

**Engaging with Care in an Early Intervention for Psychosis Program:
The Role of Language, Communication, and Culture**

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Abstract (English)

Purpose: Engagement with treatment in early intervention for psychosis programs has been conceptualized as key to facilitating better symptomatic and functional outcomes, thereby making it a focus of early intervention programs. Despite this focus, service disengagement remains a concern and numerous predictors have been identified as increasing risk for disengagement before completing the recommended two-to-five-year course of early intervention. Despite language being an important aspect of communication and language status being known to impact health care accessibility, its perceived suitability, and outcomes, its influence on treatment engagement and/or disengagement is unknown, a gap this thesis sought to address. Specifically, our study sought to investigate the impact of language on service disengagement in an early intervention psychosis program in Montreal, Quebec (a province with French as the official language). We aimed to compare service disengagement between a linguistic minority group (i.e. English) vis-à-vis those whose preferred language was French and to explore the role of language in service engagement.

Methods: Using a mixed methods sequential design, we tested preferred language and several sociodemographic characteristics known to be associated with service disengagement in early psychosis based on prior literature (age, sex, visible minority status, immigration status, duration of untreated psychosis, social and material deprivation, family involvement, diagnosis of substance use disorder, and medication adherence) in a time-to-event analysis with Cox Proportional Hazards regression models (N=338). We then conducted two language-cohesive focus groups with English (seven patients) and French-speakers (five patients) to further explore differences between the two linguistic groups. Questions focused on interactions with the

healthcare system, experience with the first-episode program, communication generally, and specific questions about language.

Results: The quantitative sample included 338 patients; 189 (55.9%) preferred receiving services in French, and 149 (44.1%) in English. French speakers demonstrated greater material [French: $M=65.8$, $SD=27.9$, English: $M=56.7$, $SD=31.6$; $t(336) = 2.78$, $p<0.01$] and social deprivation [French: $M=76.9$, $SD=17.7$, English: $M=72.2$, $SD=23.5$; $t(336) = 2.12$, $p<0.05$. Overall, 24% ($n = 82$) of persons disengaged from the service before the two-year mark. Those whose preferred language was English were likelier to disengage ($n=47$, 31.5%) than those whose preferred language was French ($n= 35$, 18.5%; $\chi^2=9.11$, $p<0.01$). Time-to-disengagement was 14.1 months ($SD=5.4$) for French-speakers and 10.5 months ($SD=5.8$) for English speakers [$t(80) = 2.84$, $p<0.01$]. In the multivariate Cox proportional hazards regression, preferred language remained significant ($HR = 2.07$, 95% CI 1.31-3.28) and there was a significant association between family involvement ($HR = 1.97$, 95% CI 1.20-3.21) and service disengagement. Two post hoc time-to-disengagement analyses were conducted. The first was done replacing preferred language with immigrant status and demonstrated no difference in disengagement rates between non-immigrants and immigrants. The second used mother tongue instead of preferred language with the findings demonstrating that English-speakers are more likely to disengage than allophones or French-speakers ($n=325$, $\chi^2=7.79$, $p<0.05$).

In both focus groups there was an overarching picture of the importance of communication as an essential mediator of the clinician-patient relationship. Two main themes related to communication were identified – technical communication/syntax and semantic communication/meaning-making. Participants identified language as one aspect of a complex

communication process between patients and clinicians and highlighted the importance of culture in the clinical encounter.

Conclusion: Our quantitative findings demonstrated that persons whose preferred language was English were likelier to disengage from our early intervention program for psychosis than those whose preferred language was French. Qualitative results helped to unpack the complexity of the relationship between language and service engagement by suggesting that language is just one component of a much broader communication process that impacts clinical/therapeutic relationships. Our findings underscore the value of establishing communication and cultural understanding in creating clinical/therapeutic alliance and ultimately improving service engagement and outcomes in psychosis.

Résumé (français)

Objectifs: L'engagement des patients dans le traitement offert par les programmes d'intervention précoce pour la psychose a été conceptualisé comme étant un élément clé associé à une meilleure évolution clinique et fonctionnelle, ce qui en fait une priorité pour ces programmes. Malgré cela, le désengagement reste une préoccupation et de nombreux facteurs prédictifs augmentant le risque de désengagement avant la fin de la période recommandée de deux à cinq ans d'intervention précoce ont été identifiés. Bien que la langue soit un aspect important de la communication et que l'on sache que le statut linguistique a un impact sur l'accessibilité aux soins de santé, sur la perception de la pertinence des soins et sur la réponse au traitement, son influence sur l'engagement et/ou le désengagement est inconnue. Notre étude visait donc à étudier l'impact de la langue sur le désengagement des patients dans un service d'intervention précoce pour la psychose à Montréal, au Québec (une province où le français est la langue officielle). Nous avons comme objectif de comparer le désengagement entre un groupe linguistique minoritaire (c'est-à-dire les anglophones) et ceux dont la langue préférée était le français et à explorer le rôle de la langue dans l'engagement des patients dans le programme.

Méthodologie: Nous avons utilisé une approche mixte séquentielle. Dans une analyse des temps d'évènement avec des modèles de régression à risques proportionnels de Cox ($N = 338$), nous avons d'abord testé la langue de préférence et plusieurs caractéristiques sociodémographiques associées dans la littérature au désengagement envers les services d'intervention précoce pour la psychose (âge, sexe, appartenance à une minorité visible, statut d'immigration, durée de la psychose non traitée, privations matérielle et sociale, implication de la famille, diagnostic d'un trouble lié à l'usage de substances et observance, à la prise de la médication). Dans le but d'explorer davantage les différences entre les deux groupes linguistiques, nous avons ensuite

animé deux groupes de discussion, l'un formé d'individus dont la langue de préférence était l'anglais (sept patients) et l'autre d'individus dont la langue de préférence était le français (cinq patients). Les discussions ont porté sur les interactions des patients avec le système de santé, leur expérience avec le service d'intervention précoce, la communication en général, et certaines questions spécifiques à la langue.

Résultats: L'échantillon quantitatif comprenait 338 patients, dont 189 (55,9%) préféraient recevoir des services en français et 149 (44,1%) en anglais. Le groupe dont la langue de préférence était le français a rapporté présenter de plus grandes privations matérielles [Français: $M=65,8$, $ET=27,9$, anglais: $M=56,7$, $ET=31,6$; $t(336) = 2,78$, $p < 0,01$] et sociales [français: $M=76,9$, $ET=17,7$, anglais: $M=72,2$, $ET=23,5$; $t(336) = 2,12$, $p < 0,05$]. Dans l'ensemble, 24% ($n = 82$) des individus se sont désengagés des services. Ceux dont la langue de préférence était l'anglais ont été plus susceptibles de se désengager ($n = 47$, 31,5%) que ceux dont la langue de préférence était le français ($n = 35$, 18,5%; $\chi^2 = 9,11$, $p < 0,01$). Le délai de désengagement moyen a été de 14,1 mois (écart-type 5,4) pour le groupe francophone et de 10,5 mois (écart-type 5,8) pour le groupe anglophone [$t(80) = 2,84$, $p < 0,01$]. Dans la régression multivariée à risques proportionnels de Cox, l'effet de la langue est demeuré significatif ($HR = 2,07$, IC à 95% 1,31-3,28) et une association significative a été trouvée entre l'implication de la famille ($HR = 1,97$, IC à 95% 1,20-3,21) et le désengagement du service. Deux analyses post hoc sur le délai de désengagement ont été effectuées. Dans la première, la langue de préférence a été remplacée par le statut d'immigration. Cette analyse n'a démontré aucune différence dans les taux de désengagement entre les non-immigrants et les immigrants. Dans la seconde, la langue de préférence a été remplacée par la langue maternelle. Les résultats de cette seconde analyse ont

montré que les anglophones étaient plus susceptibles de se désengager que les allophones ou les francophones ($n = 325$, $\chi^2 = 7,79$, $p < 0,05$).

Dans les deux groupes de discussion, l'importance de la communication en tant que médiateur essentiel de la relation clinicien-patient a été soulignée. Deux thèmes principaux liés à la communication ont été identifiés : la communication technique/syntaxe et la communication sémantique/création du sens. Les participants ont identifié la langue comme n'étant qu'un élément d'un processus de communication plus complexe qui existe entre les patients et les cliniciens et ont souligné l'importance de la culture dans l'échange clinique.

Conclusion: Nos résultats quantitatifs démontrent que les personnes dont la langue de préférence était l'anglais ont été plus susceptibles de se désengager de notre service d'intervention précoce pour la psychose que celles dont la langue de préférence était le français. Les résultats qualitatifs ont aidé à décortiquer la complexité de la relation entre la langue et l'implication dans les soins, en suggérant que la langue n'est qu'une composante d'un processus de communication beaucoup plus large qui a un impact sur les relations cliniques / thérapeutiques. Nos résultats soulignent l'importance de la communication et de la compréhension culturelle dans la création d'une alliance clinique / thérapeutique afin d'améliorer l'implication dans les soins et l'évolution de la psychose.

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Contributions to Manuscript

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Background

A first episode of psychosis has the potential to significantly impact one's life; it may disrupt a young person's life but may also provide an opportunity for growth (Jordan et al., 2019).

According to medical literature, psychosis is primarily characterized by delusions, hallucinations and thought disorder (Gaebel & Zielasek, 2015). Initial research suggested a chronic and deteriorating course associated with substantial debilitation (Kraepelin, 1896). Subsequent efforts have demonstrated that patients may reach a plateau in psychopathology and disability within the first two years of illness onset (Bleuler, 1978; Carpenter & Strauss, 1991). This spurred the development of the critical period hypothesis for first-episode psychosis, which argues that the course of the illness can be modified early on, and that the 2-5 years around the onset of illness presents an opportunity to intervene to reduce impairment and disability (Birchwood et al., 1998). With this as the foundation, there has been increasing optimism regarding the treatment of psychotic disorders as well as a shift from a focus on symptoms to focusing on functioning (Strauss & Carpenter, 1977), which has laid the groundwork for early intervention programs.

Early intervention for psychosis (EIP) programs provide high-quality, phase-specific treatment for individuals experiencing a first episode of psychosis. They began by focusing on reducing delays in receiving care, relapse prevention, psychological adjustment to illness, and social recovery (Birchwood et al., 1998). These programs have evolved and the gold-standard now are programs driven by intensive case-management, along with other aspects of comprehensive evidence-based care: medication management, psychotherapy, family psychoeducation, peer support, integrated placement and support. EIP programs have embraced the EI core principles

of early identification, high-quality stage-specific interventions, engagement and outreach, family involvement, and emphasis on social and occupational functioning (Iyer et al., 2015). This model of care has demonstrated effectiveness in alleviating the suffering created by psychotic illnesses by identifying needs early; making services more accessible and engaging; and providing high-quality treatment for approximately two years (Anderson et al., 2015; Correll et al., 2018; Iyer et al., 2015; Lal & Malla, 2015; Malla et al., 2007). The number of established EIP programs in Canada is growing. Presently, there are approximately 30 EIP programs in Quebec and 60 in Ontario, with provincial networks and policy in multiple provinces, including Quebec, Ontario, British Columbia, and Nova Scotia (Ehmann et al., 2010; Ministère de la santé et des services sociaux, 2017; Nova Scotia Department of Health, 2004; Ontario Ministry of Health and Long Term Care, 2011)

Furthermore, long-term treatment with an EIP program has demonstrated better symptomatic and functional outcomes (Addington et al., 2003; Malla et al., 2007; Schimmelmann et al., 2006; Stowkowy et al., 2012), which is one reason treatment engagement is highly emphasized in EIP care (Birchwood, 2014; Iyer et al., 2015). This focus has resulted in lower reported service disengagement rates in EIP programs compared to regular care (Correll et al., 2018).

Disengagement is most commonly defined as lack of clinical contact, though several definitions exist and various time frames are used in the literature (Reynolds et al., 2019). Although specialized EIP programs invest in keeping patients engaged in treatment, disengagement remains a concern (Lal & Malla, 2015). Previous international literature has found disengagement rates of 20-40% over the course of treatment and identified an array of risk factors for disengagement, including sociodemographic characteristics, clinical features, and care

pathways (Doyle et al., 2014). Several reasons for disengagement from EIP care have been highlighted, including dissatisfaction with services, feeling that services do not meet their needs, lack of trust, poor insight, and stigma (Lal & Malla, 2015). Previous research has also suggested that these populations may be less satisfied (Boydell et al., 2012) and less adherent to anti-psychotic medication (Forcada et al., 2013).

Importantly, some marginalized groups such as immigrants (Ouellet-Plamondon et al., 2015), those who misuse substances (Doyle et al., 2014), and individuals of low socioeconomic status (Doyle et al., 2014), have been found to be at greater risk of disengaging from EIP care.

Addressing the needs of marginalized groups, including ethnocultural minorities, is particularly important in the Canadian context given that over 20% of the Canadian population is foreign-born, 20% belong to a racial minority group (Mental Health Commission of Canada, 2016), immigrants to Canada come from over 200 countries (Statistics Canada, 2011), and many do not speak English or French fluently. Meeting the needs of these populations within the Canadian mental health care system can be challenging (Chen et al., 2010; Hansson et al., 2010; Health Canada, 1999; Tiwari & Wang, 2008); general mental health literature suggests several reasons for the reluctance of ethnocultural minority patients to seek mental health care (Whitley et al., 2006), including difficulty in navigating the system, lack of information or resources, stigma towards mental illness, inadequacies of services, or a preference for alternative treatment options (Thomson et al., 2015). The diversity of the Canadian population is also reflected in Canadian EIP programs, with programs reporting that immigrants make up 10-66%, and visible minorities 10-40% of their client population (Nolin et al., 2016). Similar to general mental health care, challenges are reported in the EIP literature with more negative contacts on the pathway to EIP

care for Black patients in Ontario (Anderson et al., 2015), longer delays to seeking treatment, and higher dropout rates for Black patients in a Montreal EIP program (Anderson et al., 2013).

Understanding the influence of social determinants of health as well as individual identities, including cultural identities, on service engagement and disengagement is essential to creating systems and services that are capable of providing equitable care to all patients. Unfortunately, the answers are not straight forward. For example, the literature for disengagement amongst immigrants in EIP programs in Montreal is inconsistent, with one program finding that immigrants were more likely to disengage (Ouellet-Plamondon et al., 2015) and another finding no difference (Maraj et al., 2018b). Our study investigating service disengagement amongst immigrants in our EIP program demonstrated that the rates of disengagement did not differ between non-immigrants, first-generation immigrants, and second-generation immigrants but that the drivers of disengagement varied between these groups (Maraj et al., 2018b). This laid the groundwork for advocacy efforts to enhance care for immigrant and ethnocultural patients in EIP programs nationally and internationally (Maraj et al., 2018a). Moreover, growing concern about individuals who are not in education, employment, or training (NEET) (Henderson et al., 2017; Nordenmark et al., 2015; Public Health England, 2014) prompted investigation into the relationship between NEET status and service disengagement in our EIP program. While NEET status at a single time point did not predict service disengagement, we found that those who were NEET at baseline and *remained* NEET after 1 year of treatment were likelier to disengage in the second year than those who were only NEET at baseline (Maraj et al., 2019). The reasons for disengagement between and within these groups are likely highly variable (Maraj et al., 2018b); however, the differential disengagement rates between groups suggests that engagement efforts

within EIP programs likely impact certain patient groups in specific ways. In other words, what may be effective in keeping one group engaged may not be meeting the needs of another group. These findings are representative of the complexity of social determinants of health and the need for research to better understand nuances, interactions, and intersections of marginalized populations – a grand task that is best served by both quantitative and qualitative research methodologies.

While there is some literature exploring engagement of immigrant and visible minority groups in EIP, there is no published literature exploring linguistic minority groups. Beyond EIP, several Canadian studies identify language as a barrier to accessing and engaging with mental health services (Brisset et al., 2014; Chen et al., 2009; Thomson et al., 2015). International work also suggests that language mismatch between clinician and client contributes to delay in accessing care and to reduced treatment participation (Aggarwal et al., 2016; Mangrio & Sjogren Forss, 2017; Memon et al., 2016). These findings suggest that difficulties in communication can impact one's comfort with and willingness to engage with the health care system (Thomson et al., 2015). Disengagement or limited engagement in EIP treatment is especially concerning as the benefits of this treatment (such as reduction in psychotic symptoms, improvement in social functioning, and quality of life) may be associated with the degree of treatment engagement (Mascayano et al., 2021). For this reason, it is important to better understand the experience of populations receiving care in EIP programs, particularly those that may be at risk of real or perceived incompatibilities in communication with service providers.

Introduction

Communication is the foundation of the clinician-patient relationship and in mental health care, effective communication can improve therapeutic alliance (Street et al., 2009), medication adherence (Thompson & McCabe, 2012), and treatment engagement (Dixon et al., 2016).

Communication has been previously defined as the transmission of information through symbols (Berelson & Steiner, 1964; Theodorson, 1969) and is a complex phenomenon with multiple components (Berlo, 1960). Language is one component of communication and an important consideration when designing health services to improve the poorer health outcomes experienced by linguistic minority groups (Bauer & Alegria, 2010; de Moissac & Bowen, 2019; Landry, 2014).

In Canada, there are two official languages: English and French (Statistics Canada, 2017a). Canada's history of Indigenous settlement and subsequent colonization by, and conflict between, the British and French have had lasting effects on the geographic distribution, legal status and protection, and politics of the two languages (Landry, 2014). French is the sole official language of Quebec; New Brunswick is officially bilingual. In all other provinces and territories, English is the predominant language with federal services being offered in both languages. In parts of the country, speakers of English or French constitute recognized minorities (e.g., Francophones outside Quebec and Anglophones within Quebec). These 'official language minorities' represent about 5.3% of the Canadian population (Statistics Canada, 2017a).

In Canada, universal healthcare is federally mandated but provincially organized and administered. No federal legislation exists for the provision of language access services for

minority groups, though some provinces have elaborated policies for that purpose (Bowen, 2001). Consequently, linguistic minorities' access to services in their preferred language varies substantially by region.

Francophones, a linguistic minority in Canada as a whole, constitute 80% of the population of Quebec (Statistics Canada, 2017a). Given the precariousness of French in North America, the provincial government of Quebec has implemented policies to protect its use and prevent its assimilation into Anglo-Canadian or American culture. For example, the 1977 *Charter of the French Language*, also known as Bill 101, promotes the ascendancy of French in Quebec society: while designating French as Quebec's sole official language, the bill authorizes certain healthcare institutions, whose catchment areas contain sufficiently large Anglophone populations, to offer services in English. Yet, Quebec Anglophones have been reported to have lower access to, and satisfaction with, health services than Francophones (Landry, 2014).

Accessibility of and engagement in treatment are particularly important in serious mental illnesses like psychotic disorders. Specialized early intervention services for psychosis aim to alleviate the suffering associated with these illnesses by identifying needs early, making services more accessible and engaging, and providing high-quality treatment, usually for two years (Iyer et al., 2015). Although such programs emphasize patient-centred communication and invest in keeping patients engaged in treatment, disengagement nonetheless remains a challenge (Lal & Malla, 2015). A number of sub-groups have been identified as being at high-risk for disengaging, including immigrants (Ouellet-Plamondon et al., 2015), those who misuse substances, and individuals of low socioeconomic status (Doyle et al., 2014). To some degree, issues around

engaging immigrant and ethnocultural minority patients in early psychosis programs have been explored (Maraj et al., 2018; Ouellet-Plamondon et al., 2015). However, the role of language in the provision of equitable care for psychosis has not been addressed. For example, it is not known whether individuals from official linguistic minority groups are likelier to disengage, despite language status being known to impact healthcare accessibility, its perceived suitability, and outcomes.

We therefore examined service disengagement among those whose preferred official language was English vis-à-vis those whose preferred language was French in an early intervention program for psychosis in Montreal, Quebec. Because this program is based in a designated bilingual institution and offers all its services in both official languages, we expected that service disengagement rates would be similar between French- and English-speakers and that language would not be perceived as a significant barrier to care by either linguistic group.

Methods

Using a mixed methods sequential explanatory design (Ivankova et al., 2006), we studied the association between language and service disengagement in early psychosis. The quantitative analysis was conducted first and used to inform the qualitative data collection that followed, resulting in equal emphasis on both phases of the study. An inductive qualitative approach with focus groups was used to compare the linguistic and cultural differences in the perceived barriers to service engagement experienced by English- and French-speaking patients. Building on the quantitative findings, the qualitative protocol was then designed to gather information on the impact of language on the experience in care and grounded in the results of the quantitative phase (Ivankova et al., 2006).

Context

This study was conducted in a single early intervention for psychosis program in Montreal, the largest city in a province (Quebec) whose sole official language is French. Of Montreal's 4 million citizens (Statistics Canada, 2017d), 11% reported English as their only mother tongue, while 63% reported French as their only mother tongue. For their preferred official language to converse in, 73.5% of Montrealers endorsed French, 18.9% endorsed English, 6% endorsed both and 1.5% endorsed neither (Statistics Canada, 2017d).

The clinical team in the early intervention program has always included a mix of individuals whose mother tongues are English, French, and other; who are first- and second-generation immigrants; and who are White and visible minority. Services are provided in either English or French by predominantly bilingual psychiatrists, case managers, and other clinicians. The few

staff members who are more comfortable in English or French are assigned patients of the corresponding language preference. Throughout, patients have the right to request services in the official language of their choice.

The publicly-funded program is the only one for first-episode psychosis in its catchment area, which includes approximately 350,000 people (Iyer et al., 2015). Individuals are admitted if they have a diagnosis of non-affective or affective psychosis, not secondary to an organic brain disorder (e.g., epilepsy); are 14 to 35 years old; have a minimum IQ of 70; and have had no more than one month of antipsychotic pharmacotherapy. The program offers a two-year follow-up including case management, pharmacotherapy, and other psychosocial interventions (Iyer et al., 2015). This report uses data from a larger study approved by the Research Ethics Board of the associated research institute.

Phase One: Quantitative Data Collection

The first-episode program is a clinical-research program in which all patients are systematically asked to participate in research. Those who consent are included in the program's research database, from which the quantitative data was acquired. The quantitative study sample included all patients who had been admitted at least 24 months before August 2018, provided informed consent to participate in research, and had complete data for the variables of interest. Language was assessed as the official language in which patients preferred receiving services. We focused on preferred official language as our focus was on service engagement and services in our program are provided in English and French. Patients who identified themselves as preferring a

third language (n=7) or as completely bilingual (n=4) were excluded from the quantitative analysis.

In line with previous analyses, a patient was considered to have disengaged from the service at the end of three consecutive months of no clinical contact (Anderson et al., 2013; Maraj et al., 2018; Maraj et al., 2019). Time to disengagement was calculated as the time from entry into the program until the first of the three consecutive months of no contact. Participants who moved or were transferred while in treatment were not considered to have disengaged and were censored at the time of move or transfer. Those who completed 24 months of treatment were censored at that time.

We assessed sociodemographic and clinical variables known to be associated with service disengagement in early psychosis (Conus et al., 2010; Doyle et al., 2014). These included age; sex; visible minority status (White or non-White and non-Aboriginal) (Statistics Canada, 2011), immigration status (non-immigrant or immigrant, including first- and second-generation) (Statistics Canada, 2011), duration of untreated psychosis (DUP; log-transformed); Social Deprivation Index and Material Deprivation Index (Pampalon et al., 2011) of patients' neighbourhoods used as proxy measures of their socioeconomic status; family involvement in treatment (defined as presence or absence of contact with the treatment team) (Daneault et al., 2019; Maraj et al., 2019); and diagnosis of substance use disorder at baseline based on the Structured Clinical Interview for DSM-IV (First et al., 2002) (yes or no). Modal medication adherence within the first year was assessed. Antipsychotic medication adherence was assessed at baseline, months 3, 6, 9, and 12 based on self-report and family reports. Medication adherence

was determined for each month and modal medication adherence was calculated over the first year of treatment. Patients were considered adherent if they had been adherent for >75% of the time (Dama et al., 2019; Daneault et al., 2019). DUP was defined as the time in weeks between the onset of the first psychotic episode (based on positive psychotic symptoms) and the commencement of adequate treatment, i.e. taking antipsychotic medication for one month. It was calculated using the Circumstances of Onset and Relapse Schedule (CORS; Payne et al., 2006).

The Social Deprivation Index is drawn from Canadian census data and combines three census indicators: the proportion of the population aged 15 and over living alone; the proportion of the population aged 15 and over who are separated, divorced, or widowed; and the proportion of single-parent families. The Material Deprivation Index combines three Canadian census indicators: the proportion of the population 15 years and over without a high school diploma (or equivalent); the employment to population ratio for those 15 years and over; and the average income of the population aged 15 years and over. Both indices are based on individuals' postal codes and are reported as continuous variables based on centiles, with higher scores denoting greater deprivation (Pampalon et al., 2011).

Phase Two: Qualitative Data Collection

The qualitative phase was added to more deeply explore and “explain” the results from our first phase (Ivankova et al., 2006). The focus group method was chosen because it allows patients to collectively construct responses by addressing each other's comments; supporting or disagreeing with one another; and sharing perceptions and experiences (Wilkinson, 1998). For the qualitative study sample, purposeful sampling was used. This technique is widely used in qualitative

research to identify information-rich cases for the most effective use of limited resources.

Clinicians briefly introduced the study to potential focus group participants. If they accepted to be contacted for further information, a trained research assistant contacted potential participants to further explain the study and invite them to the focus group. Before the focus group, the consent form was presented and consent obtained. Participants for each group were recruited based on their preferred language for receiving services to allow for homogeneity in language within each group (English or French). The English focus group was held in December 2017, and the French group in February 2018 at the early intervention program's conference rooms. Each focus group lasted approximately two hours.

Focus groups were conducted by three trained qualitative researchers fluent in English and/or French. All focus group facilitators attended a workshop conducted by author MF. This workshop covered core and advanced competencies of focus group methods; facilitator roles; privacy and confidentiality; group dynamics; eliciting participant responses; navigating difference of opinions; and post-group debriefing. All three focus group facilitators were graduate level; the English focus group was facilitated by AM (psychiatry resident and graduate student) and the project coordinator, the French group by KM (graduate student) and the same project coordinator. Following the recommendations of Krueger and Casey (2009), focus groups included opening, introductory, key, and ending questions. The focus group guide included questions about interactions with the healthcare system, experience with the first-episode program, communication generally, and specific questions about language. It also asked for participant opinions about the connection between language and service engagement. Focus groups were digitally recorded and transcribed by professional transcriptionists. AM and the

project coordinator lead the review of transcriptions to ensure accuracy. The focus group facilitators along with MF discussed the analysis. As the focus groups aimed to gather information on language, we ensured that facilitators were fully fluent in the language required to conduct each focus group. AM is a unilingual Anglophone, KM and the project coordinator are fluently bilingual (AM and project coordinator facilitated the English focus group, KM and project coordinator facilitated the French focus group). Results from the quantitative analysis were shared during the groups. Groups were facilitated in a way that allowed openness to themes or topics that participants brought up themselves. Co-facilitators debriefed with each other after each group.

Data Analysis

For the quantitative design, descriptive statistics are presented as proportions for count data and means with standard deviations for continuous data. Group differences between English and French speakers were determined using independent samples *t*-tests and Pearson's Chi-squared tests for continuous and dichotomous variables, respectively.

Kaplan-Meier time-to-event analysis was conducted using the log-rank test to compare the probability of disengaging from services between English- and French-preferring patients. Multivariate Cox proportional hazards regression analysis, including preferred language, age, gender, education, substance use disorder, DUP, Social Deprivation Index, Material Deprivation Index, and family contact was used to identify factors associated with disengagement. Two post hoc time-to-event analyses were conducted, the first replacing preferred language with immigrant status and the second replacing preferred language with mother tongue. Results are

presented as hazard ratios (HRs) with 95% confidence intervals (CIs). All analyses were performed using SPSS version 24.

For the qualitative design, thematic analysis was used to identify, analyze, and report patterns within the data. Deductive and inductive approaches were used to develop themes relevant to our research question (Braun & Clarke, 2006). Our deductive approach involved reading the transcripts and identifying themes, sub-themes, and the relationship between them (e.g. previous experience in care, power dynamics, communication). Communication emerged as a central focus in understanding participant narrative experience; thus, we used an inductive approach to link the existing coding system with communication theory. In reviewing the literature along with the participant quotes, we found a framework able to capture participant narrative, primarily the separation of communication into technical/syntax or meaning-making/semantic. This final coding system was subsequently used to re-code the transcription to ensure we could capture the complexity of communication. Analysis took a descriptive approach and was conducted by three team members, two who were fluent in both French and English to allow coding in the original language. Two members coded each focus group, each fluent in the language of the group they were coding [authors AM and MP (fluently bilingual graduate student) coded the English group, and MP and KM coded the French group]. The researchers iteratively coded data and listed emerging themes about the role of language, perceptions about services, barriers to service engagement, and service engagement and language. Focus group transcripts were analyzed in their original language (the French quotations were translated by a fluently bilingual research assistant only for the purpose of the manuscript and are italicized for ease of identification). The codebook was generated from a mix of English and French focus group content. Themes from

English-speaking and French-speaking patients were compared to determine similarities and differences.

Following individual analysis of the quantitative and qualitative data, all results were reviewed by AM and MF to conduct the mixed methods analysis. The results from both phases were integrated at the interpretation stage (Ivankova et al., 2006). Convergence and divergence of the quantitative and qualitative data were examined in relation to the primary research question.

Rigour and Trustworthiness

Lincoln and Guba (1985) defined primary criteria to assess rigour and trustworthiness of the qualitative research process. Primary criteria—credibility, authenticity, criticality and integrity—are necessary to all qualitative enquiry but they are insufficient in and of themselves.

Trustworthiness was achieved within the study through the following criteria: credibility and authenticity, attained through a method of data collection that allowed generation of rich and meaningful data where participants could build off of each other's experiences, as well as the organization of the focus groups into homogenous language groups. Integrity was enhanced through the training received by the researchers involved in data collection and analysis prior to initiation of these tasks along with team debriefing and analysis to ensure methodological effectiveness. Additionally, there was mentorship provided by a senior researcher (MF) with expertise in this area to enhance the quality of the data and analysis.

Reflexivity was always used to understand the researchers' position in collecting, analyzing, and disseminating the data. The researchers recognized that they embodied different identities (eg., gender, visible minority status, culture, language fluency) and status (eg., student/supervisor, clinician/researcher). We acknowledge that most researchers involved in this study did not have lived experience within this EIP program; we value the focus group participants' willingness to share their knowledge and experience to bring light to this understudied area.

Results

Quantitative Results

Sociodemographic Characteristics

Out of a total of 516 patients, 338 were included in the analysis and 178 were excluded due to missing data. Those excluded were older and more likely to be immigrants (see Table 1 in Supplemental Material). Of the 338 patients included in the quantitative analysis, 189 (55.9%) preferred receiving services in French, and 149 (44.1%) in English (Table 1). Of note, the language breakdown for participants was relatively proportional to that of the catchment-area population (Statistics Canada, 2017b, 2017c, 2017e, 2017f). Language preferences were similar between White and visible minority participants [$\chi^2(1, N = 338) = 2.92, p > 0.05$].

Among French-speakers, 24.9% (n=47) were first-generation immigrants; 13.8% (n=26), second-generation immigrants; and 61.4% (n=116), non-immigrants. Of the English-speakers, 24.8% (n=37) were first-generation immigrants; 33.6% (n=50), second-generation immigrants; and 41.6% (n=62), non-immigrants. Immigrants were likelier to prefer English than non-immigrants

[58.3% vs. 38.6%, $\chi^2(1, N = 338) = 13.06, p < 0.001$].

Deprivation indices were high in both linguistic groups, but French speakers demonstrated greater material and social deprivation. Material Deprivation Index score for French speakers (M=65.8, SD=27.9) was significantly higher (i.e. greater deprivation) than English speakers [M=56.7, SD=31.6; $t(336) = 2.78, p < 0.01$]. Social Deprivation Index for French speakers (M=76.9, SD=17.7) was also higher than English speakers [M=72.2, SD=23.5; $t(336) = 2.12, p < 0.05$]. There were no differences between French and English speakers in age, gender, substance abuse, family contact, medication non-adherence, or DUP (Table 1).

Service Disengagement

A total of 82 (24.3%) patients disengaged. Those whose preferred language was English were more likely to disengage from services (n=47, 31.5%) than those whose preferred language was French (n= 35, 18.5%; $\chi^2=9.11, p < 0.01$) (Figure 1). Time-to-disengagement was 14.1 months (SD 5.4) for French-speakers and 10.5 months (SD 5.8) for English speakers [$t(80) = 2.84, p < 0.01$].

In the multivariate Cox proportional hazards regression that included known predictors of service disengagement, only preferring services in English (HR = 2.07, 95% CI 1.31-3.28) and family involvement (HR = 1.97, 95% CI 1.20-3.21) were associated with service disengagement (Table 2).

A post hoc time-to-disengagement analysis was done replacing preferred language with immigrant status (n=338); in this analysis, there was no difference in disengagement between non-immigrants (n=178, 24.7% disengaged) and immigrants (n=160, 23.8% disengaged; $\chi^2=0.12$, $p>0.05$) (see Figure 1 and Table 2 in Supplemental Material). Similarly, post hoc time-to-disengagement analysis was conducted using mother tongue divided into three groups (English, French and Other/Allophone); the disengagement findings remained the same with English-speakers more likely to disengage than allophones or French-speakers (n=325, $\chi^2=7.79$, $p<0.05$) (see Figure 2 and Table 3 in Supplemental Material).

Qualitative Results

We conducted one English-speaker focus group (five males, two females) and one French-speaker focus group (three males, two females) (see Table 3 for participant characteristics).

Focus group results were similar between the two groups, each provided an overarching picture of the importance of communication as an essential mediator of the clinician-patient relationship (Figure 2). Experiences within the healthcare system prior to engaging with the program impacted the way participants initially approached communication with program clinicians.

Regarding communication at the program, two themes were identified: (a) technical communication/syntax, referring to the structure and form of language; and (b) semantic communication/meaning-making, referring to the underlying information communicated. Each theme builds on sub-themes (including French and English) depicted in Figure 2 and described below. Furthermore, communication within the therapeutic relationship impacted the way the clinical encounter was experienced, which then resulted in a feeling of being supported or not,

and at times, linked to a wish to continue engaging with care or not (Figure 1). We also describe differences in topics that emerged between the two groups.

Entering the therapeutic relationship

Participants in both groups described having past experiences with the healthcare system that impacted the attitudes with which they approached care at the early intervention program, including the initial communication with their clinicians. These past experiences encapsulated a variety of system attributes, including access to care, development of trust in the system, clinician attitude, and judgement.

“like judgement of maybe how I appear and stuff like that. Say I’m a bit disheveled, some things like that, I feel like that might affect the care that I get.” (Male)

“Sometimes it can be long in the hospital, I say that to someone and he turns his back and can start laughing at me.” (Male)

Communication and clinical interaction: Technical/syntax and semantic communication/meaning-making

Most focus group participants described the importance of communication in clinical interactions. In both groups, participants discussed the complexity of communication, identifying its multiple dimensions: a technical component comprising terms/words, syntax, and structures; and a semantic/social component generated by the meanings that terms/words embodied.

“In my opinion, they [the program team] do speak the same language, as in like English, so topically it’s the same. But underneath, no, I don’t think they speak the same language as us. Like first of all, I know their background is very different.... So like the content like of every thought is different. So, they can’t relate to us on a – I understand it’s part of the job – not on genuine, genuine, genuine level....” (Male)

Multiple participants spontaneously and explicitly identified the two aspects of communication at different times throughout the focus groups, as evident in the following exchanges:

“Moderator: “[Participant’s name], do you think your clinician speaks the same language as you?”

Participant: “Technically or metaphorically?” (Male)

“Moderator: Do you feel that clinicians, the clinical team, speaks the same language as you?”

Participant: ...but is that metaphor or is it literal?” (Male)

Within each of these aspects of communication, multiple sub-aspects were identified. Technical communication incorporated issues related to the form, structure, and delivery of language.

Three sub-themes emerged from the focus groups as important to communication in the clinical encounter:

- 1) The use of French/English language.

“I noticed that when talking to my psychiatrist, syntax was important. And depending on if you’re French or English... sometimes it’s upside down.... And depending also if you think in French and then you’re talking in English, [you] might make those syntax mistake.” (Male)

- 2) The use of specific terminology (or diction) and differences in word choice between clinician and patient based on factors such as age, social status, and familiarity with medical terminology.

“And to expand on language, a thing that I noticed and this isn’t necessarily a matter of like French and English but like using the language that the patient or client uses to describe themselves and describe their experiences is super important for me. That was a thing that was a barrier for a while. Having psyches and stuff that wouldn’t be using my vocabulary when I’m talking about my psychosis because I would describe it in like certain words.” (Female)

- 3) The impact of illness symptoms on communication. Participants described disturbances in their thoughts and ability to share their thinking in a clear and concise manner due to the symptoms they were experiencing.

“For me, it’s pretty hard to explain what I feel because of the voices and it’s not everyone who will understand that the first time either.” (Male)

Discussions of semantic communication/meaning-making also incorporated social issues, such as those of identity and relationships. Again, three sub-themes emerged related to the clinical encounter:

- 1) The importance of culture (e.g., origin, beliefs, value systems) was highlighted as an important feature of the way individuals communicate.

“Sometimes immigrants, they come here, they have a different mindset because they don’t have the same culture, not the same religion, not the same way of talking to people. That affects the language and...you can spark emotions or receive emotions. So the emotional patterns are not necessarily the same and I think that plays a role in respect. Like let’s say in my country, you could say something to someone, he won’t get offended. But here, if you say the same thing, totally offensive.” (Male)

“I seriously think that even if you come from an immigrant family...maybe establishing a relationship with professionals will be more complex.” (Male)

- 2) The power dynamics between service provider and client. Participants shared experiences of feeling dismissed and disempowered during clinical encounters as a result of providers’ behaviours and attitudes experienced routinely during patient-clinician interaction:

“And if a client... watches the psychiatrist starting to scribble down on his piece of paper, the client might freak out because he’s like, ‘Okay, what’s happening? I’m talking about something totally normal, I’m trying to communicate it.’” (Male)

“I’m a little helpless in this because I’m not the psychiatrist.” (Male)

- 3) The relational mismatch between client and service provider was highlighted.

For example, a participant commented on having to adjust his communication to cover a generational gap:

“So I find that that doctors are more of an old-school genre or era. So you got to talk to them a little bit how to say, in their way, you have to force yourself to adapt to that I find in order to get the best results or overly compensate to make them understand where you’re coming from in this day and age.” (Male)

Outcomes related to communication within the therapeutic relationship

In daily relational interactions with their treatment teams, patients could feel supported or unsupported, valued or alienated, close or distant, depending on how communication with service providers unfolded.

“I think one thing that was a nice touch at one point was I have a bit of a technical-like mathematical background. And they tried to explain... in mathematical ways. Like when I was having these sorts of delusions-type problems, like delusions of persecution, delusions of reference, well, the probability that these things are really true is low.” (Male)

“I haven’t seen her [the psychiatrist] in a bit, and she’ll go through this list of questions. And it’ll be this like monotonous tone of like asking me really intense, deep personal questions that I just kind of need to disconnect from in order to answer them. And it’s like a really dreary thing to be going into and knowing it’s going to happen.” (Female)

“I think the communication is really excellent. They offer us many options, like email or phone, directly. I like the fact that they offer us the ability to communicate at all times.” (Male)

“You’ll arrive, you’ll start talking a little bit about your problems and they’ll quickly redirect you to your medication. Sometimes, it leaves you a little...since we were talking about communication, this could be a communication problem. It’s that our communication intentions are not always the same. That can be room for improvement in terms of intervention.” (Male)

The nature of communication seemed to make patients desire or fear/avoid contact with their service providers. In choosing to engage or disengage, patients may weigh pros and cons, among which communication is likely an important one.

Language and treatment engagement

In the focus groups, the role that patients’ preferred language played in their engagement in treatment did not emerge spontaneously. We stimulated discussion on it by presenting to the participants the results of the quantitative analysis. Participants were surprised to learn that the quantitative analysis demonstrated that English-speakers were more likely to disengage.

“And there’s actually I think, I hear a lot more English spoken at [program name] than I do French amongst people who work there. So I’m just wondering – so to me, I’m a bit surprised...” (Male)

Some agreed that language was important.

“I mean it’s made me and [case manager name] have like a lot stronger of a connection because that’s like our mother tongue for both of us.” (Female)

“I seriously think that even if you come from an immigrant family, for example, or that you are an Anglophone, yes, maybe establishing a relationship with professionals will be more complex, but I do not think it will necessarily advance the quality and speed of your care.” (Male)

A few participants offered possible explanations for the quantitative findings.

“I think a lot of immigrants prefer to learn English as like a second language. So, I think that they might think in another language while they speak in English. So, the amount of reception that you get isn’t the same because there’s like more filters, it’s like twice the filter.... So, to get through to them, to give a message, it’s a bit harder.” (Male)

“Maybe because they have fewer interventions because they are English-speaking or maybe there is less communicat[ion] with them because of their language. It can be a little discouraging.” (Male)

Some, particularly bilingual participants, reported having a different experience, feeling that speaking English or French was not important.

“I’m bilingual. So, there was not a language barrier and I believe, most of my clinicians here are bilingual as well.” (Male)

“Yeah, I feel like everyone on the team that I interacted with, they spoke English and I feel like there was good communication.” (Male)

“I do not think that speaking French will get things done faster. Everyone should be understood in their language. At some point you have to know yes or no in French to tell them what you need.” (Male)

Others acknowledged that language was important but went on to suggest that other aspects of communication were more relevant.

“And to expand on language, a thing that I noticed, and this isn’t necessarily a matter of like French and English, but like using the language that the patient or client uses to describe themselves and describe their experiences is super important for me. That was a thing that was a barrier for a while.” (Female)

“...when it comes down to the relationship between engagement and language is like if you sense that the overall tone of the language is one of trying to help you and being collaborative and so on, then I think engagement is likely to correlate positively.” (Male)

“It depends on the person and not the language, I think. If he wants to, he’ll want to, he’ll find the time. Language, in my opinion, has nothing to do with it.” (Male)

Group Differences

While participants from both focus groups commented on the above topics, some topics were discussed at greater length in the English group and a number of topics emerged only in the

French focus group. Issues related to culture and relational mismatch were touched on in both groups but discussed more in the English focus group compared to the French focus group (see examples above).

In the English group, some noted personal experiences related to issues with language.

“my psychiatrist...she was Francophone. So, we spoke English anyway but it [was] difficult at first just to talk to her because she didn’t always understand what I was saying. I didn’t always understand what she was saying because she had a hard time finding the right word. I’m just saying it’s easier when you’re speaking in your mother tongue in the way that comes most easily to you without having to pick your words too much.” (Female)

“the biggest problem I think most memorably was always trying to make jokes and [my psychiatrist] didn’t understand what I was saying. That’s not really a big issue, I know...just now that I have a different person who’s Anglophone, I find I have a funner, better, easier time just talking to him about what’s going on in my life because he can immediately grasp what I’m trying to say.” (Female)

Mixed Methods Analysis

Comparison of the quantitative and qualitative findings revealed both convergence and divergence relating to the role of language in service disengagement. The quantitative analysis demonstrated a significant association between preferred language and service disengagement, with English-speakers being more likely to drop out; the qualitative data demonstrated that

language was considered significant in a variety of ways. Some shared personal experiences that aligned with this and others shared possible explanations. Divergence from the quantitative findings was evident in some participants discussing having not experienced language per se as an important factor in receiving care but seeing language as part of a larger and more complex communication process.

“In my opinion, they do speak the same language as in like English, so topically it’s the same. But underneath, no, I don’t think they speak the same language as us.” (Male)

Notably, immigrant status was identified as important by participants in the qualitative phase and informed the post hoc analysis. However, it was not associated with service disengagement in either the initial or post hoc time-to-disengagement analyses.

Discussion

To our knowledge, this is the first study to use a mixed methods approach to study service engagement for linguistic minorities in first-episode psychosis. Given concerns about the provision of equitable health care for linguistic minority groups (Landry, 2014), we investigated the role of language in service disengagement. Overall disengagement rates were relatively low; yet, in an institution required to provide services in English and French in a city that has a large Anglophone population, we found that English-speakers were twice as likely to disengage before the two-year mark from early psychosis care compared to their French-speaking counterparts. This initial finding was further explored through qualitative methods that shed light on the importance of communication in care and identified language as one component of a complex communication process.

Technical and semantic communication

Turning to the qualitative data, we see that communication in care is an important topic for patients. When we ask about language, they spontaneously identified two aspects of language: the “technical” and the “metaphorical”. Their responses align with theory that identifies both technical (or syntax) and semantic communication (August et al., 2011). Participants identified that the technical aspect of communication impeded communication in the clinical encounter if they felt their clinician did not fluently understand their preferred language (English or French), as well as if their clinicians used terminology they could not understand, or if their illness symptoms impacted their ability to communicate their thoughts. Importantly, less concern was demonstrated towards these technical aspects, while more time was spent discussing the difficulties encountered with semantic communication.

Beyond the difficulties posed by the technical aspects of communication, participants strongly felt that issues of power dynamics and relational mismatch impacted communication between clinicians and patients. The existence of a power hierarchy between patient and clinician contributed to patients feeling judged, disempowered, and excluded in their clinical encounters. A disconnect between the realities, including age and life experience, of clinicians and patients was identified as an obstacle to optimal communication. Participants felt that the use of medical jargon, note-taking, and the emphasis on medication impacted how messages were conveyed and received, and the ability to feel connected in the therapeutic relationship. They expressed a desire for clinicians to connect to patients' interests, understand their perspectives, and be more open to patient-generated solutions. Overall, the quality of patient-clinician relationships impacted the flow and openness of communication, which, in turn, further affected the relationships.

Culture and communication

Focus group participants identified various aspects of culture and identity, including country of origin, age, and sexual orientation, that impacted on communication. For the purpose of this paper, culture was defined as “systems of knowledge and practice that give our lives identity, meaning, and purpose” (Kirmayer et al., 2014).

The diversity of English-speakers in Montreal (Donovan, 2019) stems from multiple waves of immigration, starting with the British in the 18th century and then Irish, Black Canadians and multiple European groups (Jewish from Eastern Europe; Italians; Greeks) (Linteau, 2015). More recently, Montreal has welcomed immigrants from English- and French-speaking nations around

the world, has seen a rise in immigrants from Asian countries (Donovan, 2019), and a growing population of Indigenous peoples (Statistics Canada, 2017d).

Quebec employs its own immigration policies, criteria, and conditions, distinct from the rest of Canada (Labelle, 2015). Overall, immigrants make up less than 14% of the Quebec population, and 86% of Quebec's immigrants live in Montreal. In Montreal, 23% of the population are immigrants (Statistics Canada, 2017g). Quebec has a policy of interculturalism, that accepts and encourages interaction between diverse cultural groups, while insisting on maintaining the primacy of the French language and culture (Brosseau & Dewing, 2018). This stance has been reflected in government legislation, objectives, and communications (Brosseau & Dewing, 2018). The integration of immigrants, inequality, and discrimination were identified as areas of concern in the 2000s and the Ministry of Immigration and Cultural Communities was created in 2005 with the aim of improving intercultural relations (Brosseau & Dewing, 2018). Despite these efforts, respect for diversity remains an issue in the province. As recently as 2019, Quebec passed Bill 21 – legislation that prohibits the wearing of religious symbols by public workers in positions of authority and mandates that individuals must have their face uncovered when giving or receiving specific public services (National Assembly of Quebec, 2019). The bill aims to promote religious neutrality but has been criticized for discriminating against religious minorities (Kinsinger, 2019).

Also notable is that the equality of women and men is endorsed as a fundamental value of Quebec society in government policies. The province of Quebec was the world's first jurisdiction

larger than a city or county to prohibit discrimination and harassment on the grounds of sexual orientation.

Within the English-speaking group in our study, there is significant heterogeneity in multiple aspects of identity including race, ethnicity, migration experience, religion, and social class. Thus, while English-speaking participants have a common preferred official language, they differ in other aspects of cultural identity.

Most service users in the program seem to fall into two groups – White non-immigrants (the service user or their parents did not immigrate to Canada) and visible minority immigrants (the service user or at least one parent immigrated to Canada). Quantitatively, consistent with our previous findings (Maraj et al., 2018), immigrant status did not significantly impact service disengagement rates. Nonetheless, ways of communicating and engaging with institutions, including health care, may indeed differ between immigrants and non-immigrants. Also, our sample included 18.0 % individuals whose mother tongue was neither English nor French. Although they were all able to communicate in one of the two official languages in which services were provided, it may have been “harder” to discuss psychological experiences and emotions in a language that is not one’s mother tongue.

Overall, as our qualitative more than our quantitative findings suggest, intersectionality of identity (Crenshaw, 1989) may be important in fully understanding the way people engage with mental health services. Perspectives on mental illness, accessing health care, and relationships with clinicians vary greatly across cultures (Gopalkrishnan, 2018). Understanding these cultural

differences and nuance is imperative, as culture impacts on communication (Carbaugh, 2007; Hall, 2006), and language is just one facet of culture.

Of note, focus group participants identified past experiences with health care as important in approaching their present experience. These past experiences may also be enmeshed with their cultural identities. While communication in the clinician-patient relationship is important in developing a supportive relationship, there are indeed a variety of other factors that may play into an individual's decision to come to an appointment or not. Some of these reasons may be embedded in culture – such as stigma (Franz et al., 2010) and explanatory models (Maraj et al., 2017).

Strengths and limitations

Taken together, we have demonstrated that there is a discrepancy in service utilization between English- and French-speakers in a bilingual early intervention for psychosis program in Montreal, Canada. Caution must be applied to interpretation of these results. The complexity of communication, language, and disengagement make a simplistic interpretation misleading and inappropriate. Importantly, the program of study is a bilingual service, with the vast majority of clinicians being bilingual and language-matching applied in the few cases where the clinician is only comfortable in one of the official languages. Additionally, all programming is provided according to established standards of care by individuals with the necessary training and is offered in both languages. Given these longstanding features of the program, this leads us to believe that the present findings are not likely due to language mismatch.

Furthermore, it is unlikely that the availability or quality of service differs between the linguistic groups; it is reasonable to believe that language, while an important construct, is also an indicator of more complex differences related to the heterogeneous cultural groups that have been reduced to “English-speakers” in the present study.

This study has been carried out in a single early intervention for psychosis service. However, one can surmise that the experience of availing healthcare may also be impacted by linguistic minority status elsewhere, including for English-minority groups across Quebec; Francophone communities in other provinces; and linguistic minority groups in other countries. Thus, considerations of preferred language for receiving services are important in delivering equitable access to mental health care everywhere.

Our study had several limitations. Due to the number and demographics of patients excluded due to missing data, there is potential for selection bias and possible limitations in representativeness. Future work should attempt to discern the robustness of these findings through additional data gathering to minimize missingness, particularly data missing not at random, and advanced statistical techniques. We used patients’ preferred language as services are only offered in English and French. Even if clients received care in their preferred language, it may not have been their mother tongue. Our relatively small sample size precluded the investigation of interactions between demographic variables, and our assessment of culture in the present study is limited to the use of the variables of language, immigrant status, and visible minority status, which does not allow for the unpacking of intersectional identities and culture. Our focus group participants were also heterogeneous in regards to service utilization, language ability, and

cultural identity, thereby limiting the conclusions that can be drawn from the qualitative data regarding the role of culture.

Furthermore, in line with previous research, disengagement was defined as three consecutive months of no clinical contact. This is one of several operational definitions of disengagement, reflecting the complexity of this construct. While there is evidence of poorer outcomes for those who disengage from treatment, we also recognize the possibility that not returning to care could be related to improved functioning, sustained recovery, or simply finding oneself no longer needing the service.

Our focus groups also included patients who remained sufficiently engaged in services and, as such, may not have been representative of the perspectives of those who had disengaged from treatment. Those remaining in care may have had different experiences in care as compared to those who disengaged. They may not face the same challenges, or they may have resources that enable them to remain engaged despite these challenges. Moreover, previous work from our program that included individuals who were engaged in and who had disengaged from services demonstrated that dis/engagement was a dynamic process and may sometimes reflect positive progress such as engaging with life goals (Cowan et al., 2020). We were limited in our ability to investigate what contributed to disengagement given that our focus group participants had not disengaged from the program. We also acknowledge that engagement (often categorized as “engaged” or “disengaged”) may in fact represent various positionalities with respect to services and recovery.

Future directions

This study identifies the need to improve communication between patients and clinicians in early intervention programs for psychosis and to consider the role of culture in our clinical encounters. Communication between patients and clinicians can be enhanced not only by ensuring that they are matched by language (English or French in our case) but also by organizing communication around goals of fostering shared understanding, trust, mutual regard, and alliance, which, ultimately, will lead to better engagement. Services should also consider the use of translators and cultural brokers when necessary.

Future research should examine whether linguistic minority groups in other geographic contexts have poorer rates of engagement in early psychosis care; and how language, communication, and culture interact to affect engagement in, and the outcomes of, mental healthcare. Overall, patients consistently identify sub-optimal communication as a problem – making it important to develop and evaluate strategies to enhance clinician-patient communication.

Tables and Figures

Table 1. Demographic data for participants included in quantitative analysis

| | French (n=189) | | English (n=149) | | |
|---------------------------------------|-----------------------|----------|------------------------|----------|------------------|
| Characteristic | N^a | % | N^b | % | p |
| Age (M±SD) | 23.4 | 4.29 | 23.0 | 4.26 | 0.307 |
| Gender | | | | | 0.847 |
| Female | 54 | 28.6 | 44 | 29.5 | |
| Male | 135 | 71.4 | 105 | 70.5 | |
| Visible minority | | | | | 0.087 |
| White | 131 | 69.3 | 90 | 60.4 | |
| Non-White | 58 | 30.7 | 59 | 39.6 | |
| Education | | | | | 0.340 |
| Completed high school | 120 | 63.5 | 102 | 68.5 | |
| Did not complete high school | 69 | 36.5 | 47 | 31.5 | |
| Diagnosis | | | | | 0.464 |
| Affective | 132 | 71.4 | 105 | 75.0 | |
| Non-affective | 53 | 28.6 | 35 | 25.0 | |
| Substance abuse | | | | | 0.606 |
| No | 86 | 45.5 | 72 | 48.3 | |
| Yes | 103 | 54.5 | 77 | 51.7 | |
| Social deprivation (M±SD) | 76.9 | 17.7 | 72.2 | 23.5 | 0.035 |
| Material deprivation (M±SD) | 65.8 | 27.9 | 56.7 | 31.6 | 0.006 |
| Immigrant status | | | | | <0.001 |
| Non-immigrant | 116 | 61.4 | 62 | 41.6 | |
| Immigrant | 73 | 38.6 | 87 | 58.3 | |
| Family in contact with treatment team | | | | | 0.642 |
| Yes | 147 | 77.8 | 119 | 79.9 | |
| No | 42 | 22.2 | 30 | 20.1 | |
| Year 1 modal medication adherence | | | | | 0.811 |
| Adherent | 145 | 78.8 | 108 | 77.7 | |
| Non-adherent | 39 | 21.2 | 31 | 22.3 | |
| Log-DUP | 1.17 | 0.73 | 1.23 | 0.78 | 0.449 |

^aNumbers may not add up to 189 due to missing data.

^bNumbers may not add up to 149 due to missing data.

Table 2. Cox proportional hazards regression analysis

| Predictor Variable | Outcome | |
|--|---------|-----------|
| | HR | 95% CI |
| Age | 1.01 | 0.96-1.07 |
| Gender | | |
| Female | Ref. | |
| Male | 1.08 | 0.66-1.75 |
| Visible minority | | |
| White | Ref. | |
| Non-White | 1.48 | 0.77-2.85 |
| Substance abuse | | |
| No | Ref. | |
| Yes | 1.25 | 0.79-2.00 |
| DUP (log-transformed) | 1.10 | 0.82-1.47 |
| Social deprivation | 1.00 | 0.99-1.01 |
| Material deprivation | 1.00 | 0.99-1.01 |
| Immigration status | | |
| Non-immigrant | Ref. | |
| Immigrant | 0.70 | 0.37-1.34 |
| Family in contact with treatment team* | | |
| Yes | Ref. | |
| No | 1.97 | 1.21-3.21 |
| Education level | | |
| Completed HS | Ref. | |
| Did not complete HS | 0.61 | 0.36-1.05 |
| Preferred language* | | |
| French | Ref. | |
| English | 2.07 | 1.31-3.28 |

* significant at $p < 0.05$

Table 3. Demographics for focus group participants

| | French (n=5) | English (n=7) |
|------------------------------|---------------|---------------|
| Age | 25.6 (SD 6.3) | 23.8 (SD 2.3) |
| Gender | | |
| Male | 3 (60.0%) | 5 (71.4%) |
| Female | 2 (40.0%) | 2 (28.6%) |
| Visible minority | | |
| White | 4 (80.0%) | 4 (57.1%) |
| Non-White | 1 (20.0%) | 3 (42.9%) |
| Education | | |
| Completed high school | 5 (100%) | 7 (100%) |
| Did not complete high school | 0 (0%) | 0 (0%) |
| Immigrant status | | |
| Non-immigrant | 4 (80.0%) | 4 (57.1%) |
| Immigrant | 1 (20.0%) | 3 (42.9%) |

Figure 1. Time-to-disengagement curves for English- and French-speakers

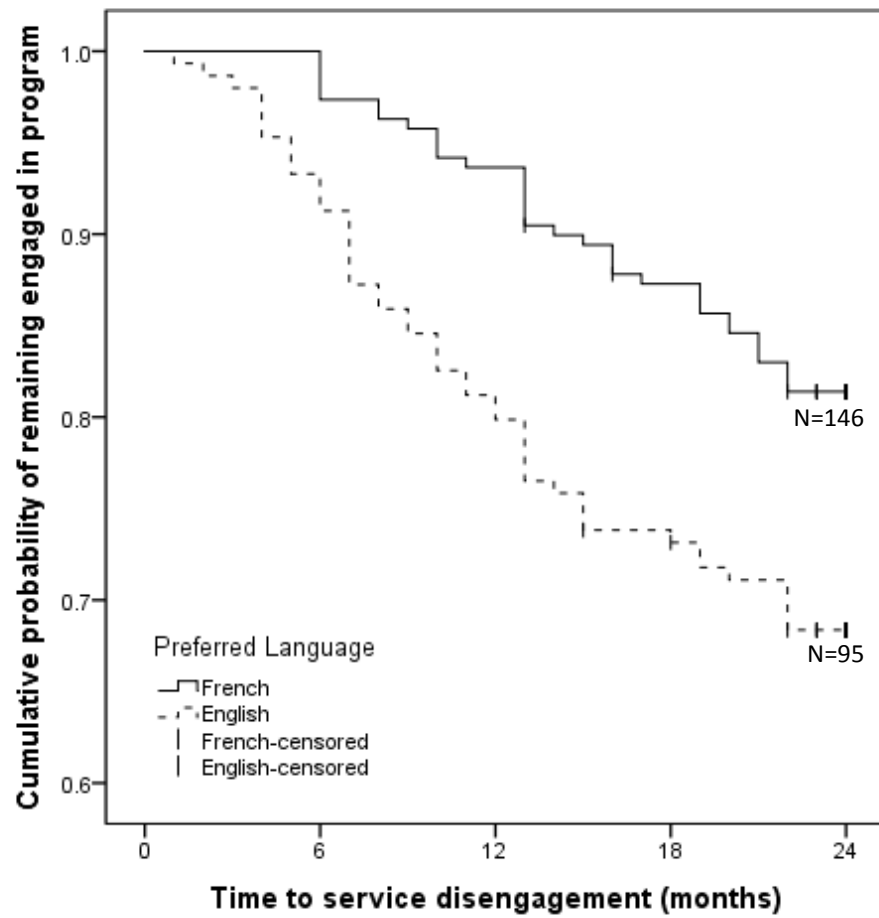
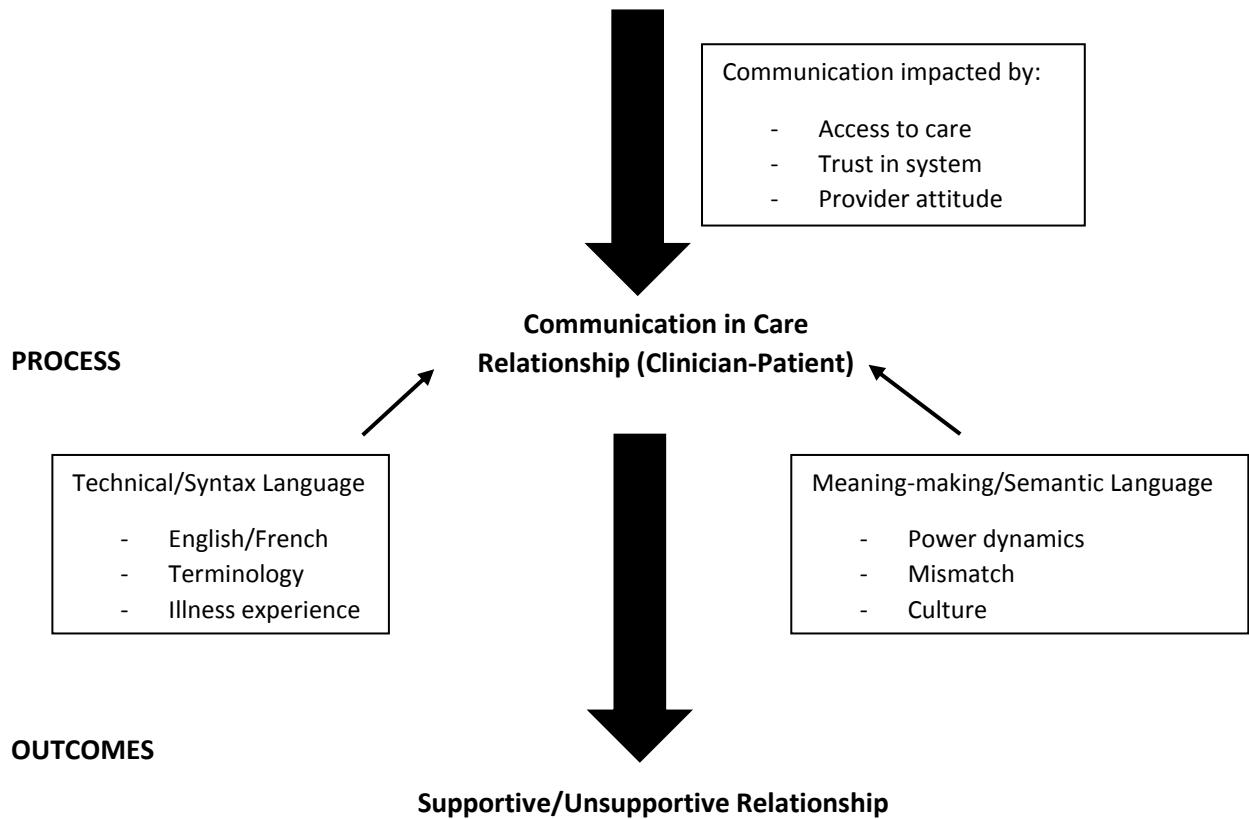


Figure 2. Factors related to communication in clinician-patient relationship

PAST EXPERIENCES WITH SYSTEM/CARE



Thesis Discussion and Conclusion

Access to health care for linguistic minorities is gaining increasing attention, particularly in Quebec where access to English-language services has been criticized (Derfel, 2020). We examined service disengagement among those whose preferred official language was English and those whose preferred language was French in an early intervention program for psychosis in Montreal, Quebec. The results demonstrated unexpected discrepancies in service engagement between English- and French-speakers, prompting considerable reflection in regards to the two complex phenomena that were highlighted – communication and disengagement.

The quantitative data demonstrated that English-speakers were more likely to disengage from treatment than French-speakers. However, results from the focus groups suggested that this discrepancy was not simply related to language mismatch between patient and service provider, but that disconnection in communication that goes beyond language comprehension was also implicated.

In the Quebec context, all major institutions – including healthcare – operate with French as the primary language of communication (and English as secondary), so it is conceivable that linguistic minorities can be inadvertently marginalized by simply preferring to engage in dialogue in a non-dominant language. As outlined by the French sociologist, Pierre Bordieu (1991), linguistic capital is one aspect of social capital and linguistic exchanges are symbolic of power relations. He states:

“Specialized discourses can derive their efficacy from the hidden correspondence between the structure of the social space within which they are produced – the political

field, the religious field, the philosophical field, etc. – and the structure of the field of social classes within which the recipients are situated and in relation to which they interpret the message.” (p.41)

Taking this into account, we must consider the possibility that patients, though unable to articulate it, may experience the health care system as not only *not* meeting their needs, but not being *made* for them. This feeling of not being valued in system design and provision may impact trust and engagement with care. Bordieu (1991) writes “The social uses of language owe their specifically social value to the fact that they tend to be organized in systems of differences which reproduce...the system of social differences” (p. 54). This reflects a systematic devaluation of non-French speakers in Quebec and may explain differences in interaction and engagement with health care despite efforts to avoid these outcomes.

Our data also suggested that language was not the only factor to be considered, but more broadly, culture played a role in clinical interactions. While this study was not designed to explore the important nuances of different cultural identities, focus group participants identified cultural differences as an issue – including those related to age, gender, background, education, etc. As discussed by Kirmayer and colleagues (2014), understanding the social and political contexts in which health and illness occur and reflecting on cultural differences including the relative power, social position, and interaction of clinicians’ and patients’ worlds are necessary to fully grasp the impact of culture. For this reason, future work should aim to better understand the cultural factors implicated in clinical interactions such as establishing aspects of identity, individual histories, and current context that most impact care interactions, strategies to mitigate identified

gaps (eg., cultural matching, cultural brokers), and developing and implementing interventions that can create a care environment that allows for true partnership despite inevitable differences between clinicians and patients.

Moreover, the data also speaks to the issue of intersectional identities. Intersectionality is a theoretical framework that considers the overlap between simultaneous marginalized social positions (Hankivsky & De Leeuw, 2011). Instead of isolating distinct social categories, such as gender, race, and class, it reflects the mutuality of multiple oppressive systems and how they join to produce particular inequalities (Viruell-Fuentes et al., 2012). Using this framework allows for consideration of the perspective of the (intersectional) group that may be missed if analyzed based on single social identity variables alone (Jackson, 2017). The existence of varied English-speaking groups in Montreal (i.e. different histories, contexts) is therefore particularly important, as one's experience is not just a sum of the experiences associated with each individual identity but uniquely based on the intersection of identities (Crenshaw, 1989). In this light, English-speakers with a particular intersection of identities, living in a certain context, may find that their needs are not being met by the available health care services.

The present study defined service disengagement as “no clinical contact for at least three months” and operationalized it as a dichotomous outcome. It is worth reflecting on the validity of this definition and operationalization. Disengagement is a complex phenomenon that occurs in different phases and in different ways. This complexity is reflected in the various criteria used to define disengagement in the literature – studies have utilized different criteria based on extent of service non-attendance, use of a categorical or continuous variable, and the use of service

engagement scales (Reynolds et al., 2019). Even with this varied criteria, most studies that look at disengagement have not differentiated between those who disengaged with and without unmet care needs, muddying the water between the processes and outcomes of disengagement, early discharge, transfer of care, and informed discharge against medical advice (Reynolds et al., 2019). Furthermore, most studies have not differentiated between attendance and engagement (i.e. one may attend an appointment but not participate in the care being offered or one may be unable to attend an appointment but be otherwise fully participating in treatment) (Reynolds et al., 2019). Future work should aim to further classify those who stop attending appointments based on unmet needs and participation in treatment to help better identify those truly at risk of poorer outcomes. This is important, as ultimately, service engagement is promoted as a means to supporting youth in their recovery and engagement in their lives and aspirations. Research on social determinants of health in psychosis will be most meaningful and beneficial to the groups we aim to support in attaining these more patient- and family-valued outcomes.

The findings of the present study, in combination with our previous work (Iyer et al., 2020; Maraj et al., 2018a; Maraj et al., 2018b), may be drawn upon to generate recommendations to enhance the care of ethnocultural minority groups. To promote more equity in access, engagement, and outcomes in psychosis, efforts should be geared towards providing personalized care (which could include language-matching between patient and clinicians and fostering shared understanding and goals), having readily available interpreters and translation resources, and access to cultural brokers and cultural consultation services. There is also a role for community outreach and family interventions (Maraj et al., 2018a). Each of these interventions will need to be systematically evaluated in the future to assess effectiveness,

feasibility, acceptability, and implementability. Of note, the majority of engagement research has looked at understanding the predictors of disengagement, with much less emphasis on developing and evaluating interventions that seek to promote better service engagement, particularly among groups that are at elevated risk for disengagement.

Given that this study is one of the first investigations of language status in EIP care, it has opened the door to several important questions. First, we focused on service engagement but broadening the focus to include other processes and outcomes is an important next step to better understand if linguistic minorities experience longer delays to adequate treatment, more difficult pathways to EIP services, poorer outcomes, or lower satisfaction with services. The need to pursue such studies is bolstered by the findings of a recent paper by Jongsma and colleagues (2020) that demonstrated that linguistic distance and social disadvantage are associated with increased odds of psychosis. Secondly, we have previously found that ongoing family involvement in treatment decreases the risk of service disengagement from early intervention for psychosis (Iyer et al., 2020) so future work should seek to understand the impact of language and other aspects of cultural identities on family involvement. Finally, while our study was carried out in a single program in Montreal, it will be important to study these questions in other programs and in other provinces to tease apart the extent to which what we observed here pertains to official linguistic minorities elsewhere in Canada or globally, and the extent to which it is tied to issues around language and identity that are quite charged in, and particular to, Quebec.

Conclusion

This study is the first to use a mixed methods approach to explore service engagement for linguistic minorities receiving care for first-episode psychosis. We first identified that official language minority patients are at greater risk of disengaging from care. Patients described the need to enhance communication between patients and clinicians, with a particular need to bridge cultural gaps (including language, age, education, etc.). These results ultimately reflect the importance of attending to communication and culture issues, as these impact the way patients experience care. Future work should aim to expand on these findings, further exploring the impact of language status on a broader range of processes and outcomes, including family engagement; investigating the replicability of these findings across the country; and evaluating interventions to enhance engagement.

Appendices

Supplemental Material

Table 1. Demographics and baseline data for included and excluded participants

| Characteristic | Included (n=338) | | Excluded (n=178) | | p |
|---------------------------------------|------------------|------|------------------|---------|------------------|
| | N ^a | % | N ^b | Valid % | |
| Age (M±SD) | 23.2 | 4.3 | 24.2 | 5.2 | 0.026 |
| Gender | | | | | 0.958 |
| Female | 98 | 29.0 | 52 | 29.2 | |
| Male | 240 | 71.0 | 126 | 70.8 | |
| Visible minority | | | | | 0.665 |
| White | 221 | 65.4 | 104 | 63.4 | |
| Non-White | 117 | 34.6 | 60 | 36.6 | |
| Education | | | | | 0.218 |
| Completed high school | 222 | 65.7 | 96 | 60.0 | |
| Did not complete high school | 116 | 34.3 | 64 | 40.0 | |
| Substance abuse | | | | | 0.120 |
| No | 158 | 46.7 | 60 | 39.2 | |
| Yes | 180 | 53.3 | 93 | 60.8 | |
| Social deprivation (M±SD) | 74.8 | 20.6 | 74.6 | 21.5 | 0.923 |
| Material deprivation (M±SD) | 61.8 | 29.9 | 61.1 | 30.8 | 0.811 |
| Immigrant status | | | | | <0.001 |
| Non-immigrant | 178 | 52.7 | 29 | 29.6 | |
| Immigrant | 160 | 47.3 | 69 | 70.4 | |
| Family in contact with treatment team | | | | | 0.759 |
| Yes | 266 | 78.7 | 138 | 77.5 | |
| No | 72 | 21.3 | 40 | 22.5 | |
| Log-DUP | 1.20 | 0.75 | 1.23 | 0.76 | 0.607 |
| Disengage | | | | | 0.593 |
| No | 256 | 75.7 | 131 | 73.6 | |
| Yes | 82 | 24.3 | 47 | 26.4 | |
| Preferred Language | | | | | 0.676 |
| English | 149 | 44.1 | 66 | 46.2 | |
| French | 189 | 55.9 | 77 | 53.8 | |

Figure 1. Time-to-disengagement curves for immigrants and non-immigrants

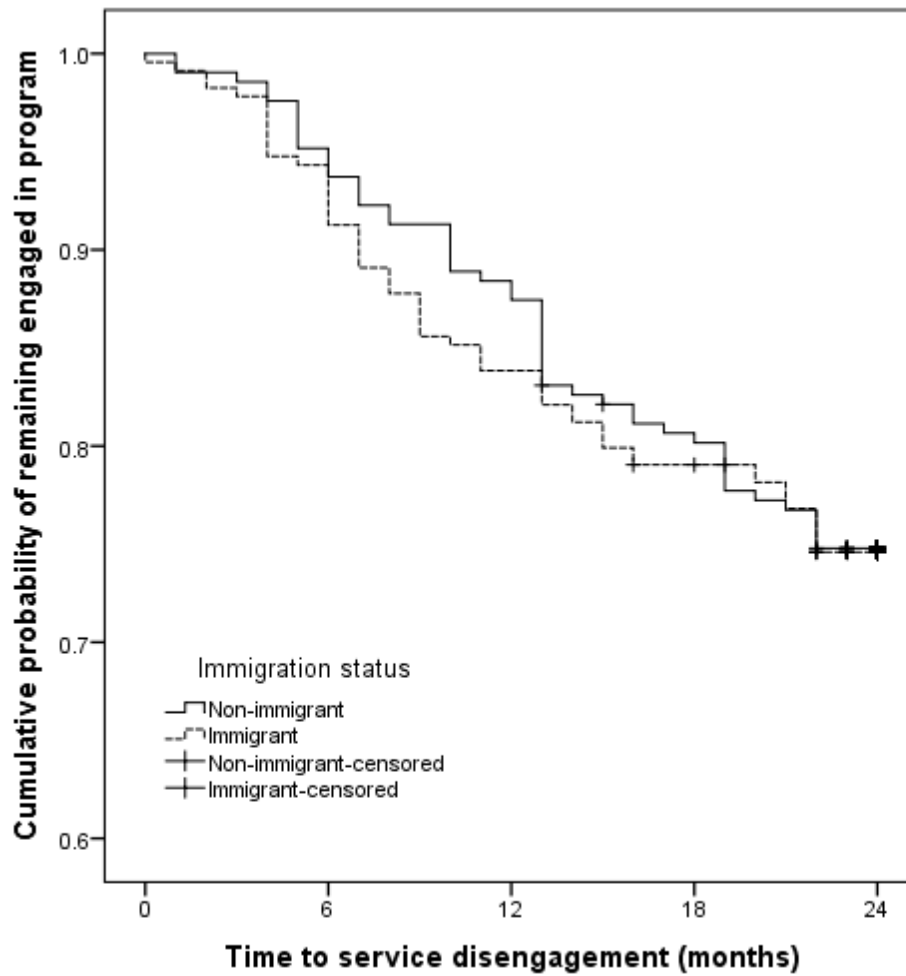


Table 2. Disengagement data for immigrants and non-immigrants

| Immigrant Status | Total | Disengaged (%) |
|------------------|-------|----------------|
| Non-immigrant | 178 | 44 (24.7%) |
| Immigrant | 160 | 38 (23.8%) |

Figure 2. Time-to-disengagement curves using mother tongue data

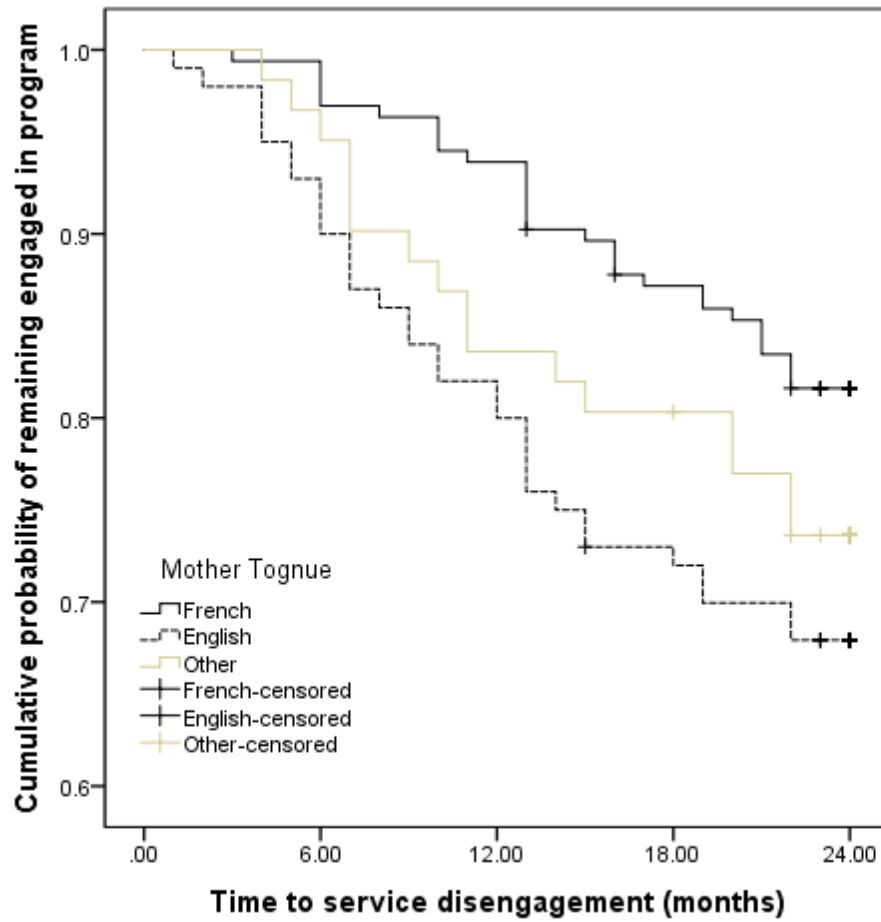


Table 3. Disengagement data using mother tongue

| Mother Tongue | Total | Disengaged (%) |
|---------------|-------|----------------|
| English | 100 | 32 (32) |
| French | 164 | 30 (18) |
| Other | 61 | 16 (26) |

Focus Group Interview Guide

Opening question

Why did you decide to participate in this focus group?

Introductory

We are interested in people's experiences with the healthcare system. Please describe your experiences with the healthcare system in Quebec.

- Ask or explore experiences related to access
- Ask or explore experiences related to care/services

What factors have influenced your experiences with the healthcare system/healthcare providers?

- Ask or explore facilitators
- Ask or explore barriers

How has speaking English/ French" impacted your ability to navigate the health care system or your interactions with healthcare providers? What about culture?

Key questions – Part 1

- Please describe your experience with the PEPP team?
 - During the intake and help-seeking process?
 - Other services attached to PEPP – ER, inpatient units, etc.
 - How did you work with (no names are needed)?
 - Activities you took part in?
- Overall, how do you find communication with the PEPP team to be?
- Explore for each (if required)
 - Psychiatry
 - Case manager

- Psychologist
- Research staff
- Other clients
- What can effective communication between you and your team look/sound like? Feel free to share examples.
- Do you think your clinicians speak the same language as you – why or why not? What impact did it have –if any?
- Can you share a situation/moment when you felt able to effectively communicate (express your needs) to your team? (Option)
- In what situations have you felt that you have been unable to communicate your needs due to language? How about other elements such as culture etc.?

Key questions – Part 2

- Based on our data, language seems to impact people’s engagement/involvement in care at PEPP, how do you understand this finding?
- Our data suggests that English-speaking people are more likely to drop out of the program than French-speaking people at PEPP. Why do you think that is?
(Our data suggests that French-speaking people are more likely to complete the program than English-speaking people at PEPP. Why do you think that is?)
- How do you feel that speaking English/French has impacted your care at PEPP?
- Are there other things that you think influence whether people decide to continue receiving services at PEPP or not?

Ending questions

How can we improve communication within PEPP? How can the PEPP team effectively communicate with clients?

Is there anything we missed?

Master Reference List

*includes all citations in the entire thesis and is inclusive of references in the main manuscript (currently under review)

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