“Now, at least, I have a direction”

A qualitative study examining the service-related needs of young people identified as having a clinical high-risk state for psychosis

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Contribution of Authors

As first author of this thesis, I (**Sarah McIlwaine**) made a significant contribution to the conceptualization, design, implementation (e.g. data collection), data analysis, interpretation of results, and writing of this thesis.

Dr. Manuela Ferrari made a significant contribution to the conceptualization, design, interpretation of results, and revisions of this thesis.

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Dr. Ian Gold contributed significantly to the conceptualization, design, and revision of this thesis.

Dr. Ashok Malla provided overall supervision and contributed significantly to the conceptualization and revision of this thesis.

Dr. Jai Shah provided overall supervision and guidance on the conceptualization, design, interpretation of the results, and revisions of this thesis.

Abstract

Background: Schizophrenia and related psychosis are debilitating conditions that emerge primarily in young adulthood. Given the negative impact schizophrenia can have on individual, family, and systemic levels, research and clinical work has aimed to identify those at clinical high risk for psychosis (CHR) and then intervene prior to the development of psychosis. Although the utility of the CHR criteria in predicting psychosis onset has been recently questioned, individuals at CHR are help-seeking and in need of care. To respond to this need CHR services have thus emerged in North America, the United Kingdom, and Europe. However, guidelines for CHR services, as well as much of the current research on this topic, focus on the assumption that needs are necessarily tied to specific symptoms or diagnoses. Indeed, there is a clear paucity of studies directly examining service-related needs from the lived experience of service users at CHR. **Objectives:** This Master's thesis thus challenges the implicit assumption in the field and addresses our current knowledge gap by addressing the following questions: 1) What are the service-related needs of young people receiving CHR-specific services?; and 2) How were these service-related needs shaped by users' subjective experience and understanding of their symptoms, and their past and current experiences with mental health care? **Methods:** A qualitative descriptive approach was used to examine service-related needs in youth at CHR. Specifically, 11 participants currently receiving CHR services were recruited for this study. Interviews were transcribed verbatim and coded using thematic analysis. **Results:** Participants described their mental health problems as an eclectic mix of various symptoms that produced significant barriers and changes to their everyday lives. These barriers and changes drove participants to seek out care. Their experiences with past mental health services set the foundation for their expectations once they arrived at the CHR service, where they then identified aspects of the service that were useful, or not useful to them. Stemming from these experiences, participants described symptom-based needs, needs related to understanding their mental health problems, and specific service/resource needs. **Discussion:** Overall, the stories expressed by participants challenge the implicit assumption that service-related needs are tied to the risk of psychosis onset, or specific symptoms or diagnoses. Moreover, the confusion regarding the CHR label and its diagnosis mirrors the ongoing debates in the field about the utility of the CHR diagnosis and its associated services. Importantly, this thesis highlights the importance of the co-construction and context-dependence of needs, and advocates for the continued exploration of the subjective experience of mental health needs in youth at CHR.

Résumé

Contexte: La schizophrénie et les psychoses connexes sont des troubles débilitantes qui se manifestent principalement chez les jeunes adultes. Compte tenu de l'impact négatif que la schizophrénie peut avoir sur les individus, la famille et le système, la recherche et les travaux cliniques visent à identifier les personnes à haut risque clinique pour la psychose (HRC) et d'intervenir avant l'apparition de la psychose. Malgré que l’utilité des critères de la CHR pour prédire l’apparition d’une psychose ait été récemment mise en doute, les jeunes à HRC recherchent de l’aide et ont besoin de soins. Pour répondre à ce besoin, des services pour HRC ont ainsi émergé en Amérique du Nord, au Royaume-Uni et en Europe. Cependant, les cadres de référence pour les services HRC, ainsi qu'une grande partie de la recherche actuelle sur ce sujet, se concentrent sur la supposition que les besoins sont nécessairement liés à des symptômes ou diagnostics précises. En effet, il existe très peu d'études portant sur les besoins liés aux services dérivés des expériences vécue par les utilisateurs des services HRC elle-même. **Objectifs:** Cette thèse de maîtrise remet donc en cause l’hypothèse implicite de ce sujet et aborde notre lacune actuelle de connaissances en répondant aux questions suivantes: 1) Quels sont les besoins des jeunes bénéficiant de services spécifiques aux HRC? et 2) Comment que ces besoins liés aux services ont-ils été façonnés par l’expérience subjective des utilisateurs, en tant que leur compréhension de leurs symptômes et leurs expériences passées et actuelles de soins de santé mentale? **Méthodes:** Une approche descriptive qualitative a été utilisée pour examiner les besoins liés aux services chez les jeunes à HRC. Plus précisément, 11 participants recevant actuellement des services de HRC ont été recrutés pour cette étude. Les entrevus ont été transcrits intégralement et codés à l'aide d'une analyse thématique. **Résultats:** Les participants ont décrit leurs problèmes de santé mentale comme un mélange éclectique de divers symptômes qui ont créé des obstacles et des changements importants dans leur vie quotidienne. Ces obstacles et ces changements ont poussé les participants à rechercher des soins. Leurs expériences avec les services passés ont établi la base de leurs attentes une fois arrivés au service HRC, où ils ont ensuite identifié les aspects du service utiles ou pas utiles. À partir de ces expériences, les participants ont décrit les besoins fondés sur les symptômes, les besoins liés à la compréhension de leurs problèmes de santé mentale et les besoins spécifiques liés aux services / ressources. **Discussion:** Dans l'ensemble, les récits exprimés par les participants remettent en cause l'hypothèse implicite selon laquelle les besoins liés au service sont liés au risque d'apparition d'une psychose, ou à des symptômes ou diagnostics précises. En outre, la confusion concernant l'étiquette HRC et son diagnostic reflète les débats en cours sur le sujet concernant l'utilité du diagnostic HRC et des services associés. Il est important de noter que cette thèse souligne l'importance de la co-construction et de la dépendance des besoins en fonction du contexte et plaide pour une exploration continue de l'expérience subjective des besoins en santé mentale chez les jeunes à HRC.

Chapter 1- Thesis introduction: Literature review and objectives

Schizophrenia and related psychoses are debilitating conditions that emerge primarily in adolescence or young adulthood. Individuals who experience a psychosis also manifest a range of vocational and social difficulties, have comorbid diagnoses, lower quality of life, and high rates of suicide [1]. Schizophrenia is estimated to account for 1.7% of years of life lived with disability globally, despite its low point prevalence (0.28%), and accounts for an estimated two billion dollars per year of Canadian direct healthcare expenditures [2]. In Montreal, the annual incidence of schizophrenia spectrum disorders is 82.9 per 100 000 males, and 32.2 per 100 000 females [3].

Given its overall impact at individual, familial, and systemic levels, decades of research and clinical work has aimed to identify those at risk for psychosis in order to be able to intervene prior to its development. Early efforts proposed the "critical period hypothesis", which maintains that providing intervention soon after symptom onset can disproportionately improve long-term outcomes compared to interventions that are provided during the later years, thus presenting a strong justification for improving clinical and functional trajectories [4,5].

1.1 From prepsychotic schizophrenia to clinical high risk and the definitions in between

Schizophrenia and related psychosis are largely believed to follow a developmental progression beginning with a premorbid stage (where individuals present with some basic or cognitive symptoms and functional difficulties, but no identifiable psychotic symptoms); followed by an "ultra" or clinical high-risk syndrome (CHR) consisting of sub-threshold symptoms combined with impairment; and then a threshold-level first episode of psychosis (FEP) [6]. In the wake of Birchwood's critical period hypothesis, early interventions for psychosis initially focussed on the

FEP as a key point where intensive clinical intervention was required [7]. However, the last two decades have witnessed an extension of the early intervention paradigm into prevention, via examining and intervening during the CHR stage of psychosis.

The concept of the “schizophrenia prodrome” initially laid the foundation of the later defined CHR syndrome: prodrome, by definition, refers to the early signs and symptoms that precede the onset of a threshold disorder, and is thus retrospectively defined [8-11].

From this early work on the schizophrenia prodrome, Yung and colleagues later created the first CHR-specific service in Australia, moving research in this domain from retrospectively to prospectively identifying the putative schizophrenia prodrome. Using a “closed-in” strategy and the DSM-III-R’s prodromal schizophrenia criteria, they proposed and tested an operationalization of “prepsychotic schizophrenia”. Three diagnostic criteria believed to increase an individual’s chance of developing psychosis were created:

1) The presence of subthreshold or attenuated psychotic symptoms (APS).
2) Transient psychotic episodes referred to as Brief (or Limited) Intermittent Psychotic Syndrome (BLIPS).
3) The presence of trait and state risk factors, including a first degree relative with psychosis and a 30% deterioration in global functioning (GRD).

Later, this group and others further refined the CHR categories by developing the first CHR diagnostic screening assessments: The Comprehensive Assessment of At-Risk Mental States (CAARMS) [12] and the Structured Interview for Psychosis-Risk Syndromes (SIPS) [13], both of which are now widely used.

The CHR diagnostic categories have historically shown strong predictive validity. For example, the initial 1996 study found that approximately 40% of those meeting the schizophrenia prodrome via the DSM-III-R developed schizophrenia within a 20-month period [14]. Following the development and utilization of the CAARMS, Yung et al.'s subsequent report similarly found that approximately 40% of individuals who scored positively for CHR on the CAARMS and the psychotic and delusional conviction subscales of the Brief Psychotic Rating Scale and Comprehensive Assessment of Symptoms and History scale (respectively) transitioned to psychosis over a 6-month and 12-month period [15].

However, the CHR criteria present a few issues. First, those meeting CHR criteria based on the CAARMS or SIPS alone do not typically develop psychosis later on (e.g. [12,16]). Moreover, even within the CHR criteria, variation exists in the predictive validity of each sub-syndrome (e.g.[17-20]). Nonetheless, the need for care in this group is demonstrated by their developing non-psychotic diagnoses (e.g. depression, anxiety or substance use disorders) [21], and/or experiencing high levels of distress [22].

1.2 Service-related needs

1.2.1 CHR services and their guidelines

CHR initiatives, services, and guidelines have been created to describe the CHR state and address service-related needs of this group. For example, the North American Prodrome Longitudinal Study (NAPLS) in the United States consists of a consortium of eight research programs. The project aims to bring together CHR datasets to determine predictors of psychosis longitudinally (NAPLS 1 study), and to describe prodromal symptoms and their change over time (NAPLS 2 study) [23].

Prior to these large-scale research projects, and in recognition of the fact that youth at CHR are help-seeking in their own right, CHR-specific clinics and interventions emerged, beginning in Australia in 1996 (Personal Assessment and Crisis Evaluation [PACE] clinic [24]); followed by the United Kingdom and Europe (e.g. Outreach and Support in South London [OASIS] [25]); and Canada (e.g. Clinic for the Assessment of Youth At Risk [CAYR] [26]; Focus on Youth Psychosis Prevention [FYPP] [27]; Prevention through Risk Identification, Management and Education [PRIME] [28]). CHR infrastructures that are organized around clinical services are generally closely linked to FEP early intervention services. Therefore, CHR services typically include: monitoring of subthreshold psychotic symptoms via follow-up assessments; outreach initiatives to improve access to specialized services; provision of as-needed case management and medication; and psychoeducation for service users and their caregivers [29,30]. For example, one catchment-based CHR service in Montreal focuses on treating current distress in youth through monitoring via follow-up assessments, as-needed case management and medication, with psychotherapy techniques employed on a case-by-case basis [26]. Similar approaches are used elsewhere (e.g. [24,25]).

Guidelines and recommendations for CHR services allude to the fact that this population has specific service-related needs. For example, Canadian guidelines [31] recommend individual cognitive behavioural therapy (CBT) with or without family intervention; interventions for comorbid disorders (e.g. depression and anxiety); interventions to prevent the persistence of social and occupational difficulties; pharmacological interventions to be used in conjunction with CBT to prevent the onset of a FEP; and monitoring of symptoms (particularly when the CHR syndrome persists) by a psychiatrist, psychologist, or trained CHR specialist [31]. Moreover, a review of early interventions and treatment approaches for CHR recommends therapeutic engagement, assessment and monitoring of symptoms and safety concerns, CBT for CHR, treatment of comorbid problems, social skills training, family interventions, supported education/employment, and a focus on healthy lifestyle (e.g. nutrition, physical activity, sleep, etc) [32]. However, given that these guidelines are either embedded in or based on early intervention for psychosis guidelines (e.g. the EPA [33] and Canadian guidelines [31]), some of the service-related needs may have been identified primarily based on the stated goal of preventing psychosis onset (reducing incidence) rather than treating current service needs (reducing prevalence). Furthermore, the recommendations from these guidelines were not necessarily drawn from the lived experience of service users themselves, and thus may not fully appreciate or account for the actual scope of service-related needs in this group.

1.2.2 Experience of help-seeking and accessing CHR services

Quantitative and qualitative studies have now begun to examine help-seeking and access to care in CHR populations. For example, CHR services present particular barriers that can render help-seeking difficult in young people. Specifically, self-stigma and public stigma were reported by young people at CHR as barriers to help-seeking and accessing care [34,35]. Moreover, the young person's emotional response can either pose barriers to or facilitate engagement with CHR services, with shame, fear, and confusion cited as problematic emotions related to accessing care [35]. Barriers were also related to the physical environment (e.g. lack of access), as well as the kind of services received [35]. Although informative, these studies did not examine how such barriers can affect the kind of services needed.

1.2.3 What is known and unknown about service-related needs

Current research further hints at the service-related needs of youth at CHR for psychosis. For example, depression and anxiety are highly prevalent in this population [36,37], and are the primary complaint when youth at CHR seek help [37]. In 78.1% of one CHR sample, difficulties with social and occupational functioning were a stronger source of distress compared to subthreshold psychotic symptoms [38]. In terms of subjective experiences with CHR services, service users have reported concerns regarding finding future employment, living accommodations, and their mental illness returning [38]. A CHR sample also expressed feeling broken, abnormal, having difficulties maintaining relationships, and poor expectations about their futures [39]. In a study examining participants' understanding and experience of the CHR state, participants expressed wanting to know more about their diagnosis, were concerned about how others would perceive their CHR diagnosis, and highlighted the importance of sharing their problems in a safe environment [40]. Moreover, social and family problems were additional important areas for intervention [41]. Although these studies provided some indication of useful intervention targets, none directly examined service-related needs from the service user's perspective. Therefore, this Master's thesis employed a qualitative approach to directly examine the service-related needs of young people who were receiving CHR services, while taking into consideration how these needs were shaped by their subjective experience and understanding of their symptoms, and their past and current experiences with mental health care.

1.3 Research questions and objectives

The objective of this thesis is to further our current understanding of the experience of help-seeking and care in young people at CHR, and to describe what such youth perceive as their service-related needs. As such, the manuscript of this thesis (Chapter 2) addresses the following questions:

1) What are the service-related needs of young people receiving CHR-specific services?
2) How were these service-related needs shaped by users’ subjective experience and understanding of their symptoms, and their past and current experiences with mental health care?

1.4 References

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Chapter 2- Thesis manuscript

Title: What are the service-related needs of young people identified as clinical high risk for psychosis?

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2.1 Abstract

Background: Schizophrenia and related psychosis are debilitating conditions that emerge primarily in young adulthood. Given its negative impact on individual, family, and systemic levels, research and clinical work has aimed to identify those at clinical high risk for psychosis (CHR) and then intervene prior to the development of psychosis. CHR services are currently in place, but guidelines for such services, as well as much of the current research on this topic, focus on the assumption that needs are necessarily tied to CHR-specific symptoms or diagnoses. However, there is very little work examining the lived experience of mental health care need in this group. Therefore, the purpose of this study was to explore the subjective service-related needs of CHR service users, and how these needs might be shaped by their understanding of their mental health problems and their experiences with mental health services. **Methods:** A qualitative descriptive approach was used. Specifically, 11 participants currently receiving CHR services were recruited for this study. Interviews were transcribed verbatim and coded using thematic analysis. **Results:** Participants described their mental health problems as an eclectic mix of various symptoms that produced significant barriers and changes to their everyday lives. These barriers and changes drove participants to seek out services. Their experiences with past services set the foundation for their expectations once they arrived at the CHR service, where they then identified aspects of the service that were useful, or not useful to them. Stemming from these experiences, participants described symptom-based needs, needs related to understanding their mental health problems, and specific service/resource needs. **Discussion:** Overall, the stories expressed by participants challenge the implicit assumption that service-related needs are tied to the risk of psychosis onset, or specific symptoms or diagnoses. Indeed, CHR-specific symptoms did not always appear to be participants' highest priority in terms of their service-

related needs. Continued research regarding the subjective experiences of youth at CHR for psychosis can enrich our understanding of help-seeking and service-related needs in novel ways.

2.2 Introduction

Psychosis development typically begins with a premorbid phase, followed by a period of sub-threshold symptoms known as a clinical high-risk syndrome (CHR), and finally a threshold-level first episode of psychosis (FEP) [1]. Early intervention posits that providing phase-specific treatment during the first years around the onset of psychotic illness – a putative ‘critical period’ – can improve the immediate and long-term trajectories of illness course [2,3]. Although early intervention programs for psychosis first emerged for the FEP stage, it has now been extended to include secondary or indicated prevention [4], with specialized services deployed for individuals who are experiencing a CHR stage of psychosis [1,5-7].

The CHR syndrome is defined by the presence of attenuated psychotic symptoms (e.g. subthreshold hallucinations or delusions); brief (or limited) intermittent psychotic symptoms (BLIPS; a brief period of florid psychotic symptoms that resolve on their own); or having a first degree relative with psychosis along with functional decline [1]. Even if psychosis does not develop, outcomes for those in a CHR state are overall relatively poor as measured by symptoms [8], or functioning [9]. Subjectively, individuals at CHR for psychosis have reported feeling “broken” or abnormal, fear becoming “crazy”, had poor future expectations, and had difficulties in initiating and maintaining relationships [10]. Moreover, young people at CHR noted that it was only when their symptoms intensified, leading to a breaking point”, that they decided to seek help [11].

In response to these experiences and associated need for care, specialized CHR services are now established in Canada, the United States, Australia, Europe and elsewhere. In many cases, these services emerged as an outgrowth of FEP programs, with an associated focus on monitoring psychotic symptoms and distress. Indeed, many of the emerging guidelines for CHR services were developed within the framework of early psychosis (e.g. European Psychiatric Association guidelines [12]; National Institutes for Care Excellence guidelines [13]; the Canadian Schizophrenia Guidelines [7]; and Québec's Programmes d'interventions pour premiers épisodes psychotiques (PIPEP)), and similarly include cognitive behavioural therapy (CBT), case management, and medication as recommended interventions (e.g. [14]).

Although current research points to potential targets for CHR intervention, these are potentially limited by the assumption that service-related needs are either tied to the risk of psychosis onset, or the presence of a specific diagnosis or symptoms. For example, although we know that depression, anxiety and subthreshold psychotic symptoms are highly prevalent and primary complaints in youth at CHR [15,16], the presence of these symptoms alone may not lead to a service-related need. Indeed, one study found that difficulties with social and occupational functioning were more distressing than subthreshold psychotic symptoms [17]. Furthermore, research that does not make this assumption has tended to focus on themes *surrounding* subjective needs (like help-seeking and pathways to care) but has not inquired about them directly. For example, one study found that family and social problems were an important issue for services to address [18] but was limited by its use of a structured questionnaire. In addition, concerns about stigma and accessing care [19,20], finding employment, living accommodations, and the fear of their mental health problems returning were found to be important to youth at CHR [11], but it is unclear whether these concerns represented specific needs that service users wanted or expected the CHR service to address. Finally, knowledge about diagnosis and the desire to share experiences were also key needs described in a small sample of adolescents at CHR [21], but it is unclear how these needs were shaped by participants' past experiences with services. Taken together, to the best of our knowledge there is no CHR study where the primary focus was on user-defined service-related needs.

To inform the further development of CHR services and their guidelines, and to add to our current knowledge on this topic, the present study explored what the subjective service-related needs of CHR service users are, and how these needs might be shaped by their understanding of their mental health problems and their experiences with mental health services. Importantly, unpacking how young people make sense of emerging mental health problems will help to clarify why service users initiate help-seeking, and how their symptoms can shape needs. Ultimately, by exploring young people's subjective experiences with mental health care services, we can understand how services can better address the needs of this group.

2.3 Methods

2.3.1 Design

An essential way to know what service users need is to ask them. A qualitative descriptive approach lends itself well to this endeavour and was used in this study. Qualitative description specifically aims to describe the phenomenon of interest as it is experienced by participants [22,23]. Importantly, qualitative description is theoretically flexible, and emphasizes the need for in-depth exploration to fully understand the phenomenon in question. This methodological approach is particularly useful in addressing needs, which are themselves heavily influenced by the contexts within which young people navigate. In light of this, we conducted open-ended interviews with youth experiencing a CHR state to examine what these service users identify as their needs in relation to their individual contexts and lived experience.

2.3.2 Study setting

All participants were recruited from a well-established CHR service in Montreal, Canada [14]. It is the sole CHR service in a catchment area of approximately 300 000-400 000 people. By design, the CHR service exists alongside a co-located FEP unit to ensure continuity of care and smooth transitions to the latter if psychosis emerges.

Similar to other CHR services in Canada, Australia, and Europe, the CHR service includes outreach initiatives to improve access to specialized services [24]; regular monitoring of symptoms and functioning via follow-up assessments; provision of as-needed case management and medication; and psychoeducation for service users and their caregivers [14].

The CHR service has an open referral policy and assesses new referrals within 72 hours of receipt [14]. As part of its protocol, all service users undergo a baseline clinical assessment. In order to be eligible for the service, users must meet CHR status based on the Comprehensive Assessment of At-Risk Mental States (CAARMS [25]; as of 2017), or more recently, the Structured Interview for Psychotic Symptoms (SIPS [26]; as of 2018) and be between 14 and 35 years old. Exclusion criteria include any history of an organic brain disorder; mental retardation (IQ of below 70); epilepsy; history of head trauma; severe substance use; and the use of anti-psychotic medication for longer than 7 days [14,23]. No anti-psychotic medications are prescribed to CHR service users. However adjunct medications (like anti-depressants or anxiolytics) are if clinically indicated.

2.3.4 Study participants

The CHR service accepts approximately 30 service users per year. For this study, any service user was eligible to participate; both English and French participants were recruited. Participants were approached after consulting with their service provider to ensure that their symptoms were not interfering with their ability to provide informed consent, or that their participation would interfere with their treatment and recovery.

During the recruitment period (1.5 years), a total of 25-30 services users were available to be approached. Using purposive sampling, 11 participants between the ages 14 and 35 were recruited from the CHR service. All participants were eligible based on criteria for the CAARMS (n = 9) or the SIPS (n = 2). Overall, 13 were approached for participation, 12 consented, and 11 participated.

2.3.5 Interview protocol

The interview guide included open-ended questions based on a review of the previous literature and discussion between the authors of this manuscript. The interview guide explored participants' journeys leading up to entering the CHR service (including their experience of mental illness throughout this time), their experiences with mental health services thus far, and the ways in which those experiences may have shaped some of their symptom and service-related needs. Each interview was conducted by S.M., who is affiliated with the CHR service in a research capacity and is familiar with the service's interventions. Although S.M. does not have lived experience of CHR symptoms, she has lived experience as a family member of loved ones with other severe mental health problems. Finally, S.M. was able to relate to many participants in age and overall interests, which facilitated rapport and the interview process.

2.3.6 Ethics

Ethics approval for this study was obtained by the Research Ethics Board of the Douglas Mental Health University Institute. Prior to participation, all participants above age 18 provided written consent. For minors, written consent from their legal guardian was provided, along with their written assent.

2.3.7 Data analysis

Each interview was audio recorded and transcribed verbatim by S.M. Interviews underwent thematic analysis; a method that involves the identification, analysis, and report of themes drawn from qualitative data [27]. Thematic analysis is theoretically flexible and complements the aim of qualitative description in providing an essentialist perspective on CHR needs [27]. Thematic analysis follows a six-phase procedure that involves familiarization with interview data, the generation of initial codes, the creation of themes, review and definition of themes, and reporting [27]. Reflexive notes were kept throughout the coding process. All interviews were coded using Atlas Ti version 8 software [28].

Interview responses are presented as individual cases and have been anonymized with the use of pseudonyms. When necessary, certain elements of illustrative quotes were altered or removed to preserve confidentiality.

2.4 Results

The results explore the experiences of 11 participants identified using a fictional name: Arnold, Benjamin, Olivia, Carolyn, Danny, Jeremy, Jonathan, Marie, Peter, Scott, and Thomas. Names were randomly chosen and correspond with their identified gender only. The average age of participants was 19.9, with three identifying as female, and eight identifying as male. Three interviews were conducted in French. Interviews were coded by S.M. regardless of language.

The results first describe how participants made sense of their mental health problems and help-seeking, their experience with past services and with the CHR service (part 1); and building from these experiences, their needs in terms of symptoms, understanding their diagnosis, and services/resources (part 2). Table 1 provides additional illustrative quotes to supplement reported themes.

2.4.1 Part 1- Looking for help: Making sense of mental health problems and pathways to care

2.4.1.1 Experiencing symptoms and recognizing barriers

Overall, participants described an array of symptoms that involved sleep disturbances, feelings of sadness and guilt, and feelings or thoughts described as weird, disturbing, and disorienting. Medical terms that could be used to summarize these experiences (e.g. depression, anxiety, subthreshold psychosis) insufficiently captured the actual lived experience of these symptoms. In other words, symptoms were not felt in isolation: rather, some participants described their mental health problems (including but not limited to psychotic-like symptoms) as a crucible of many different emotions and problems interacting with each other. For example, Jeremy's anxiety appeared to exacerbate his delusions:

> Like, the anxiety would kind of make the delusions feel more real 'cause it would cause me to panic.

The experience of symptoms (whether culminative or not) resulted in a subjective change that impacted participants' ability to engage with their communities and, in some ways, disrupted their identities/sense of self. Eventually, these changes became overwhelming and brought participants to seek help. Although Thomas agglomerated his distress as a "psychosis thing", his "weird" and disturbing thoughts and feelings of impulsivity were what finally drove him to seek help from his school counsellor. These thoughts were persistent, and seemed to warn him of an unwanted change in who he was:

> […] When the whole psychosis thing happened. I don't actually have, like, full blown psychosis, or I never did yet. I just felt depersonalized. My thoughts were just weird. I had really disturbing thoughts that I didn't like, I didn't want. And I was very impulsive […] So I told [the school counsellor], I literally thought I was turning into, like, a psycho. Like, I thought I was going to be, like, a murderer when I was older. Like, I didn't want to be, but it was just 'cause, like, the thoughts, I couldn't get them away.

Benjamin had a mixture of symptoms that eventually led him to seek help and described the peak of their severity as an "explosion". He saw his mental health in terms of duality, with one side of him wanting to "do well" while the other side does "badly":

> Depuis vraiment mes problèmes ont éclaté […] j'ai rentré dans la drogue, j'ai rentré dans l'isolement. […] Donc c'est sûr que depuis ce temps-là, c'est ce qui m'a poussé à venir justement consulter. […] C'était pas juste l'anxiété, il y a des symptômes dépressifs, il y a les phobies d'impulssances. […] C'est comme une partie de moi qui veut aller bien, qui veut s'amuser, mais il y a un autre de moi qui va mal, qu'il est détruit—pas nécessairement détruite, mais à terre, fatigué par plein d'affaires. [*Since my problems really blew up […] I got into drugs, I got into isolation. […] So, it's clear that since then, it's what pushed me to go for a consultation. […] It wasn't just anxiety, it was depressive symptoms, impulsive phobias. […] It's like a part of me wants to do well, wants to have fun, but there's another that's not doing well, that is destroyed—not necessarily destroyed, but defeated, tired from a lot of things.]*

Instead of duality, Danny noticed that his mental state was “going down”. Interestingly, the hallucinations he experienced were not perceived as disturbing; rather, it was new experiences like anger, self-harm, and feeling depressed that pushed him to seek out services:

> I’ve noticed that my mental state was going down. It first started when I was starting to get hallucinations, uh, but that I didn’t really mind. But then after I started getting really angry and then self-harm came into the picture. […] And then just getting really depressed all of the sudden, and then after I’m like, okay, something is definitely wrong.

Participants described their mental health problems as an eclectic mix of different emotions and perceptions that signalled to them that “something is wrong”. That “something” was not only the perceived emotional changes and/or symptoms, but also the newfound barriers that these changes produced. For example, symptoms like sleep and exhaustion rendered it difficult for Jonathan to go to school, and for Marie to increase her course load:

> C’était dur parce que j’avais pas d’énergie pour une journée. J’avais assez d’énergie pour, comme, trois heures. Sinon après j’étais exhausted […] mentalement et physiquement. J’étais plus capable d’aller à l’école. [*It was hard because I didn’t have energy for one day. I had enough energy for, like, three hours. Otherwise after I was just exhausted […] mentally and physically. I was no longer able to go to school.]*
>
> J’ai un cours parce que j’ai annulé les autres puisque, comme, ça devenait trop dur avec mon problème. […] Chui quand même bonne à l’école quand j’ai pas mon problème. *[I have one class because I cancelled the rest seeing as, like, it was getting too hard with my problem. […] I am still good at school when I don’t have my problem.]*

In addition, anxiety was a clear barrier to being able to work and finding a job. Peter's anxiety interfered with his ability to find work, with his fear of going outside as the main hinderance:

> It's not really going easy. It's like I said, it's—to get over the fear of getting outside and my anxiety.

In addition, Benjamin's experience with derealisation affected his ability to concentrate at work:

> Un truc que j'ai développé avec le temps, c'est la déréalisation. […] Donc ça m'empêchait un peu de travailler, parce que je travaillais mais j'avais la misère à me concentrer. J'étais pas vraiment connecter avec la réalité. [*One thing that I had developed with time was derealisation. […] So, it prevented me a bit from working, because I would work but I had a hard time concentrating. I wasn't really connected with reality.*]

Summary. In this group, the ways in which symptoms interacted with individuals' perceptions of what is "normal" and their ability to achieve their goals played an important role in initiating help-seeking. Based on participants' descriptions, symptoms and the resulting barriers drove a need to seek help but were not yet associated with specific needs. Thus, recognizing a need to seek help was partially borne from the barriers that symptoms imposed on achieving personal objectives (like finding work or finishing school) and pursuing everyday activities, not necessarily the presence or types of symptoms alone. In other cases, symptoms that produced a significant change for the individual also signaled a help-seeking need.

2.4.1.2 Setting expectations: Participants' experiences with past services and transitioning to the CHR service

A portion of participants in this study (n=4) were put in contact with the service via emergency rooms (ER) either at the host hospital or from hospitals in the surrounding area. Other referral sources included Quebec’s coordinated health and social service centres for primary care in geographically defined catchments (CLSC) (n=3), a facility related to the justice system (n=1), school counsellor (n=2), and a community volunteer organization (n=1).

ER services. Experiences at the ER were overall fairly negative. For example, although Carolyn described “being treated well”, she continued:

> I felt alone. Sometimes over there, I felt alone.

Jonathan found the ER experience long, and expressed frustration with administrative errors made:

> C’était mauvais. Dans le fonds, j’allais à l’hôpital d’enfant. Ils ont dit qu’ils allaient mettre mon dossier à [host hospital], pis finalement, ils l’ont jamais fait. Faque, on a attendu deux mois à rien faire parce qu’ils ont jamais envoyer notre dossier. […] Faque, on a attendu un--deux mois pour rien. C’était platte là. [*It was bad. Basically, I went to the Children’s Hospital. They said they would send my file to the [host hospital], but in the end, they never did. So, we waited two months doing nothing because they never sent our file. So, we waited one-two months for nothing. It sucked.]*

The ER is a particularly stressful environment, especially for a young person seeking help for the first time, perhaps in a crisis. Scott described his experience there as “Traumatic actually. Like it was—it’s scary.”

Although Thomas was referred to the CHR service by a school psychologist, he also had previous experience at the ER during a crisis. He described an inadequate service, a two-day wait time, and a physically uncomfortable environment:

> My mom brought me to the Emergency Room. We had to wait so long. […] It took, like, two days. Definitely two days. What happened is, we stayed, we talked to someone. We needed to talk to someone else ‘cause that wasn’t their profession. So, we stayed all night. And we were in a room with one chair. And, uh, it was freezing. Like freezing cold.

CLSC. An important drawback for participants who accessed services through the CLSC were the long wait times before their referral to the CHR service. Peter perceived this wait as a “game”; a difficult obstacle that must be overcome to move forward:

> That was—it was a little long. It was like a waiting game. […] It was slow to start up I would say. […] It wasn’t easy, but I made it through.

Not only can wait times be frustrating for participants like Peter, but extended waits also allowed symptoms to worsen. This was the case for Jeremy, who felt that his symptoms were growing stronger while he waited for his referral to the CHR service to go through:

> I went to the CLSC […] It was good, since they have a social worker available for the intake, so like, you can walk in and see one. […] The request [to come to the CHR service], it was like two—maybe about-- within the month. Like at first it was scheduled for kind of a long time, and then I was feeling like the thoughts were getting stronger and stronger, so I went back and asked about it. […] They said I could walk in for the Emergency Room […] then the next week, I had my actual appointment.

Other services. Strong collaboration between different services helped mitigate wait times in some cases. For instance, Marie’s experience was quick and efficient due to the collaboration between her school’s social worker and family doctor at the CLSC:

> Ben j'avais été voir l'intervenante social parce que je pense elle te rencontre avant de voir la psychologue pis tout, pis tout. Pis là, je l'avais dit, pis elle m'avait parlé d'ici. […] Là, j'allais été voir mon docteur au CLSC […] moi je l'ai dit que l'intervenante sociale elle m'avait parlé de [FEP service]. Faque [mon docteur] m'avait dit que c'était pas nécessaire, j'étais pas qualifier pour ça. […] Là, l'intervenante sociale l'a rappelé mon docteur pis elle a dit, ben il y a un autre avant, ça s'appelle [CHR service]. […] Pis c'est [l'intervenante sociale] qui m'a référé ici. […] Ça a pris une semaine. [*Well, I went to see the social worker because I think you have to meet with her first before you see the psychologist. And then, I told her, and she spoke to me about here. […] Then, I went to see my doctor at the CLSC […] me, I told her that the social worker spoke to me about [FEP service]. So, [my doctor] said that it would not be necessary, I didn't qualify for that. […] Then the social worker called back my doctor and she said, well there's one before, it's called [CHR service]. […] And it was [the social worker] that referred me here. […] It took a week.]*

In Arnold's case, he described his transition in care as difficult, but felt that the CHR service was better suited to his needs:

> I had to go through court with this. I got sent to another facility before I came to here, when they figured out it was more for my mind. It's—was hard. It was not easy and all that. […] I felt just a lot better. Like this place suited me a lot more than the other place.

Summary. Because participants' help-seeking journey generally began with other services, their experiences at those services may have played a critical role in establishing a foundation for their level of trust and expectations from the CHR service – highlighting the importance of taking such contexts into consideration when examining service-related needs.

2.4.1.3 "The right direction": Participants' experiences with the CHR service

The CHR service does not exist in isolation; rather, it can be seen as another step in participants' overall care trajectory. As such, experiences with the CHR service were greatly shaped by experiences with previous services. For many, the first appointments were the most difficult, with some participants describing feeling nervous at the start. However, as the routine of going to appointments and rapport were established, subsequent contacts became easier.

The nervousness felt by some stemmed from the uncertainty about what would happen once they started. For example, Carolyn described:

> I was nervous because I didn't know what--- I wasn't aware at the point what was going to happen. […] And then I got comfortable now because I'm used to going.

Danny also expressed feeling nervous at the start. He feared that opening up about what he was experiencing might make him vulnerable to judgment. For Danny, this may have been especially important as many of the thoughts he was having disturbed him. This fear of judgement was also perhaps emphasized as he was now seeking "professional opinion", giving the impression that his mental health problems were perhaps perceived as more serious than before.

> It was okay, I guess. I mean, I don't really know how to react when it comes to this sort of stuff. But it was all—I wasn't—I was kind of nervous, but you know, they asked me a bunch of questions, and I didn't really mind. They didn't really step, you know, over a line or whatnot. They were very considerate. […] I also didn't really want to explain what was going on in my head 'cause, you know, you're safe in your own mind, you can think about whatever you want. […] You know, you're really nervous.

Peter's entry into the CHR service was a difficult one, made worse by his confusing referral pathway where he described service providers not knowing where he should be referred to. Not only did he express a level of distrust in whether the CHR service would be helpful, but he also maintained an ongoing rhetorical question regarding whether he should continue to engage with services:

> At the starting was uh, was a little touchy because I didn't know what kind of a venture I'd be getting myself into. You know? Is this really what I want? Are they actually going to be able to help me? (…) Asking for help, coming and keep coming back… it's not easy. (…) Every week is a different battle, and then it's like, do I really want to come back here? Do I want to keep taking these pills? Do I really want to keep talking about all these problems?

Despite this, Peter later remarked: "Now, at least, I have a direction […]", bringing to mind a finality to the "waiting game" he previously described.

Experiences with previous services and the initial appointments with the CHR service may have set the stage for what participants expected from their service providers, their level of trust with the service, and what they ultimately found helpful or unhelpful by the types of interventions they received. The latter is key because it is at this point that participants began to identify which of their expectations and service-related needs were met or unmet by the services they received.

Usefulness of the CHR service. Although perhaps the first appointments were met with nervousness and uncertainty, the utility of the clinic improved as participants continued to engage with their appointments. Participants found the availability, flexibility, and sense of security (i.e. feeling cared for) assembled by the service to be essential. For example, Benjamin marveled at the availability of his therapist who sometimes took his call outside of their regular appointments- a level of commitment to his well-being that he did not feel was present in past service experiences:

> […] j'ai tout le temps eu de l'aide quand j'en voulais contrairement à d'autre place où est-ce-que j'en avais pas. Et je sais que ma psychologue, des fois quand je feelais pas bien, même si j'étais pas en rencontre avec elle, des fois elle prenait une demi-heure, 15 minutes au téléphone pour me parler pis me rassurer, même si elle était à trois minutes d'avoir une rencontre ou whatever. Elle a trouvé du temps pour me parler. Ailleurs il fallait exactement que j'attends d'avoir un rendez-vous pour pouvoir m'exprimer. [*[…] I always had the help that I wanted compared to other places where I didn't. And I know that my psychologist, sometimes when I wasn't feeling well, even if I wasn't in an appointment with her, sometimes she would take half an hour, 15 minutes over the phone to talk to me and to reassure me, even if she had three minutes until her next appointment or whatever. She would find the time to talk to me. In other places, I would have to wait until I had an appointment to be able to express myself.*]

The availability of the CHR service fostered a sense of security for most participants, which may be especially important for participants who may have difficulties at home (like Marie, who felt misunderstood by her family) or who are no longer engaged in their usual daily activities (like Jonathan, who at the time of the interview was no longer in school). As Jonathan described, this sense of security also came from the routine of regular appointments and service providers "checking in":

> On se voit à chaque semaine, je crois, pour voir comment je me sens pis tous là. Pis dire, genre, ah c'était ça que t'as dit la semaine passée, est-ce-que tu sens encore comme ça.

> […] Genre, ils s'assurent que je vais bien. [*We see each other every week, I think, to see how I am feeling and all. And to say, like, ah, this was what you said last week, do you feel like that still? […] Like, they make sure I am doing well.*]

Another important component of the CHR service was service providers having an open ear for participants. Here, feeling listened to by their service provider was perceived as a validating experience. For example, Peter described:

> I like that I can come in here and I can talk. And that I can shoot the crap, you know, getting my emotions off and say how my week has been, and that the people sitting across from me actually are sincerely listening and caring and paying attention.

The tips, advice, and tools given by service providers were also perceived as useful, as Olivia and Danny described:

> The advice is really, really good. Like, sometimes when I say something, she can immediately give me advice that I know could actually work, like, if I do it.

> Giving me little tips. So, if like, if you feel an episode of anger, just breathe in and out for a few minutes […] And that will tend to help.

Finally, despite its limitations, Peter found medication to be the primary mechanism of positive change in his symptoms:

> […] And now that I'm on the pills, it's helped a lot. It's making it a lot easier, but there's still, you know, there's still issues that I have to overcome to keep getting back out there. […] If it wasn't for the meds, I don't know if it would work. So, I think the biggest part for this would be the medication. The medication changed a lot.

Overall, the availability, open-mindedness, and the tools given by the service form a user experience that, as Benjamin put it, made him feel “alive”, compared to elsewhere where he felt like “one patient among others”:

> Ils travaillent plus avec leurs émotions, leurs cœurs. ‘Till, ils te font paraître que, ‘till, ce que tu dis c’est touchant, pis qu’est-ce-que tu dis c’est, comme, comme, pas une sorte de valorisation, mais ils te font sentir comme vivant. […] Ça parait qu’ils aiment leur job pis qu’ils veulent vraiment aider. Contrairement à d’autre places où-est-ce-que je suis allé, pis c’était vraiment juste *taps table*-- pis ‘till, un patient parmi tant d’autre. [*They work more with their emotions, their hearts. You know, they make it seem like, you know, what you are saying is touching, and what you are saying is, like, like, not a kind of validation, but they make you feel alive. […] It shows that they loved their job and that they really want to help. Compared to other places where I have been, and it was really just *taps table*-- and, you know, one patient among others.*]

Aspects of the CHR service that were not useful. Participants described certain aspects of the CHR service that they did not find particularly useful, that they did not like, or that did not match their prior expectations. These aspects varied, from individual situations with their psychiatrist, to more systemic problems like wait times. For instance, Thomas described his psychiatrist as “not asking the right questions”. Peter, who was on a waitlist for a social anxiety program, had difficulty with the long waiting time. In his case, this difficulty may have been more prominent given his difficult earlier experience with referral to the CHR service, where he had to wait to know where he would be referred. As can be read from his description, waiting once more for access to a needed program felt invalidating:

> The waiting. I would say some of the waiting for some of the, I guess, their social anxiety program and stuff like that, sometimes it's--- but for me, I'm not a patient person so it's like, I like results now […] I just don't like the waiting. For me, it's like, I told you my problem, I need you to fucking (excuse my language)—to give me a result. […] The waiting is part of the game but it's not fun.

A tension between "rapid" interventions (which some participants wanted) and letting symptoms resolve on their own was apparent in some interviews. For example, Marie and Jeremy mentioned expecting or wanting more rapid results, particularly at the start of receiving services. For Marie, she felt that her service providers expected that her issues would resolve on their own, and that she would have preferred a faster solution:

> Je trouve qu'on m'a laisser un peu—pas toute seule, mais comme ça devait se guérir toute seule. J'aurais aimé quelque chose sur le moment. [*I find that they left me a bit—not alone, but as if it would resolve on its own. I would have liked something in the moment.*]

The desire for more rapid results is perhaps unsurprising given the circumstances that brought Marie to the CHR service. In her case, getting a referral very quickly potentially set the stage for the expectation of faster resolution of symptoms later on. Indeed, in line with Marie's expectation, she saw medication as beneficial, and thus the lack of medication was perceived as a limitation of the type of service that she was receiving:

> Mais, ché même pas si ça existe des médicaments pour ça, mais je veux juste dire, comme, s'il y en aurait j'aurais voulu. Mais [service provider] m'a expliqué comme quoi ici, ils en donnent pas vraiment parce que les médicaments sont trop forts ou ché pas quoi. […] Mais quand t'es dans cet état, comme, tu veux quelque chose. [*But, I don't*

> *even know if there are medications for that, but I just want to say, like, if there was I would have wanted it. But [service provider] explained to me, like, that here, they don't really give any because the medications are too strong or whatever. [...] But when you are in that state, like, you want something.*]

Finally, a perceived lack of resources, or a suggestion for more was mentioned by a few participants. In Jeremy's case, he would have liked to know about the different resources available when he first came to the CHR service:

> I would have liked to have the [Cognitive Behavioural Therapy (CBT)] and to know that that was available. 'Cause I think that's what I was kind of expecting. But I would have liked to know about the CBT during, like, the interview process or whatnot. […] I would have liked if the CBT was recommended for me before the medication, not after.

In contrast to Marie's case, some participants wanted medication only as a last resort. This was the case for Danny:

> Medication, I'm okay with it. I'm taking anti-depressants so uhm—I'd rather not take it, you know? At first, I wanted to take anti-depressants as a last resort, so if I'm taking anti-depressants now, it's kind of—I mean, I'm going to CBT but uh, I wanted to take medication if that didn't work. I don't want to take it, but I know it might help.

Summary. The CHR service had some benefits and drawbacks for participants. Useful components of the service related primarily to the flexibility of the clinical team, the freedom to express their experiences without judgement, and the diverse tools offered by service providers (e.g. medication). However, wait times for other services, along with the perceived prioritization of medication over other resources (in some cases) were distinct limitations of the service according to participants. As they engaged with services, participants became more aware of what specific needs were met (e.g. medication, CBT, and support), and which remained unmet.

2.4.2 Part 2. What were the service-related needs of participants?

Needs were considered service-related if identified as such by the participant or based on participants' expressed experiences of symptoms and services. Based on participants' stories thus far, there were clear needs related to symptoms, validating and understanding mental health problems, and the type of resources provided.

2.4.2.1 Solving the puzzle: Symptom-based needs

The overall experience and barriers imposed by symptoms determined some needs in this group. For example, one can infer that Peter may need help with his anxiety and fear of going outside in order to alleviate some of the difficulty he had in finding a job. Similarly, finding ways to help Olivia ground herself could help with the feeling of dissociation she had while socializing at school. Carolyn expressed needing help with her anxiety, Jonathan and Thomas for their sleeping patterns, and Danny for his marijuana use. As Thomas summarized:

> I need to try to cope with whatever's happening up here.

However, as described in Part 1, participants' symptoms were diverse in their manifestation, the changes they produced, and barriers they imposed. Thus, symptom-based needs were framed as goal-oriented: needing a solution, figuring out what is happening, and getting one or more symptoms "under control". Specifically, Scott and Arnold described "solving" their hallucinations:

> Like, the hallucinations have been going on for almost a year, but nothing has been done about them. Except for the fact that I have meds. And I'm just kind of just still waiting on that to be solved.
>
> Help me solve the problem I had since I was kid, which was the voices in my head.

On the other hand, gaining control was an important solution as well, as Danny explained:

> So my goals are to kind of get this sorted out. […] I just want to get those two kind of under control—my anger and my feeling depressed.

The journey to addressing symptoms was indeed recognized as one that is, at least in part, under the control and the responsibility of the individual. As Arnold explained:

> For me, I find I just have to take one step. They could help me get up, they could help me go, but I need to take the first step. […] Honestly for [the voices], it's something that I think I need a bit of help for but at the same time, I have to do it myself.

Summary. Symptoms were perceived by participants as seemingly out of their control. To regain control, participants reported needing to understand or "solve" them. Importantly, this need was not necessarily connected to what the CHR service provided or offered; specifically, symptom-based needs were sometimes perceived as something the participant had to address on their own (as was the case for Arnold). Indeed, the needs identified focused on participants regaining control through understanding their mental health problems.

2.4.2.2 "What the hell is going on?": Needs related to understanding mental health problems

Understanding through formal information. Participants expressed needing to know their diagnosis, or at least gain a broader understanding of their symptoms and experiences. The referral process itself can foster confusion about diagnosis as individuals get transferred from one service to another, which was the case for Peter:

> To be run back and then for someone to tell you oh we're not too sure or there's not an opening or we don't know if you're going left or right- it was hard.

Participants felt dissatisfied about the information they received about their diagnosis and symptoms. For instance, Peter asked himself this relevant and rhetorical question:

> What is it that I'm suffering from? […] It's great that you're the doctor, but it doesn't feel like I just have anxiety.

Scott felt this frustration with his previous psychiatrist, but although his current psychiatrist was more helpful, ultimately, he still wanted to know his diagnosis:

> Like all he did was just shove meds in my face and not give me the thing that I actually wanted which was an answer to what the hell is going on, 'cause I still don't know. […] I have hallucinations and depressive episodes. Is that being diagnosed with depression? Do I have something like schizophrenia? They're just like okay take these meds, it will go away. But that doesn't help.

The close conceptual link between the CHR syndrome and psychosis also fostered anxiety about diagnosis. Some participants, like Olivia, felt fear when they researched their symptoms on their own. In Marie's case, she felt a sense of relief to know that she did not have schizophrenia, which was what her family doctor suspected she had:

> Elle pensait que c'était des symptômes plus pour la schizophrénie. Faque elle demandait toute des questions de schizophrénie, mais c'était pas ça que j'avais. Mais l'[intervenante

> sociale], elle savait. Faque, comme, ça m'a vraiment soulagée. [*She thought that it was symptoms of schizophrenia. So, she asked me all the questions about schizophrenia, but I didn't have that. But, the [social worker], she knew. So, like, I was really relieved.]*

At times, participants were not necessarily in need of receiving more information themselves, but instead wanted those closest to them to be better informed about their diagnosis. By doing so, the sense of validation could be achieved not solely within the context of appointments, but at home as well. Olivia explained that her parents receiving information about her mental health problems was the "best of all of it":

> […] it's really hard to explain to other people, so having a professional translate how you feel to someone you love and you want to understand is really reassuring.

Indeed, once Jonathan's family member finally learned about his experiences, he noticed a significant change:

> Puis genre, je me faisais traité comme je devrais l'être, pas comme si j'étais content toute ma vie. [*And like, I was being treated like I should be, not like I've been happy all my life.]*

Therefore, for some participants, the search for an understanding of their mental health problems would have benefitted from some formal knowledge from their service provider (including in the form of a diagnosis) given to them directly, or to those closest to them. Diagnostic knowledge can validate their experience and according to Jeremy and Scott, can empower them to "face it":

> So like, that was my motive. 'Cause I wanted to talk about the thoughts and what not. And like, I also was interested in an actual diagnosis, and maybe I have a problem and like, I've just been ignoring it. So, I wanted to, like, face it.

> […] When it comes to this stuff, I have a fear of the unknown. […] When people, like, try to summon demons, or like try to get the demons out of a house, they say if you know the demon's name it weakens them. So, if I know the name of what the hell is going on it will weaken it so I can move forward.

Being understood and "seen" by others. Feeling understood by others or being able to relate to others' mental health experiences can produce a strong sense of validation and normalize mental health problems. In some cases where the individual's social network was limited, service providers played this role. Peter, who reported not having many friends, felt that being listened to by his doctor was important:

> The people sitting across from me actually are sincerely listening, and caring, and paying attention and that to me makes—that to me is a big thing.

Jeremy did not want to talk to his friends about his experiences, so he sought out mental health services to know what was also "common":

> I also want to go to like a mental health professional because I believe that like, that they would have experience with this type of delusion, 'cause I feel like it's common or whatever. So, like, I would be able to get confirmation if it's true or if I see reality the way that most people see it.

Service providers thus played an important role in providing information about what was "common" or "normal", particularly for participants like Jeremy who felt they could not relate or disclose to their friends and family.

Outside of the clinical context, sharing with people who were the same age appeared to be important to younger participants. In Scott's case, his parents' reactions to him disclosing led him to want to seek out support from people that are closer to his age:

> […] No one wants to talk to an adult about teenager things. […] Particularly, my mother because she's very narrow minded. Whenever I try to talk about something […] she kind of like turns it on me and says why didn't you do this, or why didn't you do that […] and I'm like, I'm coming to you for help, why are you making me feel worse about it?

Olivia described her "generation" as being the most "open-minded" one yet. As she explained, many of her friends shared similar mental health experiences, which validated and normalized it for her:

> […] [My friend and I] were talking about how we both have the same medication for our depression, and we were like yeah, we got the same one as my friend. And she was like, oh my god our generation—like, you walked into a room and you just said 'God, I wanna die' and everyone else will be like, 'Yeah me too.' […] I'm less insecure about the fact that I see someone about the stuff that goes on in my head. […] Talking about it makes you realize a lot more that it's not as uncommon than I think.

Learning through others. Importantly, knowing others who have similar mental health experiences can serve as models for how to cope. Benjamin reflected on this, describing the consequences of isolation, and the benefits of connecting with others:

> S'isoler ça fait juste empirer les problèmes, ça fait juste te dire mentalement que tu mérites ça, pis qu'il y a rien que tu puisse faire qui va t'aider […] Mais, pour le vrai, rencontrer des gens, c'est vraiment ça qui m'a aidé un peu à aller mieux : voir que je suis

> pas le seul qui va mal, qu'il y en a d'autre qui ont eu des problèmes, attendre comment eux ils se sont sorti de ça. [*Isolating yourself just makes the problems worse, it just tells you mentally that you deserve this, and that there is nothing that you can do that will help you [...] But, for real, meeting people, it was really that that helped me a bit: seeing that I'm not the only one not doing well, that there are others that have problems, hearing how they dealt with them.]*

Summary. Overall, participants perceived a need to gain understanding about their mental health problems, either through a formal diagnosis, receiving validation by others, or learning about their experiences through others. Doing so was perceived as a way for participants to gain control of their problems and face them.

2.4.2.3 Service/resource needs

Service/resource needs related primarily to the ability of the CHR service to support participants' personal, social, and work-related needs. Many participants recognized the importance of having the service to fall back on in moments of crisis, mentioning the availability and flexibility of their clinical team, usefulness of medication and other tools, and the rapport with their service provider(s). However, participants also felt that the CHR service needed to provide more information and education about medication and other available resources, shorter waiting times between programs (e.g. from the CHR service to CBT), and more practical resources to support their social life and work. For instance, Carolyn described needing help with her CV, and Peter described needing help with finding work. Peter summarized his work and social needs as involving more and quicker resources, not only for himself but for others as well:

> Maybe what I would want is maybe a bit more programs, you know? Where they have groups quicker. […] You guys could be out there helping, and that’s what I would want from this place. Help more people.

Although some participants felt their psychiatrist gave adequate tools and advice, others described needing more. For example, Jonathan needed a psychologist, or for him and his psychiatrist to really talk:

> Un psychologue. […] uh, ché pas— qu’on parle vraiment. Je crois que ça aiderait. *[A psychologist. […] uh, I don’t know—that we really talk. I believe that would help.]*

For Thomas, he found his psychiatrist’s questions and approach to be unhelpful, highlighting the importance of having more guided questions during appointments:

> He asks me what I want to talk about. But I find, like, shouldn’t he be asking questions? Like I don’t get that, like, I don’t know what to say. It’s your profession, like, I don’t know what you need to know, and what you don’t need to know.

The need for more guidance was also expressed by Arnold, who reported needing seemingly more direction from his psychiatrist regarding determining what his needs are and how he should deal with his emotions:

> Just a bit of confidence to help me realize what it is I need. Not like they are not confident enough already, but it’s to show—like, how do I explain it? It’s more if it is a good idea for me to do it or not, kind of thing. If I should show all the emotions at once right away, or slowly develop it.

Guidance was also needed regarding participants' future with the service. For Jeremy and Peter, this information would give them hope moving forward:

> I want a mapped out plan to see, like, the steps that I'll take to get to my desired goal or whatever. […] I'd feel more, like, kind of hopeful. Like, I'm just kind of holding on to a rope. […] I'd be able to organize myself.

> I guess I would say I need to know that I'm going in the right direction. To be told hey, you're going to make it out of this. It's not because you have symptoms of anxiety and some paranoia that things are not going to be better in two to three years.

An important service need was for the service to continue to be there for some participants in the future. Marie described simply needing to continue to come to services and receive that support. Carolyn, who had a lot of responsibility regarding caring for an older relative, described not only needing help in that regard from the service, but also to make sure that she herself will be "okay"- an especially important need for her, as her priorities in some ways emphasized this relative rather than herself:

> Make sure I don't screw up my life, and to make sure I don't fall back into my anx— suicidal habits. And that's it.

However, to satisfy needs was recognized as not the sole responsibility of the service. Rather, Peter explained, the service is only a tool that can help meet those needs:

> There's only so much power that the clinic has, you know? You can tell them about the problem, but they can't solve it for you. They can just give you the tools and options and direct you in different ways to help you better your own situation.

2.5 Discussion

2.5.1 The foundation of service-related needs: Experiences with mental health problems and services

Participants' service-related needs were interpreted and understood relative to their experiences with mental health problems and services.

Overall, the diagnostic characterization of the CHR syndrome as an experience involving subthreshold psychotic symptoms, and other comorbid issues like depression and anxiety, does not fully capture the actual complexity of the lived experience of the mental health problems reported. Importantly, the mental health experiences described by participants were characterized by a mixture of different emotions, distressing thoughts, and barriers that interacted with their daily lives in primarily negative ways, with one participant even describing the culmination of these factors as an "explosion". In our study, feelings of sadness, guilt, issues with sleep, anxiety, and thoughts or ideas that were perceived as weird, disturbing, and disorienting often interacted with and exacerbated each other, making it difficult for participants to find work, go to school, or engage in their daily routines. Symptoms often clashed with what participants perceived as "normal", and these perceived changes and newfound barriers pushed participants to eventually seek help. Such experiences are similar to those described in Hardy et al.'s previous work examining the subjective experience of youth at CHR accessing care [11]. In their study, participants described an intensification of symptoms until a breaking point was reached, driving participants to seek help.

The commencement of the help-seeking journey produced its own challenges. For example, participants described long wait times prior to arriving at the CHR service, which led to questions about whether their needs were valid, distrust in the system, and a sense of increasing urgency as symptoms worsened. Wait times were a non-verbal symbol: they signaled that the participant and their difficulties were not being taken seriously, and the urgency of their needs invalidated. This interpretation is well supported by previous work on pathways to care in psychosis and youth mental health [29,30]. In contrast, quick and efficient transitions from past services to the CHR service were primarily due to strong links with the previous psychiatrist or family doctor, and robust collaboration between everyone involved, which was in turn experienced as empowering and validating.

Once participants began to receive CHR services, they encountered interventions that met or did not meet their expectations, received tools and strategies that worked or did not work for them, and in turn, identified what they believed was lacking in the CHR service itself. Together with their experience with mental health problems and prior services, participants' service-related needs could be identified and understood - highlighting the crucial role these individual contexts play when examining needs.

2.5.2 Service-related needs

2.5.2.1 Symptom-based needs

Symptoms were seen as problems that required some sort of solution. At times, this solution was obvious to the participant; for example, eliminating symptoms with either medication or psychotherapy was identified by some, along with having more rapid access to specific interventions like the social anxiety program offered by the CHR service. However, the majority of participants also described needing to gain a greater understanding of their mental health problems, either through diagnosis or through relating to others. This need was especially significant when a long, frustrating, and/or uncertain pathway to care was combined with confusion and lack of knowledge regarding the CHR diagnosis and its meaning. Participants believed that once they received a diagnosis, they could “face” their problems, identify their exact needs, and move forward. The desire to connect with others who share similar experiences was expressed by many participants, particularly in terms of learning how others overcame similar challenges. They wanted to feel supported when support was perhaps not otherwise available. These findings were similar to the reports from Welsh and Tiffin’s 2012 study, wherein participants at CHR highlighted the refreshing and validating experience of knowing their diagnosis, and the normalization effect that receiving the diagnosis had [21].

From the perspective of service providers and researchers, the hesitation in providing a diagnosis comes from the potential stigma the CHR label can induce [5,20,31] and its unclear diagnosis and validity [32-34]. However, our findings, combined with prior qualitative and quantitative work [21,35] suggest that at least providing more information about the CHR syndrome to service users may have some benefit. Based on this, it may be valuable to further develop psychoeducation initiatives specific to the CHR service. This service has recently provided a bi-annual, two-hour psychoeducation session for service users and their families [14]. However, it may be more fruitful to increase the frequency of these sessions and to provide additional resources such as information pamphlets and posters.

To further service users’ understanding of their mental health problems, an additional supportive resource would be a peer support worker. Having an available peer support worker would provide a valuable opportunity for service users to relate with and learn from another who may share similar experiences. Although peer support has been shown to positively impact symptoms and outcomes in individuals with severe mental illnesses [36], to our knowledge, there is no research that examines its implementation in CHR services. However, based on our findings, the inclusion of peer support could be helpful for some service users.

Overall, some participants acknowledged that while services can provide tools and guidance on how to alleviate and understand symptoms, finding these interventions was ultimately seen as, in part, the responsibility of the participant themselves.

2.5.2.2 Service/resource needs

There was a notable tension between what interventions were available and perceived by service providers as best for participants, and what interventions participants wanted. For example, those who perceived medication as unhelpful, or as a "last resort", emphasized the need to know about other available interventions like CBT, and the desire to have the option to choose this intervention over the one initially offered. This tension is amplified when considering participants' reported need to gain control over their mental health problems- medication can be perceived as a more independent approach to symptom control, which did not always mesh with the participants' needs. Indeed, available guidelines for CHR identification and care recommend non-pharmacological interventions like CBT (in conjunction with as-needed medication) which can be perceived as a more collaborative approach to symptom control [7,12]. Indeed, CBT appears to be effective in symptom improvement in CHR samples [37-39]. Other non-pharmacological interventions such as supportive therapy [37], family psychoeducation [40], and Family-Aided Assertive Community Treatment [41] have additionally shown effectiveness in symptom reduction. Thus, non-pharmacological interventions should be more readily explored as additional routes for symptom control within CHR services.

On the other hand, medication was sometimes brought up as the preferred choice by participants, with one participant in particular believing that medication would be useful to relieve her symptoms. For her, medication was a more appealing solution compared with what she described as “waiting” for symptoms to resolve over time. Current guidelines suggest that medication should only be provided if necessary and to treat comorbid conditions such as anxiety or depression [7,12]. However, more research is needed to further clarify the tension between offered and desired interventions from the perspective of both service users and providers. Importantly, more informed care practices may be warranted to help guide service users to making decisions about whether or not medication is the right approach. As such, knowledge sharing tools and shared-decision making can help facilitate better collaborative care, and further inform service users of available interventions and services as they engage with the service over time [42,43].

Some participants emphasized the need for clearer guidance regarding the path to their eventual objective of becoming “normal” again. This need again stemmed from uncertain pathways leading up to the CHR service, as well as uncertainty surrounding what their symptoms were and meant about them and their futures. This guidance was described as having a mapped-out plan, or to simply be told that they are heading in the right direction. The need for guidance and assurance about the future may be connected to the question that being “at-risk” brings to mind; will I develop psychosis or not? Therefore, the primary service/resource need in this group was to address the uncertainty inherent in this type of diagnosis. Interestingly, these reports are consistent with Hardy et al.’s and Ben-David et al.’s studies, which similarly found that participants had concerns regarding their futures and the potential for mental health problems to return [10,11].

Finally, wait times between different services and programs was a significant shortcoming of the mental health system. Although wait times are a consequence of systemic issues and so are difficult for individual services to resolve, transitions between services were particularly smooth and rapid for cases where referral sources had strong collaboration and knowledge of the CHR service and its inclusion criteria. As such, outreach initiatives would likely be fruitful in helping to mitigate wait times when these can be minimized or avoided altogether. For instance, one of the aims of the CHR service is to provide outreach to potential referral sources (such as schools, CLSCs, other hospitals, community organizations, etc.) to improve the identification of those at-risk. Our previous work found that an integrated outreach program that educates referral sources on both FEP and CHR identification effectively increased CHR referrals over time [24].

2.5.2 Strengths and limitations

The present study has many strengths. First, it is one of few studies to directly examine the question of service-related needs in young people at CHR with respect to the contexts that shaped such needs. By using a qualitative descriptive method, this study was successful in capturing needs as participants perceived and described them. Importantly, our findings directly relate to how the CHR service functions and can inform how this service can improve in highly applicable ways. Finally, given the detailed descriptions of the mental health and service-related experiences of participants generated from the interviews, this study opens the door for new avenues for further investigation in the CHR field (e.g. perceptions about medication and psychotherapy, service provider perspectives about CHR needs, implementation of peer support for CHR) that can be examined both qualitatively and quantitatively.

This study does present with some limitations related to recruitment and scope. In terms of recruitment and methodology, most of the study participants were male, which limited the perspectives we were able to capture. For instance, Ben-David's 2014 study found that male and female participants shared different perspectives regarding their subjective experience of the CHR syndrome [10]. Thus, it can be argued that men and women may have different mental health care needs that this study could not identify. Moreover, we did not gain insight into the perspectives of caregivers on CHR needs. This complementary perspective is clearly needed, as young people who use the CHR service are often minors, with their caregivers involved at many steps along their health care journey. Finally, in terms of analysis, this manuscript limited its focus to service-related needs: it did not capture needs that may be relevant to contexts outside the CHR service (e.g. needs related to family and social life). However, the larger project in which this study is nested, the results of which are forthcoming, did examine these domains.

2.5.3 Conclusions

Practitioners and services have made an implicit assumption that service-related needs are either tied to the risk of psychosis onset, or the presence of a specific diagnosis or symptoms. Over the course of the interviews, the stories and experiences expressed by participants challenge this assumption and shed light on some of the issues inherent in our understanding of the CHR syndrome (i.e. issues with its diagnosis) and associated services. Specifically, participants expressed needs related to understanding their mental health problems, learning from others, and the desire to have service providers available quick and to have them offer a variety of interventions. Indeed, even though participants experienced CHR symptoms, these symptoms did not always appear to be their highest priority in terms of their service-related needs.

In particular, this study highlights the importance of understanding the contexts that can shape needs, and advocates for the continued exploration of the subjective experience of mental health needs in this group. This is particularly salient as CHR services begin to transition from CHR-specific to more generalized youth mental health hubs (e.g. Australia's headspace centers) [44]. Unfortunately, it seems that much of the current research on needs still emphasizes CHR symptoms and their risk of evolution into psychosis. By showing that youth present to CHR services for reasons other than psychotic symptoms, this study suggests that such a perspective is limited, and that continued research regarding the subjective experiences of youth at CHR for psychosis can enrich our understanding of help-seeking and service-related needs in novel ways.

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3.7 Table 1- Participants' responses organized by theme.

Themes	Quotes
Experiencing symptoms and recognizing barriers	"I'm mentally exhausted all the time. Sometimes emotionally exhausted too, and that's when I start crying." (Olivia) "I guess you can say fighting the fear of going outside. […] I've been a little--- isolation, and stuff like that. I guess my anxiety's through the roof." (Peter) "I don't know, waking up, feeling really nasty. Kind of feeling useless or whatnot, feeling guilty." (Danny) "J'avais pas vraiment de la difficulté d'apprentissage. Moi mon problème c'était vraiment l'anxiété, les autres élèves." *[I didn't really have learning difficulties. Me, my problem was really anxiety, the other students.]* (Benjamin) "It also makes me, like, apprehensive, I think, to do stuff, and like, it affects my decisions and motivation." (Jeremy)
Experiences with past services	"First it was [at a community centre]. I came here because although that was helping, I think I needed some, uh, actual professional opinion." (Danny) "Ben, je sais pas si c'est leur façon de travailler, ou si c'est leur approche, ou si c'est comme leur professionnalisme, ou s'ils prennent au sérieux mais, peut-être que c'était pas aussi un suivi à long-terme, je sais pas mais, il avait quelque chose de différent." *[Well, I don't know if it's their way of working or their approach, or if it's, like, their professionalism, or if they take it seriously, but, maybe that it wasn't a long-term follow-up, I don't know. But, there was something that was different.]* (Benjamin)

	“At the school they had like a guy I could talk to. […] I trusted him a lot, he was nice.” (Thomas)
Usefulness of the CHR service	“[…] People are about to give me tools and ideas and stuff like that. (…) It’s not just walk in, okay tell me about your problems, and have a good day. It’s, well, how can I help you? You know? What can we do to help better--- that I like.” (Peter) “[…] it’s been okay. […] They help.” (Carolyn) “She asks not just about the bad stuff. She asks about good stuff too.” (Olivia) “It’s quiet, it’s peaceful, you don’t get bothered. […] I feel like it’s a safe environment. That makes it okay.” (Peter) “Ben que, j’ai quelqu’un que comme, ils comprennent comment je suis. (…) Faque là au moins je sais que, comme, j’ai quelqu’un-- si jamais il passe quelque chose, ici, je sais on va m’aider.” [*Well that, I have someone that like, they understand how I am. […] So like, at least I know that, like, I have someone—if ever anything happens, here, I know they will help me.*] (Marie) “That they’re always available. No matter what day. Not really what time obviously, you got to go home at some point. But I mean, they’re always there in case you need anything. And they let you know if they have to postpone anything.” (Danny) “Like, when I ask for answers, he actually gives them to me. Like, doesn't necessarily give me a diagnosis, like he has that capability, but he just doesn't necessarily know yet himself. But like, he explains stuff, like, why I'm not sleeping, and stuff like that.

	And I'm like, okay, that makes sense, I'm happy now." (Scott)
Aspects of the CHR service that were not useful	"I guess I had more, like, expectation […] expecting rapid results 'cause I wanted to be back to normal." (Jeremy) "Well, when we come in, this place is very busy. […] So I guess the least helpful thing is all the people around but I guess you can't help that because it's a place of work, and other patients are here to see other people." (Olivia) "Faque des fois j'ai besoin son avis, mais [mon docteur] m'en dit pas." *[So sometimes I need their advice, but [my doctor] won't say any.]* (Marie)
Symptom-based needs	"[Need help] with my anxiety, for sure." (Carolyn) "Quelque chose pour m'aider à faire attention à mon sommeil." *[Something to help me be careful with my sleep.]* (Jonathan) "I need to fix my sleep patterns." (Thomas) "At least definitely get the depressive moods sort of thing handled. That's the—one of the biggest things 'cause I wake up and I feel just—Like I'll spend some time at one point—a couple of days ago I spent half the day feeling like crap. […] Just me feeling nothing, just zoned out." (Danny)
Needs related to understanding mental health problems	"And I researched it a lot and I found a bunch of terms that I didn't want to explore anymore because self-diagnosis is not smart, but also because I didn't want to scare myself. […] I think the best part is just being able to talk to someone who has an idea or who has seen stuff like this before and knows what's going on more than someone who I would just be talking to about whatever." (Olivia)

	“I convinced myself I was a psychotic killer. I convinced myself that I had bipolar disorder. I convinced myself I had personality—I convinced myself. I was just like, on my phone too much, reading online, and I just kept convincing myself that I had all these different disorders and stuff. So. Turns out I was, like, risk of psychosis. I don’t know, we’re still not even sure.” (Thomas) “Like my only hope is, like, that if this delusion or something like this delusion happened to other people, to know like the method they used to solve it.” (Jeremy)
Service/resource-related needs	“Doesn’t really need to be a professional. Just an open ear. And an understanding person, open-minded.” (Danny) “Comme, parce qu’ici, c’est comme, ça m’emporte la sécurité. Juste continuer. […] Continuez à être là.” *[Like, because here, it’s like, it brings me security. Just to continue. […] Continue to be there.]* (Marie) “I guess from [new doctor], I’d like to feel comfortable with him. Which is something everyone wants, no matter what they’re doing in a day.” (Olivia)

Chapter 3- Thesis Discussion

This thesis used qualitative methods to examine the service-related needs of young people meeting CHR criteria and receiving associated care. Service-related needs were described relative to participants' understanding of their own mental health problems, and their experiences with the services they engaged with. Participants described needs related to "solving" and "gaining control" of their symptoms, understanding their mental health problems via a diagnosis or learning from others who overcame similar obstacles and problems, and in general, wanting more guidance from their service provider about their future with the CHR service and beyond. This concluding chapter will further explore our findings by discussing what it means to be "at-risk" for psychosis, the future of CHR services, and how context and interactions with service providers shape service-related needs.

3.1 What does it mean to be at-risk for psychosis?

There is a tension between service users who are trying to understand their "diagnosis" and symptoms, and their service providers who may not provide definitive answers, or who hesitate in labeling or medicalizing service user experiences. Participants who were exposed to the "at-risk" term were confused by its meaning, and therefore felt that determining the correct "diagnosis" was important. Specifically, knowing what it means to be at-risk (or knowing their diagnosis) was reported by some participants as a way to feel validated, face their problems, and move forward.

The confusion reported by participants about their diagnosis mirrors the many debates and controversies regarding the utility of the CHR criteria. For example, the use of the CHR label has been argued to be associated with potential risks, including stigma, overmedicalization, and unnecessary treatment [1, 2]. Moreover, the inclusion of the Attenuated Psychosis Syndrome in the DSM-5 appendix (rather than the main text) as a “condition for further study”, rather than an official diagnosis, can foster further hesitation among service providers in using the CHR label. Finally, the attribution and measurement of the CHR state, along with accessing CHR services (much like all mental illnesses) relies on arbitrary symptom thresholds. In our study, we observed that the presence of symptoms alone was not necessarily what drove help-seeking; the barriers that symptoms brought, no matter how “subthreshold” or “minor” these symptoms were, pushed many to seek help.

Taken together, more research is clearly needed to clarify the issues with the CHR label. In particular, future research should further explore the lived experience of the CHR state, and what service users think being “at-risk” means, topics that this study did not examine more directly. Mental health problems of those at CHR, like many other mental illnesses, cannot be easily fit into predetermined categories. Practitioners may not realize that the questions and problems identified and debated about the CHR label can be felt by service users from the time they are being assessed, through their entry into CHR services, and their ongoing interaction with service providers.

3.2 CHR services: Moving on from psychosis prevention

Our findings support the fact that individuals who are at CHR are not just at risk for a potential future condition but are already help-seeking and in need of care. Participants described distress related to the barriers their symptoms caused in finding work, socializing, attending school, and making decisions about the future. Participants therefore found the CHR service to be useful in ways beyond just symptom relief; the security of having the CHR service available should a crisis arise; the utility of the tools, medication, and advice given; the importance of having an open, nonjudgmental ear; and the flexibility and availability of service providers are just a few examples of how important these services were to participants.

However, critiques of CHR services centre on the transient and difficult to define nature of subthreshold psychotic symptoms, and that most individuals who meet CHR criteria do not go on to develop psychosis [3, 4]. Such critiques have led to broader questions surrounding the utility of CHR services, and their impact on psychosis prevention from a public health standpoint [5]. Our findings imply, however, that such critiques pay insufficient attention to the experience of help-seeking and care as a whole. For example, the usefulness and importance of the CHR service to our participants cannot be captured solely by population-level changes in incidence of psychosis: despite their limitations, CHR services proactively recognize the need for care (and associated distress) prior to the onset of threshold illnesses.

Continued exploration of CHR states and mental health problems from the service user perspective can help to clarify how CHR-like or CHR-inspired services can reduce the prevalence of mental health distress in youth. For example, utilizing or transitioning early-stage service infrastructures as transdiagnostic youth mental health services to meet the needs of young people with subthreshold, fluid mental health problems (e.g. Australia’s Headspace, Ireland’s Headstrong and Jigsaw programs, and Canada’s ACCESS Open Minds) presents one promising direction for how CHR services can develop and improve [6].

3.3 The co-construction and context-dependence of service-related needs

Social constructivist theory maintains that the co-construction of knowledge through social and cultural interactions plays an important role in the learning process [7]. A parallel claim can be made about service needs. Therefore, this thesis attempted to explore service-related needs by acknowledging their co-construction and context-dependence. By doing so, we were able to explore identifiable needs, as well as other needs that could not be easily captured by a standardized scale or a well-worded interview question. From a social constructivist standpoint, it can be argued that service users may not present with discrete, pre-defined needs; instead, it is their interaction with other stakeholders and contexts that shapes how service users come to learn and articulate what those needs are.

Importantly, needs can be co-constructed in many domains of the service users' life, including their interactions with their friends and family. Within the clinical context, our study demonstrated that interactions with service providers greatly shaped participants' conceptualization and understanding of their mental health problems. For instance, participants at times used more medical terms like derealisation, delusion, hallucinations, anxiety, depression, and depersonalisation to describe elements of their experience; these terms may have stemmed from what they learned over the course of their engagement with services.

The co-creation of needs also relies heavily on the rapport between service user and provider. Participants who did not have a strong rapport or communication with their service provider felt their needs were not being adequately met. Providers played a role in co-creating what participants' needs were based on what interventions the provider was able to provide. In some cases, this process helped participants identify what they needed to do to achieve certain goals, what strategies helped or did not help to relieve symptoms, and what parts of their mental health problems needed additional support.

It is also important to recognize that the co-construction of needs continued during these research interviews. Through probing of specific interview topics, participants engaged in a form of guided reflection about why they came to services to begin with. Sometimes participants were able to articulate their current needs and how those needs have changed over time, drawing clear connections between their reasons for help-seeking, and their past and present experiences with services. However, at other times when asked what they needed, participants were not able to identify specific needs – highlighting the complex and multi-layered interactions between symptoms, barriers, friends, family, and services which can render needs difficult to articulate. As the interviewer, my biases and understanding of the participants' experience may have influenced how the interview progressed, what needs the participant described, and which ones I chose to write about for this project.

3.4 Conclusion

Prior to this project, there has been relatively little qualitative work directly addressing the service-related needs of patients at CHR for psychosis. Most of the work on this subject has been done using quantitative methods or has proceeded from the assumption that the reasons for help-seeking were based on psychotic symptoms. Thus, the divergent findings of this project highlight the importance of using qualitative methods to explore the perspectives of service users in future work in this domain, and to break through the presumption that service-related needs are always related to the criteria by which the syndrome is defined. As eloquently stated by Tonin (2007): "Our health systems need to start listening to what we are saying and what we are asking for. To know what works best for us, the system has to become youth-friendly and youth-oriented."

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