistent pathways to mental health services**

PLWCCC who reported having been referred to a mental health service in the past reported highly variable care pathways and experiences. Some PLWCCC enjoyed rapid connections to psychiatric services while others experienced difficulties booking an appointment with a psychiatrist and long waitlists. Additionally, access to mental health services in the community at times depended on the place of residence of PLWCCC and the quality of relationship they had with their primary care physician. As a resident of a rural community, one individual living with CCC expressed their challenges accessing mental health services despite their need and desire to receive such care.

“And I think that somebody could put me on a better thought, you know, organization type of thing, why do I feel like this. Am I alright? But that’s what I don’t have and there’s not that much help available, especially in [rural community].” [PLWCCC 5]

**Poorly timed mental health services**

Inconsistencies not only arose in how PLWCCC were connected with mental health services, but also in the timeliness of care delivered. Through experiencing waitlist-related delays in receiving mental health services, PLWCCC desired mental health services that were better attuned to the trajectory of their physical health condition. While clinicians cautioned that assessments during these periods could reflect momentary changes in mental health status that may not require intervention, PLWCCC emphasized the importance of mental health support during acute deteriorations in their health.

“Basically I belong to a community clinic so internally they have services—they had a counsellor or social worker as they call it on staff...the problem with that though is that there’s a time thing so you don’t know if the person will be able to talk to you within the time period that you need them to. Because the doctor
has to do a referral to them and then they already have people they’re dealing with. So you may have to wait a week or two weeks before you get an appointment and then by that time I’m fine again… I’m no longer sick… they had to be calling me [when my health declined] because then I would have told them everything that’s going on with me and then they would have realized that it’s health-related." [PLWCCC 6]

**Ability to reach**

**Inconvenience of in-person delivery**

As individuals enrolled in the Medly program resided in diverse regions, PLWCCC emphasized the importance of having options to access mental health services remotely. PLWCCC residing in both urban and rural regions reflected on the inconvenience of needing to travel to in-person health care services, especially during periods of health decline when they felt they needed the services the most yet had the least capacity to travel. One interviewee living with CCC contextualized their preference for remote options to access mental health services in their challenges of attending cardiac rehabilitation services in person.

"...I started doing it in [urban community] but it was too far for me and normally it starts right after they refer you after you’ve become an out-patient from the hospital. So one thing I didn't like about [cardiac rehabilitation] was that it was in-person and I wasn't ready to get there. It was a bit of a journey for me to travel there." [PLWCCC 7]

**Limited human resources due to underinsurance of mental health care**

While all participants recognized the value of mental health services, there was also broad recognition that the health care system was not appropriately resourced with mental health professionals to meet the range of mental health needs of the CCC population. This was attributed to the underinsurance of mental health care in Canada, which largely relies upon psychiatric services as publicly funded mental health care. As such, there is a limited supply of publicly funded services through social workers and psychologists who may be well suited for mental health concerns that are lower in severity or offer types of mental health support that could be complementary to psychiatric care (e.g., social support, psychotherapy, etc.). When envisioning optimal care for the CCC population, one cardiologist highlighted the lack of human resources as a central barrier.

"What you’re describing is platinum level service right? And so that’s what we would want for our family members, and our patients. You know everybody; this is what you would want for yourself. So it's great to have platinum level service, but to be able to provide it you have to have the resources to do it right? You can’t offer a first class in an airplane if you don't have the seats and the legroom. So you’ve got to make sure that you have human resources to match the needs of that." [Clinician 2]

**Ability to pay**

**Lack of full insurance coverage and high cost of psychological services**

An outcome of the underinsurance of mental health care was that access to some mental health services that PLWCCC desired (e.g., psychological services that are generally not included as publicly funded mental health services in Canada) was constrained by whether the individual had third party insurance coverage. As a result, PLWCCC had to rely on third party insurance to cover the cost of psychological services and psychological medications, and in some cases, incur out-of-pocket expenses to cover their costs. For PLWCCC who were not currently employed for health and non-health reasons (e.g., retirement), the lack of insurance coverage to cover the cost of psychological services was a significant barrier that prevented access to this valued form of mental health support.

"...it’s not a very easy thing to do. Support for those kinds of things, psychologists are very expensive. If you don't have ... I’m going to say connections to get yourself into a psychiatrist so you don't have to pay, you can be left out very easily.” [PLWCCC 8]

**Appropriateness**

**Underresourced system does not allow for choice or finding fit**

While mental health services were widely recognized as scarce among all participants, the mere availability of a service was not considered sufficient. PLWCCC desired options to allow them to choose services that aligned with their needs, values, and preferences. This desire for choices not only included a variety of mental health professionals (e.g., social work, psychology, psychiatry), but also different delivery modes (e.g., in-person, digital, hybrid) and methods (e.g., video, phone, etc.).

"You got to find a mix of the right people...some people just don’t work – match up well. And the system doesn't provide for the luxury of you to pick and choose to go through it like a movie selection.” [PLWCCC 8]

The approach to mental health care adopted by clinicians was also an important factor dictating the appropriateness of mental health services. PLWCCC discussed the importance of having diverse clinicians of different demographics involved in their mental health care who were flexible and offered them an option to later back out of care if they desired. This was especially important for PLWCCC who had poor experiences with mental health care in the past. For instance, one individual living with CCC described how their previous experiences seeking services from a psychologist influenced their gender preference for mental health professionals and negatively impacted their readiness to engage with them in the future.
"Well, many years ago I went to a man and he made some suggestions to me that I didn't think I could do, and he got very, almost mad at me and just cancelled me out because I wasn't doing what he wanted to...I'm thinking a woman would understand another woman a lot better than a man. I don't know why he was like that. That wasn't in his studies I don't think... But that really put me off and I've never gone to anybody since... I think it's what I need, but I know I can't see myself doing it again... I just don't feel like I want to put myself out there for that. Probably would never happen again, but I'm just reluctant now." [PLWCCC 5]

**Insufficiency of generic mental health supports**

Once accessed, mental health services were found to be inadequate in addressing the needs of PLWCCC, as they failed to understand the nuances of their chronic condition and did not communicate with their CCC care team. PLWCCC recounted finding community mental health services that were generic (not tailored to their physical health condition) insufficient in recognizing the interconnection between their CCC and mental health. Moreover, the lack of communication between mental health services and their CCC care team detracted from the opportunity to receive holistic care, where CCC clinicians could take possible mental health impacts on their physical health into account. One interviewee living with CCC described having to compromise the appropriateness of services for rapid access to a mental health service in the community.

“So I think reaching out to the right person and knowing what resources are available to you is really important, because at that time it was kind of immediate, like I really wanted to talk to someone now, but if I were willing to wait, I maybe would’ve gotten better help, because I would’ve reached out my cardiologist [name] and said “Can you refer me to someone?”... I reached out sort of immediately and it was to the wrong person.” [PLWCCC 3]

**Discussion**

Drawing upon semi-structured interviews with PLWCCC, clinicians, and researchers, this qualitative description study offers a theoretically informed analysis of the factors impacting access to mental health care for PLWCCC, which if accounted for by service pathways, could potentially avert and address the negative mental health impacts experienced by this population. Findings of this study highlight numerous barriers at the health system and patient levels that hinder access to mental health care for those living with CCC. The discussion below will focus on the sections of the framework where the most themes were identified, with a brief focus on the other domains.

**Approachability and ability to perceive**

Per Levesque's [19] framework, the opportunity to have mental health needs met and establish a desire for mental health care initially depends on the approachability of the health care system and patients' ability to perceive their health needs. In this study, several barriers were identified at this stage, originating from both the health system and PLWCCC. CCC clinicians reported substantial difficulties detecting mental health concerns and a lack of preparedness to engage their patients in effective referral conversations. These barriers to detecting mental health concerns within CCC populations have been well documented previously. Studies have similarly highlighted clinician normalization of mental health concerns, limited time during consultations, and lack of acumen of non-psychiatric clinicians in diagnosing mental health concerns in the presence of physical health symptoms as particularly salient [24–26]. Likewise, PLWCCC in this study reported experiences of perceiving their mental health symptoms as those pertaining to their physical health condition or denying such needs altogether in order to cope. Together, these barriers suggest the need to not only promote the general mental health literacy of individuals living with CCC and their clinicians but also to equip PLWCCCs and clinicians to explore the intersections between mental and physical health. Complex intervention strategies [27, 28] that couple screening and mental health literacy education may be valuable to simultaneously improve the approachability of mental health services and individual's ability to perceive their mental health needs while living with CCC. Given the need to untangle the complex and bidirectional relationship between mental and physical health, tools to support PLWCCC and clinicians in detecting and perceiving mental health concerns may benefit from being integrated within systems to manage patients’ physical health.

**Acceptability and ability to seek**

Acceptability refers to the cultural and social factors that affect the acceptance of health care services by those seeking care [19]. In this study it is important to note that no themes were identified related to the acceptability of mental health care services. It is possible that the lack of factors identified at this stage may be due to the demographics of the sample interviewed, which were recruited from an urban academic hospital and were predominantly White, urban-dwelling, and well-educated. As previous research has documented social and cultural dimensions that shape the explanatory models, help-seeking behaviours, and mental health treatment experiences of racialized populations living with CCC [8, 29], further research with more diverse populations is needed to understand the factors affecting the acceptability of mental health services for these populations. Nevertheless, while themes related to the acceptability of mental health services were not identified in this study, clinicians reported that stigma may affect the ability to seek care of PLWCCC and should be a factor for consideration. Previous research has found that reluctance to acknowledge mental health concerns due to stigma associated with mental illness and psychiatric medication have served as barriers to treatment for PLWCCC; however, Cabassa et al. [8] posit that such attitudes may be flexible should clinicians proactively address concerns, fears, and misconceptions. This may suggest that proactive destigmatizing initiatives could be beneficial as part of upstream health promotion efforts for the CCC population, as well as a destigmatizing approach by the clinician at time of referral to mental health care supports [29].

**Availability and accommodation and ability to reach**

Once a need and desire for mental health services were established, PLWCCC and clinicians interviewed reported that the limited availability of mental health services significantly hindered access to mental health care. This barrier to accessing mental health care was especially significant for those who were unready for psychiatric care or whose mental health concerns were not severe enough to warrant such care, as there were limited alternatives to offer
PLWCCC. In a qualitative study with primary care patients and clinicians in Quebec, Canada, Roberge et al. [27] report similar findings about the limited access to psychosocial and psychological care as a key barrier to mental health care for the CCC population, especially as those with common mental health disorders tend to prefer psychotherapy over pharmacotherapy [30]. As the authors suggest, ensuring integration of psychotherapy within mental health service delivery models remains a critical need to address the mental health needs of the CCC population [27].

**Affordability and ability to pay**

Clinicians and PLWCCC noted an overreliance on psychiatric care as a barrier to access that was attributed to the Canadian healthcare system whereby mental health care is underinsured and access to publicly funded psychotherapy is highly limited [31, 32]. While efforts are underway to improve access to publicly funded psychotherapy in Ontario, Canada [33], complementary innovations such as digital mental health technologies may offer a possible avenue to address the service gaps in mental health care by allowing timely and scalable delivery of underinsured areas of mental health care (e.g., psychological services) for individuals with mild to moderate concerns that do not require psychiatric intervention [32, 34]. Such delivery methods may not only address the gaps in care and improve service *affordability*, thereby minimizing the reliance on individual's *ability to pay*, but also address challenges associated with accessing health care services in-person (e.g., travel) that were expressed by participants in this study.

**Appropriateness and ability to engage**

Finally, among PLWCCC who reported accessing mental health care services, the *appropriateness* of existing mental health care services was perceived to be low, due to a lack of options available for PLWCCC to choose from, and a particular absence of mental health services that considered the impact of their physical chronic condition on their mental health (and vice versa). Despite the profound gaps in the *availability* of mental health care services recognized by participants, PLWCCC and clinicians envisioned the need for an ecosystem of mental health supports [35] available to them, with options for them to select and choose from based on their needs and preferences. The existence of multiple options to address a specific mental health need likely far surpasses the capacity of current mental health care systems. Indeed, the lack of themes identified in the *ability to engage* domain of the framework may reflect the few patients interviewed in the study who were connected to mental health services. Nevertheless, designers of mental health services may see it beneficial to ensure that patient preferences and needs are engaged in decision making regarding mental health treatments for the CCC population [36].

**Limitations**

Study findings should be interpreted in light of the following limitations. Foremost, semi-structured interviews were conducted during the ongoing COVID-19 pandemic. Due to this, the mental health needs and barriers expressed by participants may be partly attributed to the time and circumstances in which interviews were conducted (physical distancing measures and stay-at-home orders). Future research conducted during different periods should seek to understand whether similar findings arise in periods when such restrictions are not in place. Second, despite efforts to recruit purposively across a range of demographic variables, interviews were conducted in English and the PLWCCC recruited were predominantly well-educated and residing in urban regions. Themes therefore may not adequately represent the barriers to mental health experienced by individuals living with CCC who are non-English speaking, residing in rural regions, or with limited education. Furthermore, all PLWCCC interviewed were enrolled in a heart failure management program and may have greater access to healthcare services through their more frequent touchpoints with their care team. Finally, although several participants reported experiences of seeking mental health care, only two PLWCCC in this study self-identified as having a diagnosed mental health condition. As such, findings of this study may not represent the full range of mental health needs of this population, especially as mental health conditions have been found to be strongly correlated with social vulnerability [37]. Further investigations of the factors impacting access to mental health services for individuals with CCC who are disconnected from healthcare services and/or experience social vulnerability are needed.

**Conclusion**

This qualitative description study sought to understand the factors impacting access to mental health care for PLWCCC in Ontario, Canada. Findings of this research suggest that the mere availability of mental health services, while challenging in itself to achieve in many nations, is likely to be insufficient to improve access to mental health care for the CCC population. Complex intervention strategies acting at both the health system and patient levels are needed to address the multilevel barriers to accessing mental health care for the CCC population, namely in improving the approachability, availability, and appropriateness of care, as well as enhancing the of ability PLWCCC to perceive their mental health needs. Mental health interventions and services may see it fruitful to target the aforementioned areas to improve access to mental health care for the growing population living with CCC.

**Abbreviations**

- **PLWCCC**: People living with complex chronic conditions
- **CCC**: Complex chronic conditions

**Declarations**

- Ethics approval and consent to participate
The study was approved by the UHN Research Ethics Board (Protocol #16-5789 and #20-6329) and the University of Toronto Research Ethics Board (Protocol #40274 and #41477). Written informed consent was obtained from all participants.

Consent for publication

Not applicable

Availability of data and materials

The dataset supporting the conclusions of this article cannot be shared publicly because participants did not expressly consent to their data being shared publicly.

Competing interests

The authors declare that they have no competing interests.

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Authors’ contributions

The study was conceived and designed by A. Shah, R. Nolan, G. Strudwick, S. Sockalingam, and E. Seto. Participant recruitment and data acquisition were conducted by A. Shah. A. Shah and A. Shahil analyzed all data collected, with guidance from E. Seto. All authors contributed to the interpretation of the data. The initial draft of the paper was written by A. Shah, and all authors provided substantial revisions to the manuscript. The final manuscript was read and approved by all authors.

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References

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