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Complete List of Authors:	Shah, Amika; University of Toronto, Institute of Health Policy, Management and Evaluation; University Health Network, Centre for Digital Therapeutics Shahil Feroz, Anam; University of Toronto, Institute of Health Policy, Management and Evaluation; University Health Network, Centre for Digital Therapeutics Nolan, Robert P ; University Health Network, Cardiac eHealth; University of Toronto, Department of Psychiatry; University of Toronto, Institute of Medical Science Strudwick, Gillian; Centre for Addiction and Mental Health, Information Management Group; University of Toronto, Institute of Health Policy, Management and Evaluation Sockalingam, Sanjeev; Centre for Addiction and Mental Health, Education; University Health Network; University of Toronto, Institute of Medical Science Seto, Emily; University of Toronto, Institute of Health Policy, Management and Evaluation; University Health Network, Centre for Digital Therapeutics
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Access to mental health services for people living with heart failure: A qualitative study

Amika Shah*[1,2], Anam Shahil[1,2], Robert P Nolan[5,6,7], Gillian Strudwick[1,3], Sanjeev Sockalingam[3,4,5], Emily Seto[1,2]

[1] Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada

[2] Centre for Digital Therapeutics, University Health Network, Toronto, Ontario, Canada

[3] Centre for Addiction and Mental Health, Toronto, Ontario, Canada

[4] University Health Network, Toronto, Ontario, Canada

[5] Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada

[6] Cardiac eHealth, Toronto General Hospital , University Health Network, Toronto, Ontario, Canada

[7] Institute of Medical Science, University of Toronto, Toronto, Ontario, Canada

* Corresponding author

E-mail: amika.shah@mail.utoronto.ca (AS)

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Abstract

Objectives: Amidst low recognition and treatment for mental health conditions among people living with heart failure (PLWHF), this study aimed to identify factors affecting access to mental health services for PLWHF.

Design: Semi-structured phone interviews were conducted with PLWHF (n=13) and clinicians and researchers (n=9).

Setting: Heart failure remote management program at a large urban academic hospital in Ontario, Canada.

Results: Using inductive reflexive thematic analysis, 14 themes were created and mapped to Levesque's patient-centred access to care framework, revealing barriers at the system and patient levels. System-level barriers included service approachability (i.e., difficulties detecting mental health concerns; unpreparedness for referral conversations), availability and accommodation (limited mental health services; poorly timed services; inconsistent care pathways), and affordability (i.e., 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 (i.e., low mental health literacy), as well as seek (i.e., stigma), reach (i.e., inconvenience of in-person delivery), and pay (i.e., lack of full insurance coverage and high cost of psychological services) for mental healthcare.

Conclusions: The findings suggest enhancing the approachability, availability, and appropriateness of mental health services and promoting the ability of PLWHF to recognize their mental health needs as potential interventional targets.

Keywords: Service use; Depression; Depression screening; Help seeking; Mental well-being; Mental health treatment; Mental health services; Thematic analysis

Strengths and limitations of this study

- This is the first study to qualitatively explore factors impacting access to mental health services specifically for people living with heart failure with use of a theoretical framework and consideration of both the health system and patient perspectives.

- As all participants were recruited from a heart failure remote monitoring program at a large urban academic hospital, the lower representation of those residing in rural regions, non-English speakers, and individuals with lower levels of education limit the transferability of the study findings to more diverse populations, including those experiencing social vulnerability.

Background

Depression is a prevalent yet often overlooked comorbidity affecting approximately 42% of people living with heart failure (PLWHF) globally.[1] While estimates vary across populations, comorbid depression of any severity has been found to range between 7.5% to 100% of the heart failure population, significantly higher than in the general population.[1–4] When present with heart failure, comorbid depression can double the risk of major cardiac events, increase healthcare costs, and impair self-care ability.[5–8] Scholars posit a complex, bidirectional relationship between heart failure and depression, where heart failure may contribute to depression onset, and vice versa.[9] A higher risk of depression has been observed among certain demographic (older age, female gender, lower socioeconomic status), clinical (greater severity of heart failure symptoms, use of beta blockers, multiple comorbidities), psychosocial factors (low social support, maladaptive coping styles, neurotic personality traits), underscoring the need for early treatment for those at the greatest risk.[2,4,10–12]

Fortunately, mental health treatment for depression can have a significant impact on outcomes for PLWHF, such as reduced hospitalizations, emergency department visits, and in some cases, improved survival.[13] Despite these benefits, mental health care remains underutilized within cardiology settings, including heart failure care specifically.[14,15] For instance, in Australia, although 19% (3671/20219) of heart failure patients had a recorded diagnosis for depression and anxiety, only 7% (1393/20219) of patients were found to have a mental health plan to receive government-funded mental health treatments via the Better Access initiative (10 appointments for individual or group mental health services).[16] This represented only 37.1% (1393/3671) of all diagnosed patients, suggesting underutilization of mental health treatments even when coverage is

provided for mental health treatments such as psychotherapy.[16] In a study by Latif and colleagues, decreases in referral rates of heart failure patients to psychotherapy were observed in an ambulatory setting between 2008 to 2018.[14] Although the authors hypothesize that barriers at the clinician level (e.g., time constraints, complexity of care demands) and patient level (e.g., attitudes towards psychotherapy, direct cost of services, and indirect time costs of participating in psychotherapy) explain these findings, the authors highlighted the need for future qualitative research investigating current practices that give rise to low referrals to mental health services.[14]

Amidst indications of underutilization, barriers to accessing mental health care within the heart failure population remain underexplored, although broader research on chronic disease populations suggests several potential factors. Results from a qualitative study by Schwarz et al. using Levesque's patient-centered access to care framework countered perceptions that minimal barriers to health services existed within Austria's universal health care system.[17] The authors reported that patients living with chronic conditions (pediatric bronchial asthma, adults with lower back pain, and older adults with mental illness) faced several invisible barriers to health care, including a lack of coordinated care and clear pathways, particularly at the onset of a condition. Health system barriers included poor patient-provider communication, lack of a holistic care, urban-rural care differences, limited time during consultations, and fragmented health and social systems. At the patient level, the ability to perceive their health needs and then seek and reach health services were key barriers. More closely related to the heart failure population, Collopy et al. identified that limited information about the connection between mental health and cardiovascular disease, insufficient understanding about mental health, limited identification with mental health diagnostic language, lack of interest in formal mental health services, preference for informal peer support,

and practical barriers hindered people living with cardiovascular disease from accessing mental health care in Australia.[18] Despite the focus on the cardiac population, PLWHF, a chronic progressive condition, were not represented in the study population, nor did the study engage with theoretical frameworks on access to mental health care. These limitations of the existing research hinder the development of interventions to improve access to mental health care for PLWHF.

Designing and integrating mental health services into standard care for PLWHF can benefit from understanding factors affecting access to mental health care for this population. However, a theoretically-informed qualitative analysis of the factors affecting the process of accessing mental health care for PLWHF has not yet been conducted. To address this gap, we sought to design, implement, and evaluate a mental health service to improve access to mental health care for PLWHF. As part of a multi-phase investigation, this study sought to investigate the question: *What do individuals diagnosed with heart failure, clinicians, and researchers perceive as factors impacting access to mental health care for PLWHF*?

Methodology

Study design

A qualitative study was conducted using reflexive thematic analysis, a methodology to acquire meaning within a dataset proposed by Braun and Clarke, to identify patterns in the data.[19] 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 PLWHF.

In place of more general reporting guidelines for qualitative research[20,21], Braun and Clarke have recommended use of reporting guidelines specific to reflexive thematic analysis. As such, the Reflexive Thematic Analysis Reporting Guidelines were used to guide the reporting of this study.[22]

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Recruitment

PLWHF were recruited from a heart failure management program called the Medly Program that provides smartphone-based telemonitoring as standard of care at the Toronto General Hospital, a large urban hospital in Ontario, Canada.[23] Since enrollment into the Medly Program is based on the presence of complex heart failure and high healthcare utilization, all patients in the program have heart failure. While not formally integrated into the Medly program, all patients have access to publicly-funded psychiatric services accessible via referral from their primary care physician or heart failure clinician, as well as mental health supports such as workshops through cardiac rehabilitation. Depending on employment status and place of residence, participants may also have access to additional mental health services, such as counseling, through community-based organizations, and private psychological services through employment benefits.

Individuals were recruited by phone across a range of demographic factors to ensure representation of PLWHF with respect to age, sex, ethnicity, place of birth, highest education received, place of

residence, living arrangement, income in CAD $. Efforts were also made to recruit patients with varying levels of comfort using smartphones, acknowledging that recruiting from a smartphone-based telemonitoring program might result in participants who are inclined to access healthcare virtually. All clinicians in the Medly Program were invited to participate in the study by email, and subsequent clinicians and researchers were recruited via snowball sampling. All 13 PLWHF invited to participate enrolled in the study and no individuals refused to participate or withdrew from the study. Of the 10 clinician and researchers approached for the study, nine agreed to participate.

Dataset generation

One-on-one semi-structured interviews between 40 and 60 minutes were conducted in English by authour Shah, she/her, a PhD Candidate in Health Informatics Research at the time of the study. Shah has received formal training in qualitative research and has conducted qualitative research studies in the past. This author had no prior relationship with participants, and participants were made aware of this researcher's role as study coordinator and student. One-on-one semi-structured interviews were chosen to allow for an in-depth exploration of individual experiences and to promote participant comfort, particularly for those who may find discussing mental health topics challenging. Due to safety restrictions brought by the COVID-19 pandemic, all interviews were conducted by phone, where the researcher called from a private space at home and participants called 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, I (Shah) became interested in the study topic after witnessing gaps in community mental healthcare, sparking my

curiosity in using digital technologies as a potential interventional strategy. To understand how my experiences working with people living with mental illness and interests in digital health shaped the findings, I memoed throughout the research process and engaged in ongoing discussions with other research team members with varying backgrounds. This included discussing the themes with Shahil, a nurse, and Seto, a health services researcher. Additionally, the study design and themes were constructed with input from Nolan, a clinical psychologist, Strudwick, a nurse, and Sockalingam, a psychiatrist, all of whom strengthened the consideration of clinician perspectives.

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

In alignment with Braun and Clarke's proposition of sampling as a pragmatic practice, 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 to 20 participants and *in situ* to end data collection at 23 participants.[24] This number of participants was determined by weighing the depth of data collected, the various demographic and experiential factors represented, and

pragmatic constraints of the project such as costs of transcription that limited further data collection.[24]

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. No repeat interviews were conducted. Field notes were also made by authour Shah both during and after each interview. Transcripts were not returned to participants for comments or corrections.

Data analysis

To allow for both data-based and theory-based meanings to be emphasized at different stages of the analysis, an inductive approach was initially adopted followed by deductive analysis. Two authors, Shah and Shahil, were involved in coding the data, to allow different perspectives to be brought to the data analysis process. First, Shah and Shahil read the transcripts to familiarize themselves with the data. Second, the same two authors independently coded the transcripts at the semantic and latent levels using NVivo 12 (QSR International) to manage and organize the data during the coding process. At this stage, each coder created initial themes in an inductive manner. Third, Shah and Shahil met to present and discuss their initial themes. Where differences in the initial themes were found between Shah and Shahil, the authors discussed why they saw a particular pattern in the data as important to the research question. This allowed both authors to deepen their analysis and understand how the distinct perspectives of the authors shaped different creations of themes. Following this step, both coders independently mapped their respective codes

and themes to the domains of Levesque's framework. At this stage, Shah and Shahil referenced the original data to ensure that the mapping aligned with the data excerpts for each code. In cases where Shah and Shahil found the data to align more strongly with another domain, the mapping was adjusted accordingly. Once independent mapping of the themes was complete, both coders met once again to discuss their mapping and why they had placed codes within certain domains. Finally, based on the previous discussions, both coders met to craft a final set of themes together and mapping to Levesque's framework, informed by their themes and mapping conducted in the previous phases.

Per Levesque, access is an opportunity for a perceived need for care to be met through reaching and obtaining health care services.[25] The framework outlines that access results from the interplay between supply- (i.e., health care system, services, and providers) and demand-side factors (i.e., persons, households, and social and physical environments). Factors on the supply side include the approachability, acceptability, availability and accommodation, affordability, and appropriateness of health care services. On the demand side, factors impacting access include the ability of patients and their support network to perceive a need for care as well as to seek, reach, pay, and engage with healthcare services.[25] Dimensions on each side of this framework represent potential facilitators or barriers to access to healthcare during an episode of care.[25] Table 1 displays the paired patient and health system constructs outlined by Levesque at each stage of accessing care, which include perceiving health needs and desire of care, seeking health care, reaching health care, using health care, and health care consequences.[25]

Among the various frameworks addressing access to care, Levesque's framework, which was developed based on a literature review of existing access to care frameworks, was selected for its

comprehensiveness.[26,27] Specifically, the framework's consideration of factors at the patient (supply) and health system (demand) levels as well as the treatment of access as a process or journey, allowed for a holistic view on the construct in this research.[26]

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

Stage of Access	Domain of Access (Health System)[25]	Definition[25]	Domain of Access (Patient)[25]	Definition[25]
1. Perceiving Health Needs & Desire for Care	**1a. Approachability**	A person in need of health services can identify that service(s) exist, can be reached, and have an impact on their health.	**1b. Ability to perceive**	Determined by health literacy, knowledge about health, and beliefs related to health and sickness.
2. Seeking Health Care	**2a. Acceptability**	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).	**2b. Ability to seek**	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.

3. Reaching Health Care	**3a. Availability & accommodation**	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.	**3b. Ability to reach**	Individual mobility, transportation availability, occupational flexibility, and knowledge of health care services that allow one to physically access health care service.
4. Using Health Care	**4a. Affordability**	The economic capacity of individuals to expend resources and time to use appropriate health	**4b. Ability to pay**	A capacity to generate economic resources through savings, income, or loans by which health care

		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.		services can be paid for without catastrophic expenditures of resources required for basic necessities.
5. Health Care Consequences	**5a. Appropriateness**	Service fit with an individual needs, timeliness, amount of care placed in identifying correct treatments, and quality of services received both technically and interpersonally. Appropriateness considers both service	**5b. Ability to engage**	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,

		adequacy (what services are provided) as well as quality (the way services are provided).		as well as provision of care that is commensurate with the skills of the individual affect one's ability to engage.

To strengthen the quality and trustworthiness of reflexive thematic analysis study findings, various measures were employed to promote thoughtful engagements with the data and analytic process.[28] Researchers repeatedly engaged with the raw data and had reflexive conversations among team members.[29] 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.[29] 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 (i.e., personal reflexivity), their disciplinary location (i.e., disciplinary reflexivity), and methodological choices (i.e., functional reflexivity).[30,31]

Results

In total, 22 participants were interviewed: 13 PLWHF and nine clinicians and researchers with experience in mental healthcare and/or heart failure. Participants living with heart failure 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, three were heart failure clinicians (e.g., nurse, cardiologist) and four were mental health professionals (e.g., psychologist, psychiatrist). The two researchers had expertise in heart failure. Given the number

of participants interviewed, detailed characteristics of clinicians and researchers were not reported to prevent the risk of identifying individual participants. Interviews lasted an average of 46.7 minutes. A total of 14 themes (Table 3) were generated that were mapped to the access to care domains outlined by Levesque.[25]

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

Characteristic	n (%)
Age	
21-30	2 (15)
31-40	1 (8)
41-50	0 (0)
51-60	2 (15)
61-70	4 (31)
71-80	2 (15)
81-90	2 (15)
Sex	
Male	7 (54)
Female	6 (46)
Ethnicity	
White (Caucasian)	8 (62)
Black	1 (8)
Filipino	1 (8)

South Asian	1 (8)
Chinese	1 (8)
Arab/West Asian	1 (8)
Place of birth	
Canada	8 (62)
Other	5 (38)
Highest education achieved	
High school	3 (23)
Trade or technical training	2 (15)
College or university	5 (38)
Postgraduate	3 (23)
Place of residence	
Urban	6 (46)
Suburban	4 (31)
Rural	2 (15)
Not declared	1 (8)
Living arrangement)	
Living with family/partner	9 (69)
Living alone	3 (23)
Living with friend(s) and/or roommate(s)	1 (8)
Income in CAN $	

< 15,000	1 (8)
$15,000-$49,999	3 (23)
$50,000-$74,999	7 (54)
>75,000	1 (8)
Not declared	1 (8)
Comfort with smartphone	
Very comfortable	2 (15)
Comfortable	2 (15)
Somewhat comfortable	3 (23)
Not comfortable	2 (15)
N/A (does not use smartphone)	3 (23)
Not declared	1 (8)

Table 3. Summary of Generated Themes.

Levesque's Stage in Episode of Care	**Levesque's Characteristic of Health System**	**Theme Produced from Thematic Analysis**	**Levesque's Characteristic of Patient**	**Theme Produced from Thematic Analysis**
Perceiving Health Needs & Desire for Care	*Approachability*	Difficulties detecting mental health concerns	*Ability to perceive*	Mental health literacy
		Unpreparedness for referral conversations		Denial, stoicism, and self-reliant coping methods
				Attribution of causality

Seeking Health Care	*Acceptability*	-	*Ability to seek*	Stigma surrounding mental healthcare
Reaching Health Care	*Availability & accommodation*	Limited types of mental health services available	*Ability to reach*	Inconvenience of in-person delivery
		Inconsistent pathways to mental health services		
		Poorly timed mental health services		
Using Health Care	*Affordability*	Limited human resources due to underinsurance of mental healthcare	*Ability to pay*	Lack of full insurance coverage and high cost of psychological services
Health Care Consequences	*Appropriateness*	Underresourced system does not allow for choice or finding fit	*Ability to engage*	-
		Insufficiency of generic mental health services		

Health system factors

Approachability

Difficulties detecting mental health concerns

Recognizing the high prevalence of mental health concerns among PLWHF, clinicians expressed hesitancy with detecting 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 fluctuations in mood could risk overtreating mental health deteriorations that may resolve on their own. As overtreatment could lead to unnecessary use of scarce mental health services, 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…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 PLWHF. Difficulties 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 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 of readings, change in physical health readings).

> "…the Medly nurse coordinator is in tune with the patient. Like they know that this person is calling a lot. This person is not putting in their weights. This person's weight is off a lot…Sometimes the cue is that the patient's not recording...Not something that they've said, but the fact that they're not recording in telemonitoring might tell us "oh why aren't they recording?"" [Clinician 3]

Unpreparedness for referral conversations

Nurses explained that their long-term relationships with patients through telemonitoring not only helped indirectly identify potential mental health concerns but also offered opportunities to

normalize mental health impacts as a common consequence of living with heart failure. Despite this, nurses expressed discomfort with referring PLWHF 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 PLWHF to a mental health program.

> "...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…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 heart failure 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 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 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, PLWHF felt frustrated being referred to mental health services, 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 dismissive.

> "I just didn't feel that I needed to go there. 10 years ago, seeing doctors, they would look at me going "I don't think you have a problem [with your heart], and when it gets worse, give me a call. I think it's just anxiety". So, I've been living that my whole life, saying it's panic attacks, its 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....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"—like I'm fine. I'm fine." [PLWHF 1]

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, PLWHF highlighted the few opportunities to access peer support through their heart failure 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 PLWHF 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 almost always involve patients 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

PLWHF who reported having been referred to a mental health service in the past reported highly variable care pathways and experiences. Some PLWHF 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 PLWHF and the quality of relationship they had with their primary care

physician. As a resident of a rural community, one PLWHF 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, 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]." [PLWHF 5]

Poorly timed mental health services

Inconsistencies not only arose in how PLWHF were connected with mental health services, but also in the timeliness of care delivered. Through experiencing waitlist-related delays in receiving mental health services, PLWHF 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, PLWHF emphasized the importance of mental health support during acute deteriorations in their health.

> "...you don't know if the person will be able to talk to you within the time period that you need them to.... 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 heart failure-related." [PLWHF 6]

The delays in accessing mental health services often meant that PLWHF received care only after acute deteriorations in their health had improved. This lag in mental health care was perceived by PLWHF as a missed opportunity for clinicians to recognize the connection between their mental health status and heart failure.

Affordability

Limited human resources due to underinsurance of mental healthcare

While all participants recognized the value of mental health services, there was also broad recognition that the healthcare system was not appropriately resourced with mental health professionals to meet the range of mental health needs among PLWHF. This was attributed to the underinsurance of mental healthcare in Canada, which largely relies upon psychiatric services as publicly funded mental healthcare. 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 PLWHF, one cardiologist highlighted the lack of human resources as a central barrier.

> "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]

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. PLWHF 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 or 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." [PLWHF 8]

The approach to mental healthcare adopted by clinicians was also an important factor dictating the appropriateness of mental health services. PLWHF discussed the importance of having clinicians of different demographics involved in their mental healthcare who were flexible and offered them an option to disengage from treatment if desired. This was especially important for PLWHF who had poor experiences with mental healthcare in the past. For instance, one individual living with heart failure 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. …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." [PLWHF 5]

Insufficiency of generic mental health supports

Once accessed, some mental health services were found to be inadequate in addressing the needs of PLWHF, as they failed to understand the nuances of their condition and did not communicate with their heart failure care team. PLWHF recounted finding community mental health services that were generic (not tailored to their heart failure) insufficient, as they detracted from the opportunity to receive holistic care, where heart failure clinicians could take possible mental health impacts on their physical health into account. One interviewee living with heart failure 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 and said "Can you refer me to someone?"...I reached out sort of immediately and it was to the wrong person." [PLWHF 3]

Patient factors

Ability to perceive

Mental health literacy

From the perspective of PLWHF, the ability to perceive one's own mental health impacts was a central factor impacting access to mental healthcare. However, PLWHF 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?" [PLWHF 2]

Some PLWHF noted that their understanding and perceptions of mental health and mental healthcare 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…[the psychiatrist] knew my childhood and when they 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…we never discussed it…not to the depth that maybe we needed to." [PLWHF 1]"

When patients had limited knowledge about mental health, mental health professionals (e.g., difference between a psychologist and psychiatrist), and attitudes viewing mental health issues as a personal weakness, clinicians struggled to address the mental health impacts of their patients' conditions and provide appropriate 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". [Clinician 4]

In instances where PLWHF were unable to recognize their mental health symptoms, clinicians found it difficult to discuss potential mental health interventions to support their patients.

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 heart failure. PLWHF reported using coping methods such as denial and stoicism to cope with the mental health impacts of their heart

failure. Stoicism, as framed by PLWHF, involved not recognizing or engaging with their feelings in order to live with their illness. This coping method presented barriers to accessing mental healthcare 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." [PLWHF 3]

Attribution of causality

Individual beliefs about the cause of their mental health concerns further impacted the ability of PLWHF to perceive their mental health needs and be ready to access mental health services. PLWHF 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" [PLWHF 4]

Ability to seek

Stigma surrounding mental healthcare

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 PLWHF 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 healthcare 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"…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]

Ability to reach

Inconvenience of in-person delivery

As individuals enrolled in the Medly Program resided in diverse regions, PLWHF emphasized the importance of having options to access mental health services remotely. PLWHF 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 PLWHF 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." [PLWHF7]

Ability to pay

Lack of full insurance coverage and high cost of psychological services

An outcome of the underinsurance of mental healthcare was that access to some mental health services that PLWHF 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, PLWHF 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 PLWHF 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.

"Psychologists are very expensive. If you don't have connections to get yourself into a psychiatrist so you don't have to pay, you can be left out very easily." [PLWHF 8]

Discussion

Research has observed underutilization of mental health services among PLWHF even when routine depression screening and referral processes are present, suggesting that this population may face distinct barriers to accessing mental healthcare.[14–16] Drawing upon data from semi-structured interviews with PLWHF, clinicians, and researchers, this qualitative study investigates this gap further in its theoretically informed analysis of the factors impacting access to mental health care for PLWHF. Findings of this research shed light on the complex and multifaceted barriers that PLWHF face at both the health system and patient levels.

Health system barriers

Previous studies have neglected consideration of the factors at the health system level, often focusing on barriers of awareness at the patient level.[18] Our exploration reveals substantial barriers at the health system level, specifically with the approachability, availability, and appropriateness of the health system. Access was impeded by healthcare providers' concerns of "opening the floodgates", identifying too many patients with distress that the underinsured mental health care system was not equipped to support. This apprehension was not only rooted in concern for system capacity but also fear of overtreatment when distress may resolve independently. As such, this study highlights that underinsurance of mental health services not only presented an affordability barrier for PLWHF, but it also had upstream impacts on the approachability of the health system.

The approachability of the health system was further hindered by clinicians' substantial difficulties detecting mental health concerns, owing to patient complexity from bidirectional interactions between mental and physical health symptoms, especially when no structured and formal screening methods were available. Although this study validates the finding from previous research that

mental health screening next to an initial diagnosis or hospitalization may not be ideal, participants in this study offered further guidance on specific points where screening was thought to be most helpful.[18] PLWHF found screening to be most valuable during acute health events post-diagnosis, which could facilitate reflection on the impact of their heart failure on their mental health to promote awareness that could benefit both the individual's motivation to seek mental health services and their care team. Further research is needed to personalize the timing of screening and subsequent follow up for PLWHF in different stages of their journey (e.g., beginning, post-diagnosis without acute health events, post-diagnosis with acute health events).

As reported by other scholars[18,32–34], clinicians reported a lack of knowledge and self-efficacy to engage their patients in effective referral conversations. While previous research suggests using less medicalized language like "learning to cope" to connect with patients[18], clinicians in this study found that such language can unintentionally hinder accurate communication and reinforce stigma. These findings complicate the existing literature on patient-centered communication for PLWHF, highlighting the need for further research on effective language and its impact on patient understanding and engagement.

Pathways to mental health services were highly variable, siloed from heart failure care, and of limited availability, especially for those who were unready for psychiatric care or whose mental health concerns were not severe enough to warrant such care. As studies have reported low acceptability of formal mental health services among PLWHF, our study outlines key considerations to promote the acceptability of mental health services for PLWHF.[18,35] PLWHF in this study expressed the desire for peer support. Peer support may not only serve as a treatment option but also, per the hypothesis of Collopy et al., may serve to normalize psychological distress,

improve mental health awareness, reduce stigma, and promote positive attitudes towards formal help-seeking via information provision and exposure to peers who have sought mental health services.[18] Additionally, a new finding from this research was that PLWHF who accessed mental health services reported dissatisfaction with generic mental health services (untailored to heart failure) as they perceived these services to be ill-equipped to address their mental health challenges resulting from their heart failure journey. Taken together, these findings suggest that peer support and interventions tailored to the experiences of heart failure may be valuable components of mental health services for PLWHF.

Patient barriers

On the patient side, the ability of PLWHF to perceive their mental health needs was a substantial barrier to access, including a lack of information between heart failure and mental health, limited general mental health literacy, lack of identification with clinical mental health terms, seeing mental health care as unnecessary, use of stoicism and denial coping strategies, and difficulties expressing one's feelings.[18,35,36] While many of these factors aligned with the existing literature, this study highlighted a factor not yet reflected in the literature: patients' perceptions of the cause of their mental health issues. Those who attributed their mental health challenges to their experience of heart failure were more open to referral, whereas those who saw it as unrelated required further discussion to pursue mental health services.

Similar to previous research, stigma associated with mental illness and psychiatric medication as well as social desirability was found to affect PLWHF's ability to seek care.[36] Cabassa et al. posit that such attitudes may be flexible should clinicians proactively address concerns, fears, and

misconceptions.[37] This may suggest that proactive destigmatizing initiatives could be beneficial as part of upstream health promotion efforts for PLWHF, as well as a destigmatizing approach by the clinician at the time of referral to mental health services.[38]

Several studies, including this study, have found that PLWHF face practical barriers to accessing mental health services, such as mobility challenges, financial barriers associated with travel, difficulty attending to appointments in person, issues juggling multiple health appointments, and challenges acting on a referral due to exacerbations with their chronic condition.[18,35] Once patients decided to seek mental health care, financial barriers and limited insurance coverage affected their ability to pay for mental health services, especially when seeking psychological care.[17,18] Although the expansion of publicly funded mental health services is an important step, this research and others highlight that it is unlikely to resolve all barriers faced by PLWHF, as evidenced by underutilization of such services in contexts where they are publicly available.[16] Nevertheless, the underinsurance of non-psychiatric mental health services remains a crucial constraint for both clinicians and health service planners.

Strengths and limitations

Strengths of this study include its dual focus on both health system and patient perspectives, its use of a theoretical framework, and its identification of new barriers—particularly at the healthcare provider level—that complicate current understanding of mental health care access for PLWHF. Despite these strengths, the study findings should be interpreted in light of the following limitations. Foremost, semi-structured interviews were conducted during the early stages of the 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 (e.g., 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 all participants were recruited from an urban academic hospital. Themes therefore may not adequately articulate the barriers to mental healthcare experienced by PLWHF who are of diverse ethnicities, non-English-speaking, residing in rural regions, or with limited education as well as clinicians and researchers working with such populations. For example, no themes related to the acceptability of mental healthcare services were produced in this study, which may be attributed to the demographics of the participants interviewed. Given documented social and cultural dimensions influencing help-seeking behaviors and treatment experiences among racialized populations living with chronic conditions, further research with more diverse populations is necessary to identify factors affecting mental health service acceptability in these communities.[37,38] Finally, although several participants reported experiences of seeking mental healthcare, only two PLWHF 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.[39] Further investigations of the factors impacting access to mental health services for PLWHF who are disconnected from health care services and/or experience social vulnerability are needed.[39]

Conclusion

This qualitative study sought to understand the factors impacting access to mental health care for PLWHF in Ontario, Canada. An analysis of both the patient and health system perspectives offers a nuanced and holistic view, suggesting 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 PLWHF. 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 PLWHF, namely in improving the approachability, availability, and appropriateness of care, as well as enhancing the of ability PLWHF 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 healthcare for the growing population living with heart failure.

Data availability statement

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

Ethic statements

Patient consent for publication

Not applicable.

Ethics approval

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.

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Author 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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Competing interests

The authors declare no competing interests.

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Access to mental health services for people living with heart failure: A qualitative study

Amika Shah*[1,2], Anam Shahil[1,2], Robert P Nolan[5,6,7], Gillian Strudwick[1,3], Sanjeev Sockalingam[3,4,5], Emily Seto[1,2]

[1] Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada

[2] Centre for Digital Therapeutics, University Health Network, Toronto, Ontario, Canada

[3] Centre for Addiction and Mental Health, Toronto, Ontario, Canada

[4] University Health Network, Toronto, Ontario, Canada

[5] Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada

[6] Cardiac eHealth, Toronto General Hospital , University Health Network, Toronto, Ontario, Canada

[7] Institute of Medical Science, University of Toronto, Toronto, Ontario, Canada

* Corresponding author

E-mail: amika.shah@mail.utoronto.ca (AS)

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Abstract

Objectives: Amidst low recognition and treatment for mental health conditions among people living with heart failure (PLWHF), this study aimed to identify factors affecting access to mental health services for PLWHF.

Design: Semi-structured phone interviews were conducted with PLWHF (n=13) and clinicians and researchers (n=9).

Setting: Heart failure remote management program at a large urban academic hospital in Ontario, Canada.

Results: Using inductive reflexive thematic analysis, 14 themes were created and mapped to Levesque's patient-centred access to care framework, revealing barriers at the system and patient levels. System-level barriers included service approachability (i.e., difficulties detecting mental health concerns; unpreparedness for referral conversations), availability and accommodation (limited mental health services; poorly timed services; inconsistent care pathways), and affordability (i.e., 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 (i.e., low mental health literacy), as well as seek (i.e., stigma), reach (i.e., inconvenience of in-person delivery), and pay (i.e., lack of full insurance coverage and high cost of psychological services) for mental healthcare.

Conclusions: The findings suggest enhancing the approachability, availability, and appropriateness of mental health services and promoting the ability of PLWHF to recognize their mental health needs as potential interventional targets.

Keywords: Service use; Depression; Depression screening; Help seeking; Mental well-being; Mental health treatment; Mental health services; Thematic analysis

Strengths and limitations of this study

- Levesque's access to care framework was used to understand access from both the health system and patient perspectives.
- Participants were recruited from a heart failure remote monitoring program at a large urban academic hospital, limiting the applicability of findings to rural contexts.
- The lower representation of non-English speakers and individuals with lower levels of education limit the transferability of the study findings to populations experiencing social vulnerability.
- Interviews were conducted during the early stages of the COVID-19 pandemic, which may not reflect access to mental health care when public health measures are not in place.

Background

Depression is a prevalent yet often overlooked comorbidity affecting approximately 42% of people living with heart failure (PLWHF) globally.[1] While estimates vary across populations, comorbid depression of any severity has been found to range between 7.5% to 100% of the heart failure population, significantly higher than in the general population.[1–4] When present with heart failure, comorbid depression can double the risk of major cardiac events, increase healthcare costs, and impair self-care ability.[5–8] Scholars posit a complex, bidirectional relationship between heart failure and depression, where heart failure may contribute to depression onset, and vice versa.[9] A higher risk of depression has been observed among certain demographic (older age, female gender, lower socioeconomic status), clinical (greater severity of heart failure symptoms, use of beta blockers, multiple comorbidities), psychosocial factors (low social support, maladaptive coping styles, neurotic personality traits), underscoring the need for early treatment for those at the greatest risk.[2,4,10–12]

Fortunately, mental health treatment for depression can have a significant impact on outcomes for PLWHF, such as reduced hospitalizations, emergency department visits, and in some cases, improved survival.[13] Despite these benefits, mental health care remains underutilized within cardiology settings, including heart failure care specifically.[14,15] For instance, in Australia, although 19% (3671/20219) of heart failure patients had a recorded diagnosis for depression and anxiety, only 7% (1393/20219) of patients were found to have a mental health plan to receive government-funded mental health treatments via the Better Access initiative (10 appointments for individual or group mental health services).[16] This represented only 37.1% (1393/3671) of all diagnosed patients, suggesting underutilization of mental health treatments even when coverage is

provided for mental health treatments such as psychotherapy.[16] In a study by Latif and colleagues, decreases in referral rates of heart failure patients to psychotherapy were observed in an ambulatory setting between 2008 to 2018.[14] Although the authors hypothesize that barriers at the clinician level (e.g., time constraints, complexity of care demands) and patient level (e.g., attitudes towards psychotherapy, direct cost of services, and indirect time costs of participating in psychotherapy) explain these findings, the authors highlighted the need for future qualitative research investigating current practices that give rise to low referrals to mental health services.[14]

Amidst indications of underutilization, barriers to accessing mental health care within the heart failure population remain underexplored, although broader research on chronic disease populations suggests several potential factors. Results from a qualitative study by Schwarz et al. using Levesque's patient-centered access to care framework countered perceptions that minimal barriers to health services existed within Austria's universal health care system.[17] The authors reported that patients living with chronic conditions (pediatric bronchial asthma, adults with lower back pain, and older adults with mental illness) faced several invisible barriers to health care, including a lack of coordinated care and clear pathways, particularly at the onset of a condition. Health system barriers included poor patient-provider communication, lack of a holistic care, urban-rural care differences, limited time during consultations, and fragmented health and social systems. At the patient level, the ability to perceive their health needs and then seek and reach health services were key barriers. More closely related to the heart failure population, Collopy et al. identified that limited information about the connection between mental health and cardiovascular disease, insufficient understanding about mental health, limited identification with mental health diagnostic language, lack of interest in formal mental health services, preference for informal peer support,

and practical barriers hindered people living with cardiovascular disease from accessing mental health care in Australia.[18] Despite the focus on the cardiac population, PLWHF, a chronic progressive condition, were not represented in the study population, nor did the study engage with theoretical frameworks on access to mental health care. These limitations of the existing research hinder the development of interventions to improve access to mental health care for PLWHF.

Designing and integrating mental health services into standard care for PLWHF can benefit from understanding factors affecting access to mental health care for this population. However, a theoretically-informed qualitative analysis of the factors affecting the process of accessing mental health care for PLWHF has not yet been conducted. To address this gap, we sought to design, implement, and evaluate a mental health service to improve access to mental health care for PLWHF. As part of a multi-phase investigation, this study sought to investigate the question: *What do individuals diagnosed with heart failure, clinicians, and researchers perceive as factors impacting access to mental health care for PLWHF*?

Methodology

Study design

A qualitative study was conducted using reflexive thematic analysis, a methodology to acquire meaning within a dataset proposed by Braun and Clarke, to identify patterns in the data.[19] 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 PLWHF.

In place of more general reporting guidelines for qualitative research[20,21], Braun and Clarke have recommended use of reporting guidelines specific to reflexive thematic analysis. As such, the Reflexive Thematic Analysis Reporting Guidelines were used to guide the reporting of this study.[22]

Patient and public involvement

While the overall aim of this research project was to incorporate stakeholder perspectives in the design of an intervention, patients and/or the public were not involved in the design, conduct, reporting, or dissemination plans of this research.

Recruitment

PLWHF were recruited from a heart failure management program called the Medly Program that provides smartphone-based telemonitoring as standard of care at the Toronto General Hospital, a large urban hospital in Ontario, Canada.[23] Since enrollment into the Medly Program is based on the presence of complex heart failure and high healthcare utilization, all patients in the program have heart failure. While not formally integrated into the Medly program, all patients have access to publicly-funded psychiatric services accessible via referral from their primary care physician or heart failure clinician, as well as mental health supports such as workshops through cardiac rehabilitation. Depending on employment status and place of residence, participants may also have access to additional mental health services, such as counseling, through community-based organizations, and private psychological services through employment benefits.

Individuals were recruited purposively by phone across a range of demographic factors to ensure representation of PLWHF with respect to age, sex, ethnicity, place of birth, highest education received, place of residence, living arrangement, income in CAD $. Efforts were also made to recruit patients with varying levels of comfort using smartphones, acknowledging that recruiting from a smartphone-based telemonitoring program might result in participants who are inclined to access healthcare virtually. All clinicians in the Medly Program were invited to participate in the study by email, and subsequent clinicians and researchers were recruited via snowball sampling. All 13 PLWHF invited to participate enrolled in the study and no individuals refused to participate or withdrew from the study. Of the 10 clinician and researchers approached for the study, nine agreed to participate.

Dataset generation

One-on-one semi-structured interviews between 40 and 60 minutes were conducted in English by authour A.Shah, she/her, a PhD Candidate 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 had no prior relationship with participants, and participants were made aware of this researcher's role as study coordinator and student. One-on-one semi-structured interviews were chosen to allow for an in-depth exploration of individual experiences and to promote participant comfort, particularly for those who may find discussing mental health topics challenging. Due to safety restrictions brought by the COVID-19 pandemic, all interviews were conducted by phone, where the researcher called from a private space at home and participants called 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, I (A.Shah) became interested in the study topic after witnessing gaps in community mental healthcare, sparking my curiosity in using digital technologies as a potential interventional strategy. To understand how my experiences working with people living with mental illness and interests in digital health shaped the findings, I memoed throughout the research process and engaged in ongoing discussions with other research team members with varying clinical backgrounds.

Separate interview guides with open-ended questions for each of the participant types (PLWHF, clinician, and researcher) were developed. The interview guide for PLWHF inquired about the mental health impacts experienced by participants, current approaches to managing their mental health and associated challenges, experiences accessing mental health services, and needs related to mental health services. Clinician and researcher interviews inquired about the mental health needs of PLWHF based on their clinical or research experience, experiences referring patients to mental health services, current approaches and mental health services used to support this 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 have argued that this concept is incongruous with the assumptions of reflexive thematic analysis.[24] In alignment with Braun and Clarke's proposition of sampling as a pragmatic practice, 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 to 20 participants and *in situ* to end data collection at 23 participants.[24] This number of participants was determined by weighing the depth of data collected, the various demographic and experiential

factors represented, and pragmatic constraints of the project such as costs of transcription that limited further data collection.[24]

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. No repeat interviews were conducted. Field notes were also made by authour A.Shah both during and after each interview. Transcripts were not returned to participants for comments or corrections.

Data analysis

To allow for both data-based and theory-based meanings to be emphasized at different stages of the analysis, an inductive approach was initially adopted followed by deductive analysis. Two authors, A.Shah and A.Shahil, were involved in coding the data, to allow different perspectives to be brought to the data analysis process. A.Shah and A.Shahil first read the transcripts to familiarize themselves with the data andindependently coded the transcripts at the semantic and latent levels using NVivo 12 (QSR International) to manage and organize the data. At this stage, each coder created initial themes in an inductive manner and .met to present and discuss their initial themes. Where there were differences in the initial themes, the authors discussed why they saw a particular pattern in the data as important to the research question to understand how their distinct perspectives shaped different creations of themes. Following this step, both coders independently mapped their respective codes and themes to the domains of Levesque's framework and referenced the original data to ensure that the mapping aligned with the data excerpts for each code. In cases

where A.Shah and A.Shahil found the data to align more strongly with another domain, the mapping was adjusted accordingly. Once independent mapping of the themes was complete, both coders met once again to craft a final set of themes and mapping to Levesque's framework together, informed by their themes and mapping conducted in the previous phases.

Per Levesque, access is an opportunity for a perceived need for care to be met through reaching and obtaining health care services.[25] The framework outlines that access results from the interplay between supply- (i.e., health care system, services, and providers) and demand-side factors (i.e., persons, households, and social and physical environments). Factors on the supply side include the approachability, acceptability, availability and accommodation, affordability, and appropriateness of health care services. On the demand side, factors impacting access include the ability of patients and their support network to perceive a need for care as well as to seek, reach, pay, and engage with healthcare services.[25] Dimensions on each side of this framework represent potential facilitators or barriers to access to healthcare during an episode of care.[25] Table 1 displays the paired patient and health system constructs outlined by Levesque at each stage of accessing care, which include perceiving health needs and desire of care, seeking health care, reaching health care, using health care, and health care consequences.[25]

Among the various frameworks addressing access to care, Levesque's framework, which was developed based on a literature review of existing access to care frameworks, was selected for its comprehensiveness.[26,27] Specifically, the framework's consideration of factors at the patient (supply) and health system (demand) levels as well as the treatment of access as a process or journey, allowed for a holistic view on the construct in this research.[26]

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

Domain of Access (Health System)[25]	Definition[25]	Domain of Access (Patient)[25]	Definition[25]
1. Perceiving Health Needs & Desire for Care			
1a. Approachability	A person in need of health services can identify that service(s) exist, can be reached, and have an impact on their health.	**1b. Ability to perceive**	Determined by health literacy, knowledge about health, and beliefs related to health and sickness.
2. Seeking Health Care			
2a. Acceptability	Cultural and social factors that influence acceptance of aspects of the service (e.g., sex of providers) as well as the judged appropriateness of those seeking care (e.g., cultural beliefs).	**2b. Ability to seek**	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.
3. Reaching Health Care			
3a. Availability & accommodation	Health services, including both the physical space and the associated health care roles, can be reached in a	**3b. Ability to reach**	Individual mobility, transportation availability, occupational flexibility, and knowledge of health care

	timely manner. Involves the presence of sufficient health resources that can produce services.		services that allow one to physically access health care service.
4. Using Health Care			
4a. Affordability	Individuals' economic capacity to expend resources and time to use appropriate health care services (varies based on service type). Depends on the prices of services, opportunity costs of accessing care.	**4b. Ability to pay**	A capacity to generate economic resources through savings, income, or loans to pay for health care services without catastrophic expenditures of resources required for basic necessities.
5. Health Care Consequences			
5a. Appropriateness	Service fit with an individual needs, timeliness, amount of care placed in identifying correct treatments, and quality of services received both technically and interpersonally.	**5b. Ability to engage**	Individuals' participation and involvement in treatment decision-making, as determined by their capacity, motivation, and commitment to participate in care to its completion.

To strengthen the quality and trustworthiness of reflexive thematic analysis study findings, various measures were employed to promote thoughtful engagements with the data and analytic process.[28] Researchers repeatedly engaged with the raw data and had reflexive conversations among team members.[29] 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.[29] 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 (i.e., personal reflexivity), their disciplinary location (i.e., disciplinary reflexivity), and methodological choices (i.e., functional reflexivity).[30,31]

Results

In total, 22 participants were interviewed: 13 PLWHF and nine clinicians and researchers with experience in mental healthcare and/or heart failure. Participants living with heart failure were largely White (62%), urban-residing (46%), educated (61% with college, university, or postgraduate education), cohabitating with a family member (69%) (Table 2). The mean age of participants was 60.2 (*SD* = 20.8). Of the clinician participants, three were heart failure clinicians (e.g., nurse, cardiologist) and four were mental health professionals (e.g., psychologist, psychiatrist). The two researchers had expertise in heart failure. Given the number of participants interviewed, detailed characteristics of clinicians and researchers were not reported to prevent the risk of identifying individual participants. Interviews lasted an average of 46.7 minutes. A total of 14 themes (Table 3) were generated that were mapped to the access to care domains outlined by Levesque.[25]

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

Characteristic	n (%)
Age	
21-30	2 (15)
31-40	1 (8)
41-50	0 (0)
51-60	2 (15)
61-70	4 (31)
71-80	2 (15)
81-90	2 (15)
Sex	
Male	7 (54)
Female	6 (46)
Ethnicity	
White (Caucasian)	8 (62)
Black	1 (8)
Filipino	1 (8)
South Asian	1 (8)
Chinese	1 (8)
Arab/West Asian	1 (8)
Place of birth	
Canada	8 (62)

Other	5 (38)
Highest education achieved	
High school	3 (23)
Trade or technical training	2 (15)
College or university	5 (38)
Postgraduate	3 (23)
Place of residence	
Urban	6 (46)
Suburban	4 (31)
Rural	2 (15)
Not declared	1 (8)
Living arrangement)	
Living with family/partner	9 (69)
Living alone	3 (23)
Living with friend(s) and/or roommate(s)	1 (8)
Income in CAN $	
< 15,000	1 (8)
$15,000-$49,999	3 (23)
$50,000-$74,999	7 (54)
>75,000	1 (8)
Not declared	1 (8)

Table 3. Summary of Generated Themes.

Levesque's Stage in Episode of Care	Levesque's Characteristic of Health System	Theme Produced from Thematic Analysis	Levesque's Characteristic of Patient	Theme Produced from Thematic Analysis
Perceiving Health Needs & Desire for Care	*Approachability*	Difficulties detecting mental health concerns	*Ability to perceive*	Mental health literacy
		Unpreparedness for referral conversations		Denial, stoicism, and self-reliant coping methods
				Attribution of causality
Seeking Health Care	*Acceptability*	-	*Ability to seek*	Stigma surrounding mental healthcare
Reaching Health Care	*Availability & accommodation*	Limited types of mental health services available	*Ability to reach*	Inconvenience of in-person delivery
		Inconsistent pathways to mental health services		
		Poorly timed mental health services		
Using Health Care	*Affordability*	Limited human resources due to	*Ability to pay*	Lack of full insurance coverage and high cost of psychological services

		underinsurance of mental healthcare		
Health Care Consequences	*Appropriateness*	Underresourced system does not allow for choice or finding fit	*Ability to engage*	-
		Insufficiency of generic mental health services		

Health system factors

Approachability

Difficulties detecting mental health concerns

Recognizing the high prevalence of mental health concerns among PLWHF, clinicians expressed hesitancy with detecting 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 fluctuations in mood could risk overtreating mental health deteriorations that may resolve on their own. As overtreatment could lead to unnecessary use of scarce mental health services, 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…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 PLWHF. Difficulties 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 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 of readings, change in physical health readings).

> "…the Medly nurse coordinator is in tune with the patient. Like they know that this person is calling a lot. This person is not putting in their weights. This person's weight is off a lot…Sometimes the cue is that the patient's not recording...Not something that they've said, but the fact that they're not recording in telemonitoring might tell us "oh why aren't they recording?"" [Clinician 3]

Unpreparedness for referral conversations

Nurses explained that their long-term relationships with patients through telemonitoring not only helped indirectly identify potential mental health concerns but also offered opportunities to normalize mental health impacts as a common consequence of living with heart failure. Despite this, nurses expressed discomfort with referring PLWHF 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 PLWHF to a mental health program.

> "...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…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 heart failure 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 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 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, PLWHF felt frustrated being referred to mental health services, 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 dismissive.

> "I just didn't feel that I needed to go there. 10 years ago, seeing doctors, they would look at me going "I don't think you have a problem [with your heart], and when it gets worse, give me a call. I think it's just anxiety". So, I've been living that my whole life, saying it's panic attacks, its 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....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"—like I'm fine. I'm fine." [PLWHF 1]

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, PLWHF highlighted the few opportunities to access peer support through their heart failure 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 PLWHF 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 almost always involve patients 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

PLWHF who reported having been referred to a mental health service in the past reported highly variable care pathways and experiences. Some PLWHF 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 PLWHF and the quality of relationship they had with their primary care physician. As a resident of a rural community, one PLWHF 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, 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]." [PLWHF 5]

Poorly timed mental health services

Inconsistencies not only arose in how PLWHF were connected with mental health services, but also in the timeliness of care delivered. Through experiencing waitlist-related delays in receiving mental health services, PLWHF 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, PLWHF emphasized the importance of mental health support during acute deteriorations in their health.

> "...you don't know if the person will be able to talk to you within the time period that you need them to.... 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 heart failure-related." [PLWHF 6]

The delays in accessing mental health services often meant that PLWHF received care only after acute deteriorations in their health had improved. This lag in mental health care was perceived by PLWHF as a missed opportunity for clinicians to recognize the connection between their mental health status and heart failure.

Affordability

Limited human resources due to underinsurance of mental healthcare

While all participants recognized the value of mental health services, there was also broad recognition that the healthcare system was not appropriately resourced with mental health professionals to meet the range of mental health needs among PLWHF. This was attributed to the underinsurance of mental healthcare in Canada, which largely relies upon psychiatric services as publicly funded mental healthcare. 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 PLWHF, one cardiologist highlighted the lack of human resources as a central barrier.

> "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]

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. PLWHF 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 or 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.” [PLWHF 8]

The approach to mental healthcare adopted by clinicians was also an important factor dictating the appropriateness of mental health services. PLWHF discussed the importance of having clinicians of different demographics involved in their mental healthcare who were flexible and offered them an option to disengage from treatment if desired. This was especially important for PLWHF who had poor experiences with mental healthcare in the past. For instance, one individual living with heart failure 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. …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." [PLWHF 5]

Insufficiency of generic mental health supports

Once accessed, some mental health services were found to be inadequate in addressing the needs of PLWHF, as they failed to understand the nuances of their condition and did not communicate with their heart failure care team. PLWHF recounted finding community mental health services that were generic (not tailored to their heart failure) insufficient, as they detracted from the opportunity to receive holistic care, where heart failure clinicians could take possible mental health

impacts on their physical health into account. One interviewee living with heart failure 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 and said "Can you refer me to someone?"...I reached out sort of immediately and it was to the wrong person." [PLWHF 3]

Patient factors

Ability to perceive

Mental health literacy

From the perspective of PLWHF, the ability to perceive one's own mental health impacts was a central factor impacting access to mental healthcare. However, PLWHF 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?" [PLWHF 2]

Some PLWHF noted that their understanding and perceptions of mental health and mental healthcare 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…[the psychiatrist] knew my childhood and when they 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…we never discussed it…not to the depth that maybe we needed to." [PLWHF 1]"

When patients had limited knowledge about mental health, mental health professionals (e.g., difference between a psychologist and psychiatrist), and attitudes viewing mental health issues as a personal weakness, clinicians struggled to address the mental health impacts of their patients' conditions and provide appropriate 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". [Clinician 4]

In instances where PLWHF were unable to recognize their mental health symptoms, clinicians found it difficult to discuss potential mental health interventions to support their patients.

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 heart failure. PLWHF reported using coping methods such as denial and stoicism to cope with the mental health impacts of their heart failure. Stoicism, as framed by PLWHF, involved not recognizing or engaging with their feelings in order to live with their illness. This coping method presented barriers to accessing mental healthcare 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." [PLWHF 3]

Attribution of causality

Individual beliefs about the cause of their mental health concerns further impacted the ability of PLWHF to perceive their mental health needs and be ready to access mental health services. PLWHF 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" [PLWHF 4]

Ability to seek

Stigma surrounding mental healthcare

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 PLWHF 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 healthcare 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"…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]

Ability to reach

Inconvenience of in-person delivery

As individuals enrolled in the Medly Program resided in diverse regions, PLWHF emphasized the importance of having options to access mental health services remotely. PLWHF 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 PLWHF 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." [PLWHF7]

Ability to pay

Lack of full insurance coverage and high cost of psychological services

An outcome of the underinsurance of mental healthcare was that access to some mental health services that PLWHF 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, PLWHF 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 PLWHF 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.

"Psychologists are very expensive. If you don't have connections to get yourself into a psychiatrist so you don't have to pay, you can be left out very easily." [PLWHF 8]

Discussion

Research has observed underutilization of mental health services among PLWHF even when routine depression screening and referral processes are present, suggesting that this population may face distinct barriers to accessing mental healthcare.[14–16] Drawing upon data from semi-structured interviews with PLWHF, clinicians, and researchers, this qualitative study investigates this gap further in its theoretically informed analysis of the factors impacting access to mental health care for PLWHF. Findings of this research shed light on the complex and multifaceted barriers that PLWHF face at both the health system and patient levels.

Health system barriers

Previous studies have neglected consideration of the factors at the health system level, often focusing on barriers of awareness at the patient level.[18] Our exploration reveals substantial barriers at the health system level, specifically with the approachability, availability, and appropriateness of the health system. Access was impeded by healthcare providers' concerns of "opening the floodgates", identifying too many patients with distress that the underinsured mental health care system was not equipped to support. This apprehension was not only rooted in concern for system capacity but also fear of overtreatment when distress may resolve independently. As such, this study highlights that underinsurance of mental health services not only presented an affordability barrier for PLWHF, but it also had upstream impacts on the approachability of the health system.

The approachability of the health system was further hindered by clinicians' substantial difficulties detecting mental health concerns, owing to patient complexity from bidirectional interactions between mental and physical health symptoms, especially when no structured and formal screening methods were available. Although this study validates the finding from previous research that mental health screening next to an initial diagnosis or hospitalization may not be ideal, participants in this study offered further guidance on specific points where screening was thought to be most helpful.[18] PLWHF found screening to be most valuable during acute health events post-diagnosis, which could facilitate reflection on the impact of their heart failure on their mental health to promote awareness that could benefit both the individual's motivation to seek mental health services and their care team. Further research is needed to personalize the timing of screening and subsequent follow up for PLWHF in different stages of their journey (e.g., beginning, post-diagnosis without acute health events, post-diagnosis with acute health events).

As reported by other scholars[18,32–34], clinicians reported a lack of knowledge and self-efficacy to engage their patients in effective referral conversations. While previous research suggests using less medicalized language like "learning to cope" to connect with patients[18], clinicians in this study found that such language can unintentionally hinder accurate communication and reinforce stigma. These findings complicate the existing literature on patient-centered communication for PLWHF, highlighting the need for further research on effective language and its impact on patient understanding and engagement.

Pathways to mental health services were highly variable, siloed from heart failure care, and of limited availability, especially for those who were unready for psychiatric care or whose mental health concerns were not severe enough to warrant such care. As studies have reported low

acceptability of formal mental health services among PLWHF, our study outlines key considerations to promote the acceptability of mental health services for PLWHF.[18,35] PLWHF in this study expressed the desire for peer support. Peer support may not only serve as a treatment option but also, per the hypothesis of Collopy et al., may serve to normalize psychological distress, improve mental health awareness, reduce stigma, and promote positive attitudes towards formal help-seeking via information provision and exposure to peers who have sought mental health services.[18] Additionally, a new finding from this research was that PLWHF who accessed mental health services reported dissatisfaction with generic mental health services (untailored to heart failure) as they perceived these services to be ill-equipped to address their mental health challenges resulting from their heart failure journey. Taken together, these findings suggest that peer support and interventions tailored to the experiences of heart failure may be valuable components of mental health services for PLWHF.

Patient barriers

On the patient side, the ability of PLWHF to perceive their mental health needs was a substantial barrier to access, including a lack of information between heart failure and mental health, limited general mental health literacy, lack of identification with clinical mental health terms, seeing mental health care as unnecessary, use of stoicism and denial coping strategies, and difficulties expressing one's feelings.[18,35,36] While many of these factors aligned with the existing literature, this study highlighted a factor not yet reflected in the literature: patients' perceptions of the cause of their mental health issues. Those who attributed their mental health challenges to their experience of heart failure were more open to referral, whereas those who saw it as unrelated required further discussion to pursue mental health services.

Similar to previous research, stigma associated with mental illness and psychiatric medication as well as social desirability was found to affect PLWHF's ability to seek care.[36] Cabassa et al. posit that such attitudes may be flexible should clinicians proactively address concerns, fears, and misconceptions.[37] This may suggest that proactive destigmatizing initiatives could be beneficial as part of upstream health promotion efforts for PLWHF, as well as a destigmatizing approach by the clinician at the time of referral to mental health services.[38]

Several studies, including this study, have found that PLWHF face practical barriers to accessing mental health services, such as mobility challenges, financial barriers associated with travel, difficulty attending to appointments in person, issues juggling multiple health appointments, and challenges acting on a referral due to exacerbations with their chronic condition.[18,35] Once patients decided to seek mental health care, financial barriers and limited insurance coverage affected their ability to pay for mental health services, especially when seeking psychological care.[17,18] Although the expansion of publicly funded mental health services is an important step, this research and others highlight that it is unlikely to resolve all barriers faced by PLWHF, as evidenced by underutilization of such services in contexts where they are publicly available.[16] Nevertheless, the underinsurance of non-psychiatric mental health services remains a crucial constraint for both clinicians and health service planners.

Summary of recommendations for research and practice

Based on the multifaceted barriers identified at both the health system and patient levels, complex interventions integrating multiple components are needed to address the barriers identified in this

study.[39] In developing and evaluating these interventions, researchers and practitioners should consider the following recommendations:

1. Develop tools to support PLWHF and clinicians in detecting and perceiving mental health concerns and untangle the complex and bidirectional relationship between mental and physical health.

2. Deliver mental health literacy education to improve patients' ability to perceive their mental health needs and incorporate proactive destigmatization efforts for PLWHF to encourage earlier help-seeking.

3. Train heart failure clinicians to improve their self-efficacy in providing effective referrals to mental health services.

4. Investigate person-centred language to discuss mental health with PLWHF in an accurate yet destigmatizing manner.

5. Expand mental health services to encompass peer support interventions.

6. Improve access to publicly funded psychotherapy, and consider scalable delivery methods such as digital mental health technologies, which could reduce costs and logistical barriers (e.g., travel). As participants were recruited from a remote management program when COVID-19 physical distancing measures made virtual care a primary option for healthcare

access, this recommendation may be most transferable to settings where virtual care continues to play a large role.

Strengths and limitations

Strengths of this study include its dual focus on both health system and patient perspectives, its use of a theoretical framework, and its identification of new barriers—particularly at the healthcare provider level—that complicate current understanding of mental health care access for PLWHF. Despite these strengths, the study findings should be interpreted in light of the following limitations. Foremost, semi-structured interviews were conducted during the early stages of the 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 (e.g., 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 all participants were recruited from an urban academic hospital. Themes therefore may not adequately articulate the barriers to mental healthcare experienced by PLWHF who are of diverse ethnicities, non-English-speaking, residing in rural regions, or with limited education as well as clinicians and researchers working with such populations. For example, no themes related to the acceptability of mental healthcare services were produced in this study, which may be attributed to the demographics of the participants interviewed. Given documented social and cultural dimensions influencing help-seeking behaviors and treatment experiences among racialized populations living with chronic conditions, further research with more diverse populations is necessary to identify factors affecting mental health service acceptability in these communities.[37,38] Finally, although several participants reported

experiences of seeking mental healthcare, only two PLWHF 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.[40] Further investigations of the factors impacting access to mental health services for PLWHF who are disconnected from health care services and/or experience social vulnerability are needed.[40]

Conclusion

This qualitative study sought to understand the factors impacting access to mental health care for PLWHF in Ontario, Canada. An analysis of both the patient and health system perspectives offers a nuanced and holistic view, suggesting 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 PLWHF. 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 PLWHF, namely in improving the approachability, availability, and appropriateness of care, as well as enhancing the of ability PLWHF 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 healthcare for the growing population living with heart failure.

Data availability statement

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

Ethic statements

Patient consent for publication

Not applicable.

Ethics approval

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.

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Author 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, including input from R.Nolan, a clinical psychologist, G.Strudwick, a nurse, and S.Sockalingam, a psychiatrist, all of whom strengthened the consideration of clinician perspectives. 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. A.Shah is the guarantor of the study.

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Competing interests

The authors declare no competing interests.

PLHF Interview Guide

Introduction

1. Could you tell me about the conditions that you live with?

2. Can you tell me a little bit about what your health journey has been like since you have been diagnosed with heart failure?

3. From your perspective, what does it mean to have good mental health when living with heart failure? What role do you think you play in this, if any?

Perception of Care Needs

4. How has your journey with heart failure impacted your mental health? For example, are there times that you have felt stressed, or where it has impacted your emotions, behaviour, or relationships with others?
    a. During these times, what helped you know that your mental health was affected?

Ability to Seek Care

5. How do you generally manage your mental health, if at all?

6. Who have you talked to about your mental health, if anyone? (professional or informal)
    a. Have you ever talked with a healthcare provider about your mental health?

7. Are there any mental health services or support you are aware of? How did you come to learn about them?

8. What role has your heart failure clinicians played in helping you find mental health care services?
    a. If they have not played a role, what role would you have wanted them to play in helping you find mental health services?

Ability to Reach Care

9. If you have accessed mental health services, what has been your experience trying to access mental health care services?
    a. What was your experience like…
        i. Traveling to the service?
        ii. Location/format of these services?
        iii. Booking an appointment (if applicable)? Once you booked an appointment, how long did it take for you to connect with a mental health professional (if applicable)?
        iv. Hours of operation/support of the service?

Ability to Pay for Care

10. Were there any financial costs involved in any of the mental health services you accessed? If so, how did this affect your journey of seeking mental health care?

Ability to Engage with Care

11. What has been the quality of care you received from mental health professionals?

12. Do you feel your mental health needs were met through this care? If not, what do you feel was missing to improve your experience?

Closing

13. Is there anything else you would like to share about your journey with your mental health when living with heart failure that we haven't touched upon today?

Clinician Interview Guide

Introduction

1. From your perspective, what does it mean for people to have good mental health when living with heart failure? What role do you think you play in this, if any?

2. What are some of the common impacts of heart failure on mental health that you are aware of based on your clinical practice?
    a. While each patient's journey with heart failure may be different, are there specific stages or events in an individual's health journey that you notice mental health is often affected?

Approachability

3. How do you typically identify when a Medly patient's mental health has been negatively affected? For example, do you conduct any screening, formally or informally? Where, when, by who, and what is this information used for?
    a. Can you recall an example of when a patient discussed their mental health with you? How do these conversations typically go?

Acceptability

4. What approaches, formal or informal, do people living with heart failure use to manage their mental health, based on your clinical practice?
    a. What role do you play in this, if any?

5. If you suspected that a Medly patient's mental health has been negatively affected, what are the current approaches to managing this?
    a. Have you referred patients to mental health services? If so, which ones? If not, what are some of the contributing factors to this?
        i. Can you recall any particular examples where you referred a Medly patient to a mental health service? How do these conversations typically unfold?
        What do you find helpful or challenging about these conversations or processes?

Availability & Accomodation

6. Can you describe the booking process for Medly patients to access mental health services?
    a. From your perspective/understanding how accessible is it for patients to make appointments (if applicable), and how long does it typically take for them to connect with a mental health professional once an appointment is booked?
    b. Based on your clinical practice, are there specific aspects of the mental health services you refer to that help or hinder access to these services. For example, what are your thoughts on their location, format, and hours of operation, etc.?
    c. Can you recall any examples of Medly patients accessing mental health services and what their experience was like?

Affordability

7. How affordable do you believe mental health services are to Medly patients?

Appropriateness

8. From your perspective, what constitutes quality mental health services for people living with heart failure? To what degree do you feel these elements are present or not present in the mental health care available to patients in the Medly program?
    a. Can you describe an example of when a patient received high or low quality mental health care?

9. Do you feel that patients in the Medly program are having their mental health needs met? If not, what improvements do you see are needed?

Closing

10. Is there anything else you would like to share about your observations or experiences supporting the mental health impacts people living with heart failure face, and their journey accessing mental health services?

Researcher Interview Guide

Introduction

1. From your perspective, what does it mean for people to have good mental health when living with heart failure? What role do you think you play in this, if any?

2. What are some of the common impacts of heart failure on mental health that you are aware of, based on your research?
    a. While each patient's journey with heart failure may be different, are there specific stages or events in an individual's health journey where mental health is often affected?

Approachability

3. What are some common or best practices to identify when a patient living with heart failure is experiencing negative impacts on their mental health? Ideally, how should these conversations typically go?

Acceptability

4. What approaches, formal or informal, do people living with heart failure use to manage their mental health, based on your research?
    a. From your perspective, what role do clinicians play in this, if any?

5. If a clinician suspected that a Medly patient's mental health has been negatively affected, what are the current approaches to managing this?

Availability & Accomodation

6. Can you describe the booking process for Medly patients to access mental health services?
    a. From your understanding how accessible is it for patients to make appointments (if applicable), and how long does it typically take for them to connect with a mental health professional once an appointment is booked?
    b. Based on your research, are there specific aspects of the mental health services you refer to that help or hinder access to these services. For example, what are your thoughts on their location, format, and hours of operation, etc.?

Affordability

7. How affordable do you believe mental health services are to Medly patients?

Appropriateness

8. From your perspective, what constitutes quality mental health services for people living with heart failure? To what degree do you feel these elements are present or not present in the mental health care available to patients in the Medly program?

Closing

9. Is there anything else you would like to share about your observations or experiences researching the mental health impacts people living with heart failure face, and their journey accessing mental health services?