Family Involvement in
Early Intervention Services for Psychosis in Canada

Helen Martin
Department of Psychiatry, Faculty of Medicine and Health Sciences
McGill University, Montreal
April 2024

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of

Doctor of Philosophy

Dedication

This thesis is dedicated

to

an exemplary visionary and my dearest ever-loving mother, Nirmala Lawrence,

and

my esteemed supervisor, Dr. Srividya N. Iyer,

for their steadfast faith in me.

Table of Contents

Abstract

Background: Despite being beneficial, family involvement is inconsistently implemented in early psychosis care and poorly studied from the perspective of patients, families and clinicians. Addressing these gaps, this thesis aimed to synthesize and appraise family-focused recommendations in early psychosis guidelines; explore patients', families', and clinicians' views about involving families in early psychosis care; and examine forms of and attitudes towards family involvement as reported by patients, families, and clinicians over two years of early psychosis care.

Methods: **Study 1** involved a systematic search for Canadian early psychosis guidelines. Two reviewers screened records; extracted, content-analyzed and mapped family-focused recommendations onto an engagement framework; and appraised guidelines. **Study 2** used a modified nominal group technique. Three patients, three family members and three clinicians from a Canadian early psychosis service participated in a one-day group discussion and then ranked statements generated from that discussion. Qualitative thematic analysis was used to analyze discussion data. Ranks were grouped to identify most, moderately and least important statements. **Study 3** included data from patients, families and clinicians on six questions about concrete forms of and attitudes towards family involvement at months 1, 12 and 24 after entering two Montreal early psychosis services. Generalized estimating equations and proportional odds models were used to examine change over time and between patients (n=82), families (n=113) and clinicians (with respect to 147 patients).

Results: **Study 1** included seven guidelines. Ninety-six specific family-focused recommendations were extracted and classed into twenty-one themes. Only two themes were endorsed by five of seven guidelines. Most recommendations were about direct care, and few about engaging families in design, governance and policy. Quality was lower for family-focused recommendations than for overall guidelines. Families' values and preferences were rarely elicited in developing guidelines. In **Study 2**, three themes were identified: meaning and value of family involvement; factors influencing family involvement (including consent and confidentiality); and preferred ways and methods of family involvement. Stakeholders agreed that maintaining contact with one other was the responsibility of treating teams and families; and that when patients did not want families involved, treating teams could receive information from and share general information with families and discuss the benefits of family involvement with patients. In **Study 3,** families were reported as issuing fewer medication and appointment reminders and accompanying patients to appointments and having contact with treating teams less often over the course of a follow-up. Family involvement was seen as less helpful over time. Clinicians perceived families as issuing fewer medication and appointment reminders than did families. Patients reported that their families accompanied them to appointments and had contact with treating teams less often than did families. Compared to families, clinicians and patients saw family involvement as less helpful (but still positive).

Conclusions: Family involvement is valued in guidelines and by all stakeholders. Poor quality and implementability of family recommendations and misalignment in views regarding level, helpfulness, and ways of involving families may lead to implementation gaps in family engagement and interventions in early psychosis care. These gaps can be bridged by sustained dialogue between patients, families and clinicians about family involvement, the integration into guidelines of stakeholder values, and strategies to navigate consent and apply standards in varied contexts.

Resumé

Contexte: Bien que bénéfique, l'implication des familles n'est pas toujours mise en œuvre dans les services d'intervention précoce pour la psychose et est peu étudiée du point de vue des patients, des familles et des cliniciens. Pour combler ces lacunes, cette thèse visait à synthétiser et évaluer les recommandations portant sur la famille dans les lignes directrices sur l'intervention précoce pour la psychose ; à explorer les opinions des parties prenantes sur l'implication des familles dans les soins ; et à examiner les formes d'implication familiale et les attitudes à l'égard de l'implication familiale des patients, familles et cliniciens en intervention précoce pour la psychose.

Méthodes: **L'étude 1** a consisté en une recherche systématique des lignes directrices canadiennes sur l'intervention précoce pour la psychose. Deux évaluateurs ont examiné les documents, extrait, analysé le contenu et évalué les lignes directrices. **L'étude 2** a utilisé une technique de groupe nominal modifiée. Trois patients, trois familles et trois cliniciens d'un service canadien d'intervention précoce ont participé à une discussion. Une analyse thématique qualitative a été utilisée pour analyser les données. **L'étude 3** a utilisé des données provenant de patients, de familles et de cliniciens sur les formes concrètes d'implication familiale et les attitudes à l'égard de l'implication de la famille aux mois 1, 12 et 24 après l'entrée dans deux services montréalais d'intervention précoce. Des équations d'estimation généralisées et des modèles de probabilité proportionnelle ont été utilisés pour examiner les changements au fil du temps et entre les patients (n=82), les familles (n=113) et les cliniciens (concernant 147 patients).

Résultats: **L'étude 1** comportait sept lignes directrices. Quatre-vingt-seize recommandations spécifiques axées sur la famille ont été extraites et classées en vingt-et-un thèmes. Seuls deux thèmes ont été rapportés par cinq des sept lignes directrices. La plupart des recommandations portaient sur les soins directs et peu sur l'implication des familles dans la conception, la gouvernance et les politiques. La qualité des recommandations axées sur la famille était inférieure à la qualité générale des lignes directrices. Les préférences des familles ont rarement été considérées dans l'élaboration des lignes directrices. **L'étude 2** a permis d'identifier trois thèmes : la signification et la valeur de l'implication des familles ; les facteurs influençant l'implication des familles; et les modes et méthodes préférés d'implication familiale. Les parties prenantes ont convenu qu'il incombait aux équipes traitantes et aux familles de rester en contact les unes avec les autres. Lorsque les patients ne souhaitent pas que leur famille soit impliquée, les équipes peuvent recevoir des informations de la part des familles, partager des informations générales, et discuter des avantages de l'implication de la famille. Dans **l'étude 3,** il a été rapporté que les familles effectuaient moins de rappels concernant la prise de médicaments et les rendez-vous, qu'elles accompagnaient les patients moins souvent aux rendez-vous et qu'elles étaient moins en contact avec les équipes traitantes au cours du suivi. Par rapport aux familles, les cliniciens et les patients considèrent que l'implication de la famille est moins utile (mais toujours positive).

Conclusions: L'importance de l'implication des familles est reconnue dans les lignes directrices et par toutes les parties prenantes. La mauvaise qualité et l'inapplicabilité des recommandations sur l'implication familiale, ainsi que les divergences d'opinion concernant le niveau, l'utilité et les moyens de les impliquer peuvent entraîner des lacunes au niveau de la mise en œuvre d'interventions et dans l'engagement des familles. Ces lacunes peuvent être comblées par un dialogue soutenu entre les parties prenantes, et par l'intégration dans les lignes directrices des valeurs et des stratégies permettant de mettre en œuvre les normes dans des contextes variés.

Acknowledgements

These quotes accurately summarize my journey as a Ph.D. scholar:

'It Takes a Village' - Jane Cowen-Fletcher (1994)

"***We will either find a way or make one***" – Hannibal Barca (218 BC)

Firstly, I express my gratitude to my supervisor, Dr. Srividya N. Iyer, who has been an inspiring leader, mentor, and friend throughout my doctoral journey as an international student. Her unwavering support has shaped my academic and personal growth, and I owe much of my current accomplishments to her guidance. Your guidance, patience, tolerance, encouragement, optimism, and support, particularly during the COVID-19 pandemic, were pivotal in helping me complete this doctorate and empowering me through the process. I desire to refer to you respectfully and warmly as a "superwoman," which attests to your intellectual ability to guide people around you and me with wisdom intertwined with personal virtues like equity, integrity, and benevolence for the greater good and with simplistic and pragmatic academic skills. You conduct yourself with these traits that are rare to find, and these are also reflected in your research pursuits (and now mirrored in mine). Thank you for being an incredible role model and your aspiration to imbibe supreme people skills. I am grateful for your tremendous support throughout my Ph.D. journey. You have also implicitly gifted me with the space, resources, and time to support my path toward holistic self-discovery, for which I am eternally thankful.

To the members of my thesis committee: Drs. Ridha Joober, Martin Lepage, and Norbert Schmitz. You all have supported and guided me during my research. Thank you for your critical feedback, for sharing valuable insights, and for your encouragement.

I consider myself privileged to be an integral member of the PEPP-Montreal team. Thank you to Dr. Ashok Malla, who passionately conceived this program. Drs. Jai Shah and Ridha Joober, Kevin MacDonald (my biggest cheerleader and for introducing me to ball hockey), Julie Le (my constant), Nicole Pawliuk (invaluable critic) - the whole present and past clinical and research staff - thank you for establishing such a welcoming and engaging atmosphere; I learnt so much here and am glad for the colleagues and friends I met and made over the years. During my graduate studies at the Douglas Institute, I was fortunate to collaborate, share, and work with some of the brightest and nicest fellow graduate students on whom I depended for intellectual stimulation and camaraderie.

I am beyond grateful to my parents, Nirmala Lawrence, and Martin Stanislaus, my siblings Prianga Antony, and Henry Martin, and my brother-in-law, Antony Jegan, for your unceasing emotional support and comfort during difficult times. My wonderful nieces, Jovetta and Jofina Antony, thank you for your amicable companionship and for serving as delightful and affectionate diversions.

My lifelines and pillars – Drs. Catherine. C, Aparna. G, Aarati. T, and Prince. A; Bhagya. S, Margaret. D, Jackson. B, Divya. T, and Seloua. R for their affection, wit, understanding, reassurance, and fortitude amidst periods of instability and uncertainty. Plus, my newfound friendships in Montreal – Dicki, Daniel, Jason, Nithya, Konstantina, Srikar, Swati, Meghomita, Gabriella, Ranjani, Swati, Carlyn, and family, Valerie and family, Pierre and family, Laura and family played a crucial role in maintaining my social life, thereby preserving my mental well-being while being away from family and friends in India.

Finally, a special acknowledgement and sincere gratitude to the individuals who have graciously rendered financial and in-kind support, namely Coleman. M, Drs. Hema. T, Vijaya. R, Aparna. G, Konstantina. C, Padmavati. R, Shantha. K; Jebin. B, Divya. S, Swati. C, Aseem. H, Mukund. K; and Sudha Ma. I express my heartfelt gratitude for your confidence in my abilities and the rapid and generous assistance provided during India's demonetization phase and my days in Montreal, as it significantly and confidently assisted me in embarking on this transformative journey.

Acknowledgements related to the production of this thesis

I would like to extend a grateful acknowledgement for the financial assistance provided by McGill university throughout my doctoral studies, which includes the McGill psychiatry department's Graduate Excellence Fellowship in Mental Health Research (2017) and Graduate Excellence Awards (2017, 2018, 2019), McGill Graduate Writing Course Sponsorship

(2017); Graduate Research Enhancement and Travel Awards (2017); Post Graduate Student Society's Graduate Research Enhancement and Travel Awards (2017, 2019, 2021, 2022); Duncan Pederson Global Mental Health award (2017); McGill Merit and Need-based Bursary (2022, 2023, 2024); McGill-AGSEM Mutual Financial Aid (2022); and funding received from Dr. Srividya N. Iyer's Canadian Institutes of Health Research (CIHR) Foundation grant (2017-2023).

I would like to extend my gratitude to the diverse group of individuals who have contributed to the data collection and overall research process for my doctoral research.

Foremostly, Dr. Aarati Taksal has been an instrumental support in creating a conducive atmosphere that facilitated the acquisition of statistical and scholarly knowledge, thereby promoting the development of critical and pragmatic thinking. During my thesis's culmination, she was my informal mentor and instructor, accompanying me along the path. Ms. Nicole Pawliuk played a vital role as the second independent reviewer for the literature review (Manuscript I) and as the data manager for the overarching research project that generated the data for my project 3, which is included in this thesis (Manuscript III) and for providing timely feedback on my thesis. I would like to acknowledge study participants, particularly patients, family members, and clinicians from Prevention and Early Intervention for Psychosis, Douglas Mental Health University Institute and Prevention and Early Intervention for Psychosis, McGill University Health Centre who volunteered to share their time and experience, leading to knowledge generation.

I would also like to thank Drs. Navdeep Kaur, Aarati Taksal, and Kathleen MacDonald for their review and feedback on the numerous thesis drafts. I would like to thank Kevin Macdonald for assisting with necessary research logistics and Salome Xavier for providing valuable input on this dissertation.

Contribution of Original Knowledge

This thesis consists of three distinct scientific manuscripts. Collectively, these provide an original perspective on the topic of family involvement in the treatment of young individuals experiencing a first episode of psychosis and receiving early intervention services for psychosis in Canada.

1. The first manuscript focused on synthesizing the state of clinical practice recommendations for family work (family interventions and family involvement) in early intervention services for psychosis in Canada. While multiple reviews have been conducted on family interventions in early psychosis, no review has focused on understanding comprehensive family work from a policy standpoint. We undertook the first implementability assessment of existing clinical practice recommendations/guidelines for early psychosis in Canada. We extracted and content analyzed family-focused recommendations from Canadian early psychosis guidelines and mapped them along a family engagement framework. Based on this review, we highlighted how the content, quality and implementability of family-focused recommendations in extant guidelines may contribute to difficulties in involving families and offering family interventions in early intervention services for psychosis in Canada. Furthermore, we found a gap pertaining to eliciting and integrating stakeholders' preferences for family involvement in treatment of early psychosis in developing guidelines.

2. Addressing this gap, we sought to explore views and preferences regarding family involvement in early intervention for psychosis from the perspective of patients, families, and clinicians. Although previous qualitative research has investigated perceptions about, barriers to, and experiences with family involvement in treatment in single or two stakeholder groups, to our knowledge, no study has looked at both views and preferences for family involvement in early intervention contexts from the standpoints of all three pertinent stakeholder groups. Our group discussion, followed by a ranking exercise of statements and recommendations generated from the discussion, resulted in the identification of both nuanced insights and stakeholder priorities with respect to types of family involvement, influences on family involvement, contact between families and treating teams, and consent and confidentiality.

This is the first attempt to derive the preferences of multiple stakeholder groups for family involvement in early psychosis treatment in Canada and generate clear recommendations for navigating the logistics of family involvement and patient consent vis-à-vis family involvement.

3. The next original contribution to the field addressed a knowledge gap regarding how concrete forms of (e.g., reminders to take medication) and attitudes (e.g., perceived helpfulness) towards family involvement in treatment evolve over the course of follow-up in early intervention services for psychosis. Again, to our knowledge, no previous quantitative study has examined whether patients, families and clinicians differ in their reports regarding these concrete forms of and attitudes towards family involvement in treatment. The study makes many important original contributions by documenting that family involvement reduces over the course of follow-up, and more importantly, that there are important differences between clinicians and families' and between patients and families' perceptions regarding family involvement, with families generally viewing family involvement in treatment more positively and as occurring to a greater extent than patients and clinicians. These findings have substantive clinical implications as they clarify why families may feel less included in care than they desire, and highlight the importance of dialogue between families, patients, and clinicians at repeated junctures to align preferences and perceptions regarding family involvement.

Overall, this thesis substantively advances knowledge about (a) the positioning of family involvement in Canadian clinical practice guidelines for early psychosis, (b) patients', families' and clinicians' views and preferences regarding family involvement in early psychosis treatment (c) evolution in concrete forms of and attitudes towards family involvement in early psychosis treatment and (d) convergences and divergences between patients', families' and clinicians' reports regarding and attitudes towards family involvement in early psychosis care.

Collectively, it also yields clear recommendations for (a) improving early psychosis guidelines, particularly by integrating stakeholder values and strategies to apply recommendations in varied contexts (b) transforming positively current practices around family involvement in treatment through sustained dialogue between patients, families and clinicians about family involvement; strategies to navigate consent that view it as a fluid, multifaceted process that need not impede family involvement; and sustained contact between families and treating teams over the course of a follow-up in early psychosis services.

Contribution of Authors

This dissertation comprises six chapters and three manuscripts. I, Helen Martin, was responsible for the conception and writing of all components of this thesis. I am the first author of all three manuscripts included.

Manuscript I. A Critical Appraisal of Family-Focused Recommendations in Canadian Guidelines for Early Intervention Services for Psychosis

Prepared for submission to the Canadian Journal of Psychiatry, 2024

I conceived the idea of this project in collaboration with my supervisor, Dr. Srividya N. Iyer, in response to considerable knowledge gaps regarding family work recommendations for clinical practice in early intervention services for psychosis in Canada. I determined that an ideal first step would be to conduct a literature review of the state of family work recommendations and their implementability. I devised the research question, collaborated with co-authors to develop the search strategy, and handled all data extraction and analysis. I drafted the study's manuscript, which all co-authors revised and edited. Listed below are the specific contributions of each co-author.

- **Helen Martin** was involved in the project's conception, protocol development, data extraction, analysis, and interpretation, and manuscript writing.
- Nicole Pawliuk and Ruben Valle extracted data, analyzed, and provided feedback on the manuscript.
- Srividya N. Iyer was involved in the project's conception, methodology development, data extraction and analysis, and gave feedback on manuscript drafts.

Manuscript II. Exploring the Preferences of Multiple Stakeholder Groups for Family Involvement in Early Intervention Services for Psychosis Using Modified Nominal Group Technique

Prepared for submission, 2024.

I formulated this project in collaboration with Dr. Srividya N. Iyer. In analyzing results from the appraisal of implementability of family recommendations (the previous manuscript), I uncovered a key finding that the preferences of key stakeholders were inadequately reported or not elicited in the formulation of the clinical practice recommendations. We felt that efforts should be made to understand and explore stakeholder preferences regarding family involvement in early intervention services for psychosis.

I concluded that consultations with all pertinent stakeholder groups (patients, families, case managers and psychiatrists) using a modified nominal group technique was the appropriate methodology to complement our earlier efforts. Dr. Srividya N. Iyer, an expert in stakeholder engagement, provided key inputs in developing stakeholder engagement methodologies. I took primary responsibility for conception, recruitment, data collection, analysis, interpretation, and manuscript preparation. Drs. Taksal and Iyer, and I co-facilitated the group discussions and supported data analysis. I wrote the manuscript for this study, which was subsequently revised and edited by Drs. Taksal and Iyer. The specific contributions of each co-author are listed below.

- **Helen Martin** was involved in the project's conception, protocol development, data collection, analysis, and interpretation, and manuscript writing.
- Aarati Taksal supported data collection, analysis, revisions, and gave crucial feedback on the manuscript.
- Srividya N. Iyer was involved in the project's conception, methodology development, data collection and analysis, and gave feedback on manuscript drafts.

Manuscript III. Real-World Evidence for Family Involvement in Early Intervention Services for Psychosis in Canada - a Multi-Stakeholder Perspective

Prepared for submission, 2024

Our literature review and a preliminary analysis of manuscripts revealed a significant lack of empirical evidence regarding the actual nature of and attitudes towards family involvement in early intervention services for psychosis. Even more rarely, this has been examined from the perspectives of the three key stakeholder groups in the clinical encounter – the patient, the family member, and the clinician. With input and ideas from Drs. Taksal and Iyer, I iteratively identified pertinent research questions and the appropriate dataset for answering these questions. I also selected the appropriate statistical methodology with assistance from Daniel Rabouin (who has expertise in statistics) in actual analysis. I wrote the manuscript, and all co-authors provided feedback and edits. The specific contributions of each co-author are listed below.

- **Helen Martin** was involved in the project's conception, methodology development, data analysis and interpretation, and manuscript writing.
- Aarati Taksal was involved in the project's conception, supervised data identification, and provided feedback on the interpretation and manuscript.
- Daniel Rabouin was involved in data analysis and provided feedback on data interpretation and manuscript feedback.
- Srividya N. Iyer was involved in the project's conception, methodology development, data interpretation, and gave feedback on manuscript drafts.

Chapter 1. Literature Review

Section 1.1. Overview of Psychosis and Early Intervention

1.1.1 Symptomatology and Phenomenology of a First Episode of Psychosis

Psychosis is a mental illness characterized by symptoms such as delusions, hallucinations, social withdrawal, lack of motivation, disorganized thoughts, cognitive deficits and difficulties in occupational, relational, and social functioning. When people initially experience psychosis, they may exhibit a few or all these symptoms, feel agitated or sad, be highly aware of what is going on, or have no awareness at all (1). According to several studies (2-4), in the early stages of psychosis, individuals frequently encounter sadness, a sense of helplessness, and loss of emotions that are connected to both their present situation and their concerns about their prospects. The onset of psychosis is usually in late adolescence and early adulthood (5), with some variations based on context (e.g., higher age of onset in India compared to Nigeria and Trinidad, (6)).

A first episode of psychosis is also typically diagnosed in adolescence or young adulthood (2, 7, 8). In practice, this is often operationalized both in terms of meeting diagnostic criteria for a primary diagnosis of either schizophrenia-spectrum psychotic disorder or affective psychosis, with one or more of the following criteria (i) being a first treatment contact; (ii) not having used antipsychotic medication at all or not having used it for more than a specified period; and/or (iii) symptoms of psychosis or the psychotic episode have lasted for less than a specified time (9). First-episode psychosis generally impacts the achievement of routine developmental goals such as completing education, acquiring and retaining employment, and establishing interpersonal relationships (2, 10). Since onset is typically when young people form peer networks, transition to greater independence, and figure out their place in the world (11), first-episode psychosis can be particularly disruptive. Young people's aspirations for the future, their job, and their social ambitions are frequently threatened by this "disruption" (12). Individuals experiencing a first episode of psychosis benefit immensely from social support, especially family support (13). Given their young age, many individuals may still be living with their families, and most times, their families provide emotional, practical, and financial care and support.

1.1.2 Economic Burden of Mental Illness

It is estimated that the global burden of mental illness is 32.4%, and mental illness ranks as the 5th top cause of disability (14). Recent research by the Mental Health Commission of Canada (2011) found that mental health issues cost the Canadian economy $48.5 billion annually. Mental health issues are responsible for roughly 30% of short and long-term disability claims, resulting in $6 billion in lost productivity expenses (15, 16). In Australia, total government spending on mental health grew by 178% in real terms between 1992–1993 and 2010–2011 (17). With regards to the epidemiological burden of the disorder, the Global Burden of Disease (GBD) index is 15% of life years lost. Between 2011 and 2030, worldwide, the estimated economic cost due to mental disorders is US $16.3 trillion (18).

1.1.3 Incidence and Prevalence

The incidence of first-time psychosis is approximately 50 in 100,000, and for schizophrenia, it is about 15 in 100,000 people worldwide (19). Within Canada, 4% of Canadians (more than 1.5 million) will have an first-episode psychosis (20). Schizophrenia, in particular, the most prevalent psychotic disorder, affects around 1% of Canadians and has grown by 3% each year on average from 2002 to 2016 (21). In Quebec, the age-standardized prevalence of schizophrenia was reported to be over 33,000 individuals (0.4%) in 2009-2010 (22). Individuals with psychosis face several health issues, including a mortality rate that is 2.8 times higher than that of the general population (21). It is one of the top ten causes of Disability-Adjusted Life-Years (DALYs) (23), with the majority of psychosocial impairment in schizophrenia occurring within the first five years, if not sooner (23). In many high-income countries where this has been studied, the rates of psychosis are higher in immigrants and visible minorities (24, 25), with explanations for this finding typically centring around stress, adversity, and discrimination. However, some have argued that diagnostic biases and other systemically and structurally “racist” aspects of psychiatry may also have played a role in this regard (26, 27).

1.1.4 Etiology of Psychotic Disorders

There is no one specific known cause of psychosis. Instead, there are multiple pathways intersecting with each other that increase an individual's vulnerability to experiencing psychosis. Also, the current understanding is that risk factors may exert their influence at different points along the life course. Social determinants of health, such as the experience of adverse childhood events, violence, trauma, parental deprivation and neglect, poor living conditions, social deprivation, racism and discrimination, migrant status, urbanicity, and cannabis use, have been associated with increased risk for psychosis (28-37). Further, biological factors such as altered brain chemistry, neuroanatomy, and genetic factors are also known to predispose an individual to experiencing psychosis (38, 39). Fusar-Poli et al. (40) grouped 19 risk factors for psychosis, all of which had evidence from meta-analyses, into four categories: parental (e.g., parental psychosis), perinatal (e.g., pregnancy complications), social (e.g., immigrant status) and later (e.g., childhood trauma and adversity, cannabis use) risk factors.

1.1.5 The Psychosis Prodrome and Duration of Untreated Psychosis

An episode of psychosis is usually preceded by a prodrome (41-43). A prodrome of psychosis is a period characterized by persistent affective symptoms, anxiety, subthreshold psychotic symptoms, depression, social withdrawal, etc., often accompanied by a decline in overall functioning, which directly precedes the onset of a first episode of psychosis (44). The prodrome can extend for months or years before the psychotic symptoms can start manifesting clinically, according to retrospective and prospective research (45, 46). Attenuated positive psychotic symptoms, such as growing suspicion, unusual thoughts, and odd perceptual experiences, start to appear at this stage.

The period between the onset of a psychotic episode and the beginning of effective treatment is known as the duration of untreated psychosis (DUP) (47). A longer duration of untreated psychosis has been associated with less optimal short- and long-term patient outcomes (47, 48). There is also an abundance of research linking a longer duration of untreated psychosis with higher levels of depression, anxiety, and disorganization symptoms, as well as poorer quality of life and lower cognitive and social functioning (48-53). Additionally, there is also some research linking the duration of untreated psychosis with neurobiological consequences, including functional brain connectivity (54) and a reduction in grey matter volume (55, 56); however, the evidence for this is still equivocal (57).

In an umbrella review and random-effects meta-analysis including 13 meta-analyses (129 individual studies, total sample = 25,657 patients), Howe et al. (58) concluded that there was strong, clear evidence for duration of untreated psychosis being an important prognostic factor for positive symptoms, negative symptoms, and self-harm at first presentation and positive symptoms, negative symptoms, and remission at follow-up. There was trend-level evidence for the impact of DUP on functioning at a follow-up. Beyond this evidence, the duration of untreated psychosis has also been shown to be socially toxic (impacting relationships and social-functional roles at critical stages in young people's development) (59) and cause suffering (60), the latter providing the most robust ethical rationale for reducing treatment delays.

1.1.6 Early Intervention Services for First-Episode Psychosis

Research has indicated that initial outcomes after the onset of psychosis significantly influence its longer-term outcomes (7, 61, 62). The 2–5-year period after the first episode of psychosis is also an optimal time to intervene, provide treatment, and positively change the trajectory of psychosis (63). Along with the evidence for the detrimental consequences of the duration of untreated psychosis, this perspective regarding the prognostic significance of the first 2-5 years, called the critical period hypothesis (61), propelled the development and implementation of early intervention services for psychosis. Rejecting the historically bleak outlook towards psychosis, early intervention services for psychosis are characterized by optimism, recovery, orientation, and hope (63).

Early intervention services are typically offered to youth between 14 and 35 years old. It aims to potentiate recovery in young people experiencing their first episode of psychosis and prevent relapses by offering high-quality interventions early in the course of psychosis (typically for 2-3 years) (64-66). It comprises multidisciplinary teams (case managers, psychologists, psychiatrists, nurses, occupational therapists, etc.) which offer individualized outpatient based assertive case management and medical treatment with low-dose second-generation antipsychotic treatment, along with a range of additional psychological and psychosocial interventions such as supported employment and education supports, cognitive behaviour therapy, cognitive remediation, psychoeducation, family interventions, peer support for patients and families, etc.

Several randomized controlled studies (including (67-69)) and meta-analysis (including (70)) have shown that early intervention services are associated with better patient outcomes than standard care. In Correll et al.'s (71), meta-analysis (10 randomized clinical trials, 2176 patients), early intervention services were associated with better outcomes than treatment as usual, with respect to 13 domains, including all-cause treatment discontinuation, total symptom severity, positive symptom severity, negative symptom severity, general symptom severity, global functioning, remission, involvement in school or work, recovery, number of psychiatric hospitalizations, duration of psychiatric hospitalizations, depressive symptom severity, and quality of life (listed in descending order of outcomes with the best impacts of EIS being listed first and so on).

Early intervention services acknowledge and situate families as caregivers, care receivers and advocates for youth experiencing their first episode of psychosis, arguably to a greater extent than traditional psychiatric services. Globally, early intervention service guidelines encourage the involvement of families in the care and treatment of patients with first-episode psychosis (72-74).

1.1.7 Early Intervention Services in Canada

Early intervention services in Canada began in the late 1990s, with the first set of programs developing around the same time in Quebec, Ontario, and Nova Scotia. Thereafter, multiple services have started to be established across Canada in the provinces of Ontario (N=60) (75), Quebec (N=31) (76), Alberta (N=2) (77, 78), British Columbia (N=50) (79), Nova Scotia (N=4) (80) and New Brunswick (N=4) (81). Many of these services are concentrated in urban areas, with people in remote and rural areas and some jurisdictions having reduced access compared to others.

In Canada, early intervention services are provided through stand-alone programs (e.g., Prevention and Early Intervention Programme for Psychosis, Montreal (63)), hub and spoke models, early intervention embedded within assertive community treatment or other mental healthcare teams and sometimes combinations (e.g., the Nova Scotia Early Psychosis Programme is a stand-alone program for residents in the Capital Region of Nova Scotia and also provides only consultation and specific other services to those in other regions of the province or other Maritime provinces (80, 82, 83)).

In Canada, healthcare is primarily provincially administered. Only four Canadian provinces—Ontario, British Columbia, Quebec, and Nova Scotia—have provincial early intervention service standards and have prioritized it for psychosis in their mental health policies (84). Early intervention services differ in terms of availability, style of delivery, and policy/funding allocation across and within those provinces. Currently, Canada lacks a pan-Canadian federal policy commitment to early intervention for psychosis, and there are no national, pan-Canadian guidelines for early psychosis (63). This stands in sharp contrast to both Australia's federal government's intention to follow Britain's lead and the UK's policy-driven scaling expansion of early intervention services to cover the entire population (85).

Section 1.2. Families and Caregiving Experiences in Psychosis

1.2.1 Caregiving Experiences of Families

Families are the first kinship group an individual is a part of. Caring is fundamental to being human and takes several forms depending on historical, societal, and cultural circumstances. In the context of mental health, family can refer to any individual who is identified as invested in the recovery of the person with mental health problems, and there can be biological, emotional, legal, or social relationships between the family and the affected person (86). Usually, families are not professionally trained and do not receive monetary compensation for caring for a person with mental health problems (87, 88).

Families who have a loved one experiencing psychosis face multiple challenges during their caregiving journey. While they may witness changes in the young person, they may not be able to identify it as psychosis or understand that mental healthcare needs to be sought. Even if they have awareness, systemic barriers such as poor availability, low accessibility, long pathways to care, and long wait times may prevent patients and families from receiving timely help (89). Further, mental healthcare systems and clinicians may prioritize addressing only the patients' needs, not their families' (90).

Families have to acquire new behaviours and ways of thinking in order to cope with these changes occurring in their lives. Thus, the experiences of families in caring in psychosis are often characterized as emotional rollercoasters. While caring can be seen in some cultures as an extension of "normal caregiving", it can impact the social, work, and recreational lives of families. Working hours may need to be reduced or a family member may need to quit their job, which will exacerbate any financial difficulties that exist and also cause conflicting emotions like anxiety, worry, shame, unrest, resentment, and fear (91).

In addition, those living in rural locations are less likely than people living in urban regions to obtain mental health therapy (92). Rural residents frequently lack proper access to doctors (93), mental health services (92), and emergency psychiatric treatment (94) since rural regions usually have fewer and more dispersed resources. Issues like lengthy commuting hours to consultations or a lack of high-quality services may make it more difficult for caregivers to access services when they live in underdeveloped or remote locations (95).

1.2.2 Family Burden

Traditionally, the term "burden" has been used to reflect the impact caring has on families (96). It is frequently used in research to describe "all the difficulties and challenges experienced by families as a consequence of someone's illness" (97)). This might include psychological distress, monetary strain, laborious caring obligations, disturbance of regular routines and other household chores (98). Concretely quantifiable and measurable negative effects on families (e.g., costs incurred by being unable to work as many hours as before due to caregiving, financial costs in supporting an ill one's medication, treatment or housing expenses, time spent in travelling to appointments, etc.) are included in the concept of objective burden. The psychological anguish brought on to families by their loved one's mental illness and the negative emotional impact it has on them are both examples of subjective burden (99).

1.2.3 Personal, Physical, Emotional, Social, and Economic Impacts

Caregiving can affect a family's physical and emotional wellbeing in addition to causing financial strains. Taking a public health perspective and focusing on caregiving more generally (beyond only mental health), Talley and Crews (100) cautioned that families need and deserve support from a nation's public health system to maintain their own health (p. 226). They argued that families incur higher morbidity and mortality because of their engagement in caregiving activities. Higher stress levels and decreased engagement in preventative health behaviours such as exercise, well balanced eating, routine visits to the doctor for one's own health and sleep, are frequently contributing factors to the deterioration in families' wellbeing (100).

Various specific situations faced by family caregivers of loved ones with psychosis, such as receiving a diagnosis of early psychosis, not adhering to treatment, societal stigma, being hospitalized for psychiatric reasons, and participating in shared decision-making, have been studied to better understand the psychological aspect of family caregiving for persons with mental illnesses. Caregiving experiences can also vary based on other intersecting identities of families, e.g., younger caregivers may experience more burden (101, 102).

In a systematic review, Shiraishi and Reilly (103) highlighted the emotional effects of caring for individuals with mental disorders to be both positive and negative. Negative emotions included a sense of duty (104); sacrifice (105); sorrow (106, 107); responsibilities, stress and exhaustion when participating in shared decision-making regarding their relative (108); and distress in response to their relative's hospitalization (109). Family caregivers experience emotions like fear, suspicion or even insecurity when their loved one does not follow treatment recommendations or medication plans (110). Providing care can also have a detrimental effect on the primary caregiver(s)' social relationships (111). Conversely, studies have also documented positive emotions in family caregivers such as appreciation, personal development, love, empathy (112), fulfillment, a sense of endurance, value, and success (96).

Individuals experiencing mental health problems often find themselves facing stigma. Eventually, the stigma of mental illness impacts not only those who struggle with it but also their families just by being associated with them, called stigma by association (113). Stress and worry, a decline in social connections, social isolation, and feeling treated poorly or with less respect in society were described by family members who had encountered stigma by association. Studies show that some family members invest their time and resources into masking their ties to the person who has a mental illness, as a result of these experiences (114, 115).

According to a recent study that used data from Statistics Canada's 2018 General Social Survey (116), the replacement cost of family caregiving for physical or mental health conditions is estimated to be 5.7 billion hours of work, with a potential cost of $97.1 billion to $112.7 billion (117). According to the 2012 General Social Survey, 390,000 Canadians quit their occupations to care for others, 600,000 cut back on their hours worked, 160,000 declined paid employment, and 1.6 million took time off work (118, 119). In addition to workers' and employers' employment-related expenditures, society bears the consequences of lower tax generation and increased pressure on the health and social support systems as a result of caregiving (120, 121).

1.2.4 Needs of Families of Persons with First-Episode Psychosis

Families of individuals with first-episode psychosis have significant challenges gaining access to appropriate care. They sometimes report experiencing healthcare personnel's demeaning and superior attitudes, claiming that their lived expertise and knowledge about their ill family member is ignored in favour of professional expertise (122, 123). Evidence from a review in Canada (124) shows that specialized, integrated first-episode psychosis services that appreciate and engage families can help them maintain caring for their loved ones with psychosis. During the initial contact with mental health services, families are interested in learning about psychosis, how it is treated, how psychotropic medicines function, and any potential adverse effects, and how long psychosis and treatment will last (125, 126).

It is necessary for family caregivers to receive direction on how to use literature and internet resources, and available mental health services (125). A realistic timeline for diagnosis, treatment, and recovery can be presented by the treating team (127). It is crucial for families to identify early indicators of relapse after a person is in remission (125, 127). One way to communicate knowledge to families is through a handbook, with modules making it simple to return to topics later (125). However, such psychoeducation per se is insufficient. When delivered independently, caregivers report feeling despondent and helpless about the future (126). In this tough time, being armed with information does not meet the needs of families. They frequently perceive clinicians as not recognizing the affective component of their supportive duties (127), and not considering them as treatment partners (128). Strategies around consistent and deep involvement of families may be required to help families feel empowered.

The philosophy of early intervention services emphasizes shared decision-making and engaging families as partners in the treatment and care of the person with psychosis. Such a philosophy can also help families feel supported and respected (128). To summarize, caregivers need psychoeducation, problem-solving skills, support from their peers, and professional guidance to deal better during this period (129, 130).

1.2.5 Benefits of Family Involvement in Care and Treatment of Persons with Psychosis

Research over the last many decades has shown that involving families in the care and treatment of a person experiencing psychosis has immediate and long-term benefits for the person’s recovery. Family involvement has been shown to result in favourable patient outcomes in psychosis, such as fewer relapses (131-135), a longer time between each relapse (132), fewer hospital admissions (131, 136-138), shorter hospitalization periods (139), social and vocational functioning (140), better subjective recovery (141, 142); and lower long-term unnatural-cause mortality(143, 144). For individuals with schizophrenia, family involvement has been proven to reduce residual psychotic and neurocognitive symptoms, as well as aid in the earlier detection of relapse signs (145).

Patients' improved self-reported quality of life is also connected with family involvement (146, 147) as are fewer social impairments (137, 138, 148). There is proof that these gains last if family engagement is regularly maintained during the time of illness (134, 149). Also, families could support patients in gaining access to mental healthcare during times of crisis (150, 151). Family involvement is advantageous not only to the patient, but also their families. Further, as families receive care for themselves from mental healthcare services (in the form of psychoeducation, family therapy, peer support, etc.), family burden, caregivers stress and expressed emotions decrease, and families experience better quality of life and improved health outcomes for themselves and feel better equipped to support their loved one's recovery (125, 130, 135).

Participation by families in advocacy groups has had several positive effects, including changes in laws and government regulations; better policies and practices for promotion of mental health, safeguarding, advancing of the rights and interests of people with mental disorders and their families, prevention of mental disorders, and better mental health services, treatment, and care (152).

Family members tend to pass through phases of coping and acceptance before entering a third phase of political and personal advocacy (153). The study conducted by Muhlbauer (154) focused on phases in a family's journey in their caregiving for individuals experiencing chronic and severe mental illness. The findings indicate that after experiencing a period characterized by instability and crises, families subsequently entered a phase marked by growth and advocacy. In spite of challenging circumstances, they gained confidence to act as their own best advocates and recognized their abilities. A significant number of participants demonstrated a sense of competence in effectively articulating the needs and requirements of their ailing loved ones.

Various forms of advocacy efforts exist, encompassing activities such as disseminating information, raising awareness, providing mutual aid, offering counselling services, mediating conflicts, and safeguarding interests. The aforementioned initiatives aim to mitigate various obstacles to recovery, including the limited availability of mental health services, the social stigma surrounding mental illnesses, the violation of patients' rights, inadequate advocacy efforts, insufficient access to housing and employment opportunities (155).

The role of the family in services for mentally ill individuals is crucial and multifaceted (156). Firstly, families act as advocates for their mentally ill family members in the healthcare system. They possess intricate knowledge about their loved one's condition, treatment history, and specific needs. This knowledge, combined with their emotional investment in the individual's recovery, enables them to articulate concerns and preferences to healthcare clinicians. In doing so, families can ensure that the treatment plan aligns with the needs and goals of the individual. In addition, there are indirect benefits to involving families as they aid in their loved ones' activities of daily living (if needed) (e.g., personal self-care, etc.); instrumental skills development (e.g., managing finances, interpersonal relationships, etc.) and restoration and recovery journeys – their presence and involvement are often a point of continuity even as treatment teams change or transition or reduce their involvement. It is no surprise that there is consistently strong evidence for the associations between family involvement in treatment and increased medication and treatment plan adherence (137, 157) and better service engagement (158-162).

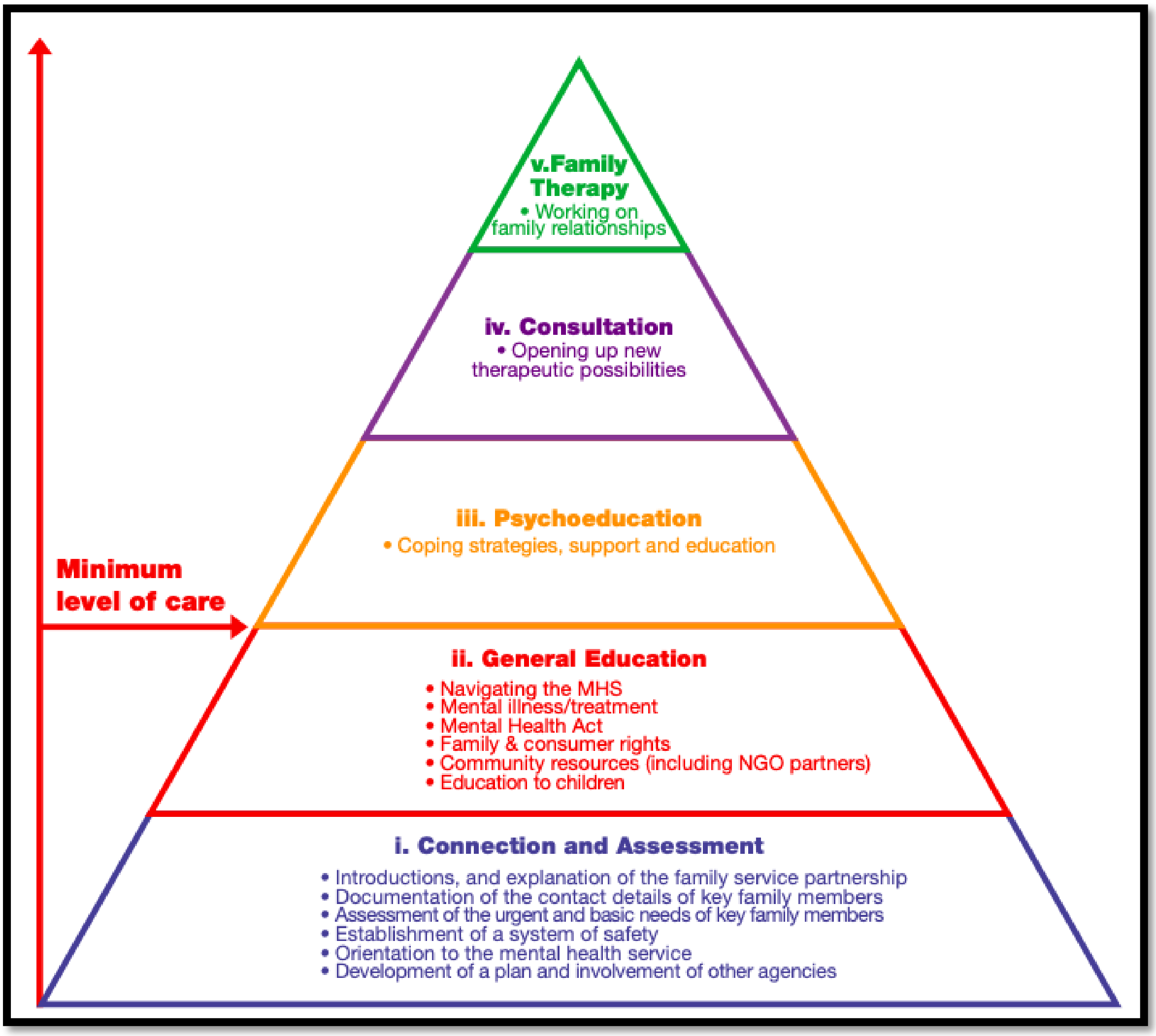
Section 1.3. Frameworks for Family Involvement in Treatment of Psychosis

Family involvement in treatment refers to a spectrum of ways in which families promote the treatment of a person with psychosis, receiving mental healthcare services, including early intervention services for psychosis (163). At the start, families act as key informants, sharing information about the young person that can facilitate with the identification of treatment goals and creation of treatment plans. Further, they can receive interventions which can help them understand psychosis and the treatment better (e.g., psychoeducation), help them reorganize family dynamics (e.g., family therapy) and cope better with the changes that psychosis brings to the family (e.g., problem-solving skills, communication skills). In turn, their burden reduces, they are better skilled at supporting their loved one's treatment and recovery journeys; the family environment has reduced expressed emotion and stress. Another way for families to get involved is for clinicians to include them in shared decision-making regarding treatment. Families may also take up an advocacy role, not only advocating for their specific family member with psychosis, but generally for making systemic changes to improve outcomes in psychosis (164). Engaging families in the treatment of a person with psychosis is an ethical responsibility of the mental healthcare system and clinicians as there is growing emphasis on developing stakeholder-driven mental healthcare services with a recovery orientation (165).

1.3.1 Pyramid of Care

The pyramid of care (166) reflects how families can be involved in mental health treatment (167). When adapted to the context of psychosis, levels 1 and 2 indicate that treating teams must establish a connection with all families, assess their needs, improve their awareness, educate them about psychosis, empower them with generic coping skills and strategies to manage psychosis and the family, and help them access available resources (e.g., community or hospital-based, online, reading materials, etc.). Thus, it is suggested that a basic and universal level of care be assured to *all* families.

Support mechanisms available at levels 3-5 can be provided by clinicians to families who want more help in the form of intensive psychoeducation and family therapy (166). Thus, the pyramid of care is based on a stepped-care approach (168). Multiple levels of support implies that there is scope for continued family involvement in treatment which can be modified based on the changing needs of the person with psychosis and of the family.



***Reassessment of individual and family needs and connecting with other services must be carried out at each level of care.**

Figure 1: Pyramid of family care.

Image from: Bickerton, A., Hossack, K., & Nair, J. (2007). Also used in Martin, H., Taksal, A., Xavier,S., Levasseur, M. & Iyer, SN (2022). Family involvement in mental healthcare. In Lecomte, T and Leclerc, C (Eds.). Manuel de réadaptation psychiatrique. 3e édition. Presses de l'Université du Québec.

1.3.2 Triangle of Care

The Triangle of Care was developed by families in England to provide clinicians with a framework that they could use to involve families in the treatment of persons with mental health problems, including psychosis (169, 170). The framework emphasized families as collaborative partners in providing treatment. The Triangle of Care lists six primary standards of family involvement in treatment and advocates for the provision of resources to assist clinicians in effectively including and supporting families during episodes of acute mental illness. The primary objective of the Triangle of Care approach is to foster a partnership between clinicians and families across various levels of care, ranging from individual care provision to the broader scope of service planning. Thus, the Triangle of Care is broader in its scope for involving families in treatment, compared to the pyramid of care (166).

The involvement of families is advantageous for clinicians, families, and patients alike. The notion of a triangle has been put forth by numerous families who aspire to be recognized as engaged collaborators within the caregiving team. Many families acknowledge the importance of establishing a collaborative relationship among patients, families, and clinicians. In this three-way partnership, all voices are valued and have an impact on care treatment decisions, ultimately increasing the likelihood of successful recovery.

The effectiveness of the Triangle of Care is contingent upon the willingness of both the clinicians and the families to actively participate and engage in treatment. There is an ethical and moral responsibility on clinicians and services to actively promote and encourage this collaborative partnership between families, patients, and themselves.

The Six Key Standards of Triangle of Care
1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2) Staff are ‘carer aware’ and trained in carer engagement strategies.
3) Policy and practice protocols regarding confidentiality and sharing information are in place.
4) Defined post(s) responsible for carers are in place.
5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6) A range of carer support services is available.
Source: Worthington, A., Rooney, P., Hannan, R. (2010). The Triangle of Care Carers Included: A Guide to Best Practice in Mental Health Care in England. Second Edition.

Section 1.4. Types of Family Interventions

1.4.1 Family Psychoeducation

Psychoeducation refers to the knowledge (illness-related, communication skills, problem-solving skills, etc.) provided by clinicians (sometimes along with family and patient peers) about psychosis and its treatment to families (171). Psychoeducation often comes through individual or group training (in person or online), with participants including patients and/or families, and clinicians providing information (172-176). It is a key component of evidence-based care for patients diagnosed with psychosis (175, 177).

Numerous randomized controlled trials and systematic reviews attest to the clinical and recovery benefits of families participating in psychoeducation, including reduced relapse rates, improved understanding of symptom triggers and warning signs of despair, a boost in self-efficacy and hope, a sense of empowerment, and a greater use of mental health services (178-180). Given this, it is regarded as a recommended practice to provide family members with the right education (Health Service Executive (HSE), 2019). According to several studies (174, 181-183) , positive engagement of family members with psychoeducation programs has been linked to interrupting problematic patterns of interaction between the patient and family members. Additionally, it has been demonstrated to have a good influence on the caregiver’s perceived burden, coping skills, and crisis problem-solving (184).

Few studies have specifically investigated attributes that influence involvement with group psychoeducation. The research that has been published on various dimensions of involvement reveals that clinician, participant, and intervention factors all influence families’ participation in psychoeducation programmes. Family-related variables include their mood (185), conflicting demands (185, 186), challenges in the group contexts, and confidentiality concerns (187). Personal conviction in the therapeutic value of group psychoeducation (188) and their abilities in encouraging participant engagement (185, 189) are examples of clinician-related variables.

A recent study (190) found that some elements that increased involvement in psychoeducation were driven by participants, well-involved clinicians, peer co-facilitation and assistance, and trained and sensitive facilitators. Some of the barriers identified were patients' poor readiness to involve their family member(s), their concerns about stigma and confidentiality, a need to dissociate oneself from mental health services, a lack of encouragement for program engagement within households and uneasiness within the group. With regards to the programme, inconvenient timing and barriers related to the duration, accessibility and visibility of the program were noted. Poor skillsets possessed by clinicians were a barrier to engagement from the clinician's side. Racial-ethnic differences have also been noted in the uptake of family interventions such as psychoeducation (191).

Briefly, a few notable mentions of different kinds of psychoeducation for psychosis developed in Quebec, are 1) AVEC (French)/WITH (English) (Accompagner, Valider, Échanger, Comprendre/ Wellness, Inform, Talk, Help), a multifamily group intervention for family cognitive behaviour therapy for early psychosis (CBTp) (192) and 2) and Profamille, a two-year, evidence-based family group psychoeducation programme for psychosis spectrum disorders (193, 194). Most early intervention services for psychosis offer group family psychoeducation (82), with varying rates of uptake and low uptake particularly among family members other than mothers (195).

1.4.2 Multifamily Group Therapy

Multifamily group therapy is an evidence-based therapy which combines elements of family psychoeducation and behavioural family therapy (196), provided to multiple families (and their loved ones with psychosis) in a group setting (197, 198). Multifamily group therapy is a four-stage method that begins with creating rapport with families, followed by psychoeducational seminars on the illness, relapse prevention utilizing problem-solving skills, and ultimately, offering vocational and social skills training. It is believed that by learning and sharing their experiences in a group setting, families can expand their social networks and social capital, decrease isolation and stigma, enhance their problem-solving abilities, and reduce the impact of psychosis on the person and the family. Over a two-year period, evidence suggests that multifamily group therapy is effective in lowering relapse and hospitalizations and enhancing family wellbeing (171). Despite this, there are several challenges to establishing and sustaining multifamily group therapy in clinical practice (around bringing 4-5 families and patients together regularly for many months; funding for hiring and training therapists; drop-outs, and so on).

1.4.3 Family Therapy

In the context of psychosis, many families can effectively address conflicts and enhance relationships and emotional wellbeing by themselves or through shorter interventions like psychoeducation. However, some families may require more intense, extensive and long-term assistance. Family therapy is a form of psychotherapeutic intervention that aims to alleviate distress or conflicts within families by altering the dynamics and interactions among its members, facilitated by a family therapist (199). The objective of family therapy in cases of severe mental illness is to discern familial dynamics that may contribute to the exacerbation of the patients' distress, while concurrently shifting the emphasis towards treating the family as a unit, rather than an individual person who experiences the illness.

Family therapy can be grounded in various theoretical frameworks. Family therapy, which is grounded in the theoretical framework of Family Systems Theory (200), conceptualizes each family as a complex system comprised of various subsystems (such as parents, children, couples, and siblings). Additionally, families are seen as existing within a larger supra-system (such as a caste, tribe, culture, society, or legal framework) that exerts influence and shapes their functioning.

According to Shi et al. (2017) (201), within the framework of systemic family therapies, symptoms of psychosis are regarded as playing a substantial role in familial relationships and interactions. Systemic family therapists aid families in dismantling detrimental patterns of interaction by engaging in discussions regarding the significance they attribute to symptoms, as well as identifying the ways in which symptoms are perpetuated through circular interactions. According to Burbach (2018) (202), the outcome of this phenomenon is the re-evaluation of behaviours, enhanced comprehension among individuals, and the amelioration of interactions and the overall emotional atmosphere within the familial unit.

Behavioural family therapy (196) is an intervention that focuses on imparting skills to family members. This intervention aims to educate them about the illness and its management, enhance their communication abilities, facilitate problem-solving, and promote effective stress management. In the management of severe mental disorders, it is frequently employed either as a stand-alone intervention or in conjunction with family psychoeducation. The sessions encompass the participation of the patient as well as other family members, typically spanning a duration of 10-12 sessions conducted over a period of six months. Behavioural techniques, including the implementation of reinforcement, role plays, rehearsal, homework exercises, and instructions, are employed as a means to induce change.

1.4.4 Family Peer Support

Family peer support is based on the premise that establishing meaningful interpersonal connections and fostering a collective sense of community are fundamental to the healing process (203). This model of family involvement emerged from the framework of self-help groups. Family peer support groups are support groups where families get together to listen and support each other as they care for their loved one who is experiencing psychosis.

Peer support is commonly distinguished by its reciprocal and egalitarian nature, wherein individuals who have encountered comparable challenges engage with others in a supportive manner. Adapted to families, peer support refers to the provision of social and emotional support, often accompanied by practical assistance, by individuals with similar conditions and difficulties (204). Within the framework of the peer support group, it is possible for a family to encounter individuals who share similar conditions and identify themselves as actively engaged in the process of facilitating recovery (205, 206,207, 208).

Cohen and Mullender (209) categorize peer support groups into three distinct types, namely remedial, interactional, and social, based on their respective emphases on personal, interpersonal, and/or sociopolitical aspects within the recovery process. The remedial group places its emphasis on the individual's process of recovery, while the interactional group focuses on both interpersonal relationships and personal experiences. On the other hand, the social goals group integrates the personal, interpersonal, and political aspects.

Family peer support is often employed to assist behavioural change and self-care in an array of chronic diseases (210). The milieu of a peer support group generates a sense of psychological support, information sharing, camaraderie, reassurance and acceptance among group members, unlike typical healthcare facilities, which are frequently stigmatized by the wider community (211, 212). It is thought that these positive attributes can successfully address hopelessness and behavioural issues related to mental illness, specifically psychosis-spectrum disorders, by means of interpersonal sharing, modelling, and help within or outside of group sessions (213, 214). In early psychosis, family peer support has been associated with hope, wellbeing, and empowerment (203).

Section 1.5. Barriers to Family Involvement in Care and Treatment for Psychosis

Despite documented benefits of family involvement for patients' recovery and families' wellbeing, there are many reports that mental healthcare systems and clinicians do not provide adequate space for involving families in treatment for persons with psychosis (215-217).

Generally, more families are inclined to be involved in treatment, than not, in treatment for psychosis (218, 219). Nonetheless, in psychosis in general and in early intervention services for psychosis in particular, family involvement in treatment and the uptake and implementation of family interventions like psychoeducation is not always consistent (220). Racial-ethnic differences have been noted in the uptake of family interventions such as psychoeducation (191). In a large, randomized trial of NAVIGATE, a specialized treatment program for psychosis in the USA, 69% of family members did not take part in family psychoeducation and only 29% attended five or more appointments(221), with non-Caucasian families being more likely to have not attended at least 5 appointments. Secondary analyses found that families of black participants were less likely than those of white participants to receive family psychoeducation(191).

A multinational study in early psychosis that was carried out in Norway and Denmark found that 89% of families agreed to be involved along with their loved ones in a multifamily psychoeducational program while 8% (n=20) of the family overtly refused, and other reasons for non-participation majorly stemmed from a patient’s refusal to involve families (n=79, 33%), or language barriers or history of sexual abuse within family, or families were far away from the clinic or caring for physically ill individuals (n=26, 9%) (218). Another study in Italy revealed that 23% of family members declined an invitation to participate in psychoeducation, while the rest actively attended (222).

In the Canadian context, 88% of families were reported to attend at least one of three sessions of psychoeducation in a Montreal early intervention service for psychosis (195). For this same program, Iyer et al. (162) found that while a high percent of families (70-80%) were involved during the first few months of treatment, this reduced over the course of treatment. This study is among less than a handful of studies in early psychosis that have looked at how family involvement changes over the course of a follow-up. Furthermore, the literature is also generally restricted to a course, binary indicator of whether families are involved or not at a point in early psychosis treatment, typically upon entry (223, 224). On the other hand, in a large early intervention program in Ontario, family reported top barriers for treatment disengagement endorsed by both patients 28.7% (n = 48) and families 39.2% (n = 31), was medication side effects, the location of services (26.6%, n = 21), the hours that services are available (19.0%, n = 15), patients' desire to handle issues on their own (16.5%, n = 13), and patients' dislike or lack of trust in the doctor (17.7%, n = 14) (225).

While it is well acknowledged (as well as documented in qualitative research) that families are involved in various ways in treatment for early psychosis, few (if any) studies have documented about the actual extent to which families concretely support treatment, for example, by reminding their loved one to take medication or by accompanying them to their appointments (one of the gaps my doctoral work seeks to address). Overall, however, there is consensus that we need to better understand and systematically address factors that influence family involvement in treatment and the successful implementation of family interventions in early intervention services for psychosis.

Below we summarize the literature on barriers to family involvement in psychosis, most of which comes from multiple-episode schizophrenia studies with a smaller proportion from early psychosis. Further, while theoretical and evidence synthesis on barriers (226) have organized barriers at the level of various stakeholders (patients, clinicians, families, systems), most investigations, including in early psychosis, have rarely studied family involvement from the lens of various stakeholder groups within the same study (again, these knowledge gaps informed by doctoral work).

Individuals with psychosis may be unwilling to have their families involved in treatment, with concerns about privacy, being judged, worry about causing more stress and burden, fear of being stressed through their involvement, and poor interfamilial relationships (227-230). In addition, for persons with psychosis, stigma and discrimination also prevent them from reaching out to others and getting them involved in the treatment process (114, 231, 232). Lack of patient consent to involve families is also mentioned as an obstacle to their involvement in treatment by professionals (89, 127, 233).

Some reasons why families may not be keen to get involved in treatment maybe that they think their participation would not make a difference to their ill loved one or that their ill loved one does not require help (186, 219). Further, the families might not think that the treatment process concerns them (234). Families may also not realize the value in continuing to participate in the treatment after the initial contact with clinicians (235)). Studies have also found that families withdraw from getting involved when they receive inadequate and unclear information about psychosis and the treatment (236, 237).

Sometimes families may be concerned about how their loved ones may react when they share some information about them to the clinicians. Being wary of disrupting their personal relationship with the patient and the therapeutic relationship between the patient and the clinician, families may be selective with the aspects of treatment they want to get involved in (238, 239). Families sometimes express concerns about whether they are the ideal family member to get engaged in the process. Competing demands such as job, child and elderly care and social commitments can also impede family involvement (239, 240). Difficult family dynamics (226, 241), families' frustrations with mental health services, their procedures, wait times, poor service management (242) or use of jargon in communication (243) can further hinder families' involvement.

First-time family carers of a person experiencing psychosis may face two specific additional barriers to their involvement in treatment. First, they may have a limited understanding of resources; and second, an uncertainty about how to access services. Some families may be unsure of whom to turn to for assistance or where to find relevant resources. Also, when approaching various agencies, families may not succeed in accessing services for their loved one because of restricted criteria for entry, such as diagnostic and age restrictions or because some services do not take on “cases” when only a family member seeks help (without their ill family member). However, with perseverance, first-time carers often finally learn about the existence and location of early intervention services, sometimes through friends and even through general physicians (244).

Clinicians have also reported challenges in identifying supportive family members and involving them in treatment (112, 245-250). Family involvement in treatment is a question of both how willingly clinicians and services invite families on board, and about families themselves taking the initiative (or having the capacity) to be involved. Recently, a study in Montreal, Canada reported that the family contact with the treatment team in an early intervention service decreased over the course of a follow-up. The median months of contact was 10 out of a total of 24 months. A deeper examination indicated that over the course of the service, the number of families for whom clinicians deemed contact as not necessarily increased with time (162). Thus, clinicians' perspectives influence family involvement in treatment. Clinicians maybe unwilling to include families in treatment if they are seen as overly involved (104, 251) or have poor knowledge of mental illness (186, 248, 251). However, few studies have examined how clinicians navigate competing priorities such as family involvement and a heavy caseload with many imminent responsibilities.

Prior research has shown that among patients with psychosis, a significant minority reported that clinicians' attitudes and beliefs also impeded family involvement in treatment (187, 252). Clinicians sometimes place an excessive emphasis on the privacy of the treatment which hinders family involvement and denies families access to important information (even general information about the illness or treatment which is possible even if their ill loved one has denied consent) (237, 253). Clinicians' belief that families should take the responsibility for caring for their relative without feeling that treatment teams should then be responsible for informing and equipping them, as well as the constant struggle of who knows the best for the ill individual remain major issues (238, 254).

At the other end of the spectrum, clinicians report having fears, uncertainties and questions about their own competence in involving families in treatment (246, 255, 256) and working with them collaboratively (186, 237, 256, 257). There may also be instances of inter-professional conflict (between nurses versus psychiatrists) about who should lead family interventions and each of their specific roles and responsibilities in this regard (256).

Yet another barrier related to clinicians and services perceived by families is that care is not flexible enough to accommodate family needs (252). Family members' descriptions of organizational barriers include the absence of resources required to execute family involvement, such as time, space, etc. (237, 238). Large-scale organizational impediments described by clinicians include the shortage of time for family interventions and logistical challenges (186, 187, 237, 239, 248-250, 256-259), and issues with assigning family interventions a higher priority within the service (112, 247, 249, 256).

First-time caregivers face three major first-episode psychosis service-focused barriers because of both systemic and procedural flaws in service delivery. One structural barrier that they may face is a lack of mental health services specializing in first-episode psychosis or meeting the specific needs of younger patients. Another obstacle to overcome is that their ill family member must seem truly ill to physicians; otherwise, they could be refused admission to service. Thus, caregivers continue to struggle to find help for their family member until they are admitted to services. Concerns regarding poor service response in crisis situations, particularly during late-night hours and weekends, are another service-related procedural obstacle.

1.6. Caregiving in Psychosis - the Canadian Context

A Statistics Canada report (260), evaluated various categories of family caregivers based on their relationships to care recipients (patients). Note that this was not an exclusively mental health-focused study. This report observed that in 2012, 8 million Canadians, or 28% of the population over the age of 15, cared for loved ones or acquaintances who had a chronic illness, a disability, or issues related to ageing. According to the survey, 8% of the most common/regular caregivers—those who provided care for a loved one at least two hours each week—cared for their spouse or partner, and 5% of them looked after children under 18 years of age.

For all caregivers of children (i.e., those below 18 years of age), mental health issues were the primary cause of caregiving (23%). For caregivers of a spouse or partner, mental health stood as the 4th cause. Moreover, although elder parents' caregivers were more numerous, they have less overall stress than caregivers of partners and children. The study also discovered that they were more affected by the psychological, physiological, financial, and occupational repercussions of caregiving. Psychological symptoms of caregivers included worry and anxiety, exhaustion, rage, and agitation, feeling weighed down, and difficulty sleeping. Many people claimed to believe that providing care has a negative impact on their own general health and that their financial commitment was also significant. One in four working family caregivers of a partner or child with a mental health problem had fewer working hours which translates to lower pay.

Lately, a few policy documents and initiatives have been launched to address the taxing circumstances of caregivers and their special needs. Among these initiatives are the *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses* (121) developed by the Mental Health Commission of Canada and launched in the year 2013. Likewise, two others are *the Canadian Employers for Caregivers Plan* (261) and the *Mobilizing Action, Family Caregivers in Canada project* (262). Though not specific to caregivers of individuals with mental illness, these initiatives support the implementation of benefits for caregivers. Finally, there is the *National Standard of Canada for Psychological Health and Safety in the Workplace* (263) launched in early 2013, which is not exclusively directed at caregivers but nonetheless has some mentions specific to them.

In summary, the dynamics of families caring for individuals with psychosis are complex, characterized by numerous challenges such as identifying the illness, accessing mental healthcare, and navigating emotional and financial strains. Despite systemic barriers and limited resources, involving families in care has proven beneficial, leading to fewer relapses and improved quality of life for both patients and families. Various frameworks like the Triangle of Care and interventions like family psychoeducation emphasize collaborative partnerships between key stakeholders, patients, clinicians, and families, however, existing research approaches on understanding family involvement in early psychosis care are predominantly focused on individual stakeholder perspectives, i.e., multi-stakeholder (e.g., patients, families, clinicians) and policy perspectives are ignored. There is a need to understand meaningful family engagement practices in real-world service delivery through preference-based and measurement-based care approaches from a holistic standpoint. Due to this rationale, certain researchers in the field of family engagement advocate for the augmentation of multiple and mixed methods, which involve combining various research approaches, in order to comprehensively investigate complex implementation research inquiries (176, 226).

Chapter 2. Research Rationale, Objectives, Research Questions and Approach

2.1 Research Rationale

Families play a pivotal role in taking care of, supporting, seeking treatment, and advocating for their loved ones living with early psychosis. All stakeholders, including patients, families, clinicians, and policymakers, acknowledge the benefits of family involvement in promoting clinical and functional outcomes and the need for partnership with families in regular clinical care in early intervention services (EIS) for psychosis. Yet, families consistently describe feeling disrespected and neglected by the system, in that, their needs are unmet, and their involvement is obstructed by various barriers (264, 265). For example, ambiguity around elements of involvement (such as consent and confidentiality, nature, and logistics of involvement) act as significant barriers to uptake of family involvement in practice. Currently, in Canada, there is a lack of in-depth knowledge about preferences of multiple stakeholders regarding how families should be involved in the care and treatment within early intervention services for psychosis. These knowledge gaps must be addressed to truly improve family involvement practices in early intervention services for psychosis in Canada.

The present research addresses several knowledge gaps regarding family involvement in early intervention services for psychosis. While some albeit limited prior research has been conducted on understanding family involvement in mental health services from multiple stakeholder perspectives, there is limited research into understanding family involvement (among first-time caregivers) in early intervention services for psychosis from a system and triadic perspective (triadic here referring to the perspectives of patients, families, and clinicians/treatment providers). This knowledge gap is problematic as current implementation efforts in early intervention services for psychosis across the world strongly endorse families as partners in routine care. Yet little is known about how various stakeholders prefer families to be involved in care and treatment and how they are currently involved in care. Past research has demonstrated the importance of and need for involving families to promote better patient engagement and outcomes in early intervention treatment. This requires knowledge of barriers that early intervention services, families, patients, and policymakers face when trying to involve families in their context and of patterns, convergences, and divergences between various stakeholder groups with respect to family involvement in routine care (both in terms of preferences around and actual expressions of family involvement). Such knowledge has significant implications for increasing uptake of family involvement in routine care, which in turn can improve outcomes, prevent significant delays in seeking treatment, and alleviate distress among patients and their families and clinicians and the overall care system.

This work also addresses gaps in implementing family involvement in early intervention services for psychosis. While their heightened need for family involvement is well-acknowledged, few studies have investigated stakeholders' preferences of family involvement in early intervention services for psychosis, including for types of involvement, and regarding navigating consent and confidentiality. Understanding the various components of family involvement and multiple stakeholders' perspectives and preferences regarding these is essential for the better uptake of family involvement and improving overall delivery of early intervention services for psychosis. Overall, this work will examine family involvement in a novel and comprehensive manner – analyzing guidelines, perceptions, and preferences; and actual expressions of family involvement in treatment, from the perspective of patients, families, clinicians, and policymakers, and using policy analysis, qualitative and quantitative methods. The knowledge generated through these studies can help inform policy and service recommendations for family involvement in early intervention services for psychosis and facilitate collaborative, patient-and "family-friendly" delivery of care (which, based on the literature on the benefits of family involvement (140), we argue will definitely improve patient and family outcomes).

2.2 Specific Objectives

This dissertation aims to advance understanding regarding the involvement of families in the treatment of young people receiving early intervention services for psychosis, with a view to guiding efforts to improve service delivery in the Canadian context, with respect to family involvement and interventions. The three specific objectives of this dissertation are to:

1) Identify, synthesize and appraise clinical practice recommendations for family work in early intervention services (EIS) for psychosis in Canada, specifically focusing on dimensions related to their implementability and identifying gaps that can contribute to their poorer uptake.
2) Understand the views and preferences of multiple pertinent stakeholder groups (patients, families, clinicians, and program administrators) regarding family involvement in early intervention services for psychosis.
3) Examine concrete forms of and attitudes towards family involvement in early intervention services for psychosis as reported by patients, families, and clinicians.

2.3 Research Questions

To achieve the objectives, the following three research questions were addressed:

1) What is the current state of clinical practice recommendations for family involvement in early intervention services for psychosis and are these implementable?
2) What are the views and preferences of patients, families, and clinicians regarding the involvement of families in early intervention services for psychosis?
3) How do concrete forms of and attitudes towards family involvement change over the course of a follow-up in early intervention services for psychosis? And are these similar or different across patients, their families and their case managers?

2.4 Research Approach

This dissertation comprises three manuscripts. In the first manuscript, a systems approach was utilized through the examination of clinical practice recommendations for family interventions and involvement, through a grey literature review of clinical practice guidance documents published in and for populations in Canada.

In the second manuscript, a multi-stakeholder perspective approach was employed, through a qualitative consultation session regarding family involvement in early intervention services for psychosis and a quantitative prioritization of preferences activity. This study involved patients, families, and clinicians from a Montreal-based early intervention service for psychosis.

Finally, in the third manuscript, a multi-stakeholder, data-driven approach was employed, using longitudinal data on specific types of family involvement from two specific early intervention services for psychosis in Montreal, Canada. The findings derived from these investigations will contribute to the expanding corpus of scholarly work that examines family involvement and its application in early intervention services for psychosis.

This dissertation embraces the paradigm of pragmatism as its guiding framework. Pragmatism is an epistemological framework that posits that research should be driven by the intention to generate practical knowledge and should encompass a diverse range of methodologies that are appropriate for addressing specific research inquiries (266). Pragmatic research orientations primarily prioritize the consequences or outcomes of research inquiries, rather than placing primary emphasis on the employed methodologies (267). The adoption of this approach was motivated by the overarching objective of the research to prioritize real-world issues and ascertain practical solutions to address them.

2.5 Researcher Reflexivity and Positionality

The first author on the following papers, Helen Martin (HM), is a doctoral candidate in a Canadian university, where the majority of the students and faculty are white. The university is situated on the lands which long served as a site of meeting and exchange among Indigenous peoples, including the Haudenosaunee and Anishinabeg nations. HM acknowledges and thanks the diverse Indigenous peoples whose presence marked this territory on which the peoples of the world, and she now gathers. HM identifies as an able-bodied, middle-class city dweller, a first-generation university student with modern and westernized (colonial) educational and mental healthcare practitioner experiences and a person of colour from a low- and middle-income country (of South Asian descent). She belonged to a religious minority group in India where she lived before migrating to Canada for graduate studies.

HM is a former clinical social worker who worked with people with chronic mental illness and first-episode psychosis for four years. Her cross-disciplinary training and experience in India fuelled her interest and research in evidence-based methods, knowledge translation, implementation science, cross-cultural research, and stakeholder engagement. During her doctoral training, she was based at the Prevention and Early Intervention for Psychosis, an early intervention service for psychosis in Montreal, Quebec, a predominantly French-speaking province of Canada.

HM is fluent in English and has limited French proficiency; hence, she relies on translators when needed. These translators have been professional colleagues from the clinic, and sometimes they are other students. Her research is informed by a commitment to minimizing and closing the gap between research and real-world practice, also known as the know-do gap in mental healthcare, through an implementation and knowledge translation lens. HM reflected on her positionality and valued reflexivity in carrying out all aspects of her research including conception, recruitment, interpretation, and knowledge translation.

Chapter 3

Manuscript I

A Critical Appraisal of Family-Focused Recommendations in Canadian Guidelines for Early Intervention Services for Psychosis

Helen Martin, Nicole Pawliuk, Ruben Valle, Srividya N. Iyer.

Prepared for submission to the Canadian Journal of Psychiatry, 2024

Abstract

Background: Despite the well-known benefits of family involvement and interventions, gaps remain in their implementation across early intervention services for psychosis. Guidelines/standards have been developed to guide early psychosis services and bridge evidence-implementation gaps. But no attention has been paid to the nature and quality of these guidelines and what they recommend regarding family involvement and interventions. We therefore aimed to identify, critically synthesize, and appraise the quality of family-focused recommendations in Canadian guidelines for early psychosis.

Methods: We systematically searched grey literature to identify Canadian guidance documents for early psychosis. From each document, bibliographic information (e.g., publication year) and family-focused recommendations were extracted. All family-focused recommendations were subject to content analysis and mapped against a multidimensional patient and family engagement framework. All guidelines were appraised using AGREE-REX, which assesses rigor and implementability. Family-focused recommendations were separately rated on three AGREE-REX items. Results are presented descriptively.

Results: Seven documents were included, with five provincial early psychosis guidelines and two Canada-wide guidelines for schizophrenia-spectrum disorders with early psychosis sections. 96 specific family-focused recommendations were extracted covering 21 themes. Only two themes (family psychoeducation; involving families in treatment planning) were endorsed by five/seven guidelines, with other themes in ≤4 guidelines. 77.4% of recommendations were about direct care; 22.5% about involving families in organizational design and governance; 0% about involvement in policymaking. No guidelines had recommendations for involving families in inpatient care and only two for navigating consent vis-à-vis family involvement. AGREE-REX item ratings for selecting relevant outcomes and local applicability of recommendations were lower for family-focused recommendations than overall guidelines. Nearly all guidelines fared poorly in eliciting families' values/preferences in developing guidelines.

Conclusion: Few family-focused recommendations featured consistently across early psychosis guidelines. There was little guidance on navigating well-acknowledged barriers to family involvement (e.g., consent, confidentiality). Our analysis revealed critical gaps, including the need to view families not only as care recipients but also as partners in treatment decision-making and services and policy-design. Future guidelines must integrate stakeholders’ values and preferences, and guidance on implementing recommendations in diverse real-world settings.

1. Background

As most individuals are young at the onset of psychosis[1], families play a critical role in the lives and treatment of persons with first-episode psychosis, initiating help-seeking, supporting and promoting service engagement and medication adherence, and liaising with treating teams particularly during crises[2, 3]. Numerous studies have linked family involvement with myriad outcomes such as reduced relapses and all-cause mortality, improved quality of life and functional and subjective recovery[4, 5]. In psychosis, family interventions (e.g., family psychoeducation, multiple family group therapy) are among the interventions with the strongest and most consistent evidence for their benefits[6].

Despite these well-known benefits of family involvement in early psychosis treatment and family interventions, gaps remain in their implementation and uptake, including in Canada. Despite sometimes starting off high, family involvement in treatment reduces and becomes inconsistent over the course of treatment[7, 8]. Implementation rates for family interventions range from 57-80%[9, 10] and uptake is even lower, for instance, with only 0.1-32 % attending all family psychoeducation sessions[11, 12]. More disconcertingly, qualitative research points to families consistently feeling excluded, not regularly informed, their perspective not adequately considered, their needs not sufficiently assessed or met[13] and their involvement obstructed by various barriers[11, 14-18]

To promote standardized, evidence-based service delivery across early psychosis programs, several provincial and Canada-level clinical guidance documents have been published[19-21]. Indeed, healthcare practices are mandated by and monitored/audited using clinical practice guidelines, which also serve to reduce inconsistencies in implementation of core components. But no attention has yet been paid to the nature and quality of early psychosis guidelines themselves and what they recommend with respect to family involvement and interventions. Our study therefore undertook a review, critical synthesis and quality appraisal of family-focused recommendations in guidelines for early intervention services for psychosis in Canada.

While the literature points to family-focused interventions with robust and persistent evidence[3], we do not know if these have been codified into guidelines. Multiple factors can facilitate and hinder the implementation and uptake of evidence-based interventions[22, 23], and healthcare programs and providers need support and guidance to apply evidence-based practices/recommendations in real-world settings, that vary in terms of populations, context and service resources and capabilities. The extent to which extant Canadian psychosis guidelines are attentive to implementability considerations has not yet been studied.

In Canada and globally, patients and families are increasingly seen not merely as care recipients but as partners in their care, as well as in designing services, research, guidelines and policies[18, 24]. Furthermore, patient and family engagement are widely acknowledged as foundational in early intervention for psychosis[25, 26]. Whether and how these professed values are operationalized within guidelines and their recommendations remains unknown. By addressing these knowledge gaps, our study is an important starting point to improving family involvement and interventions in early psychosis.

The study's specific objectives were to:

1. Identify and critically synthesize family-focused recommendations in early intervention services for psychosis and map them against a multi-dimensional patient and family engagement framework.[27]
2. Assess the quality and implementability of overall and family-focused recommendations.

2. Methods

Our study is a systematic review of Canadian clinical guidance documents on early psychosis, followed by their critical synthesis and quality appraisal.

2.1 Search Strategy

We primarily searched for grey literature as clinical guidance documents are generally non-peer-reviewed publications[28]. Using terms related to psychosis/schizophrenia, early intervention/first-episode and guidelines/guidance/standards/policy, we carried out Google search and an advanced Google search (first five pages) and validated our results by experts. Search was conducted in 2022 and updated in April 2024.

2.2 Inclusion and Exclusion Criteria

Documents were included if they: i) were labeled as guidelines/standards; ii) exclusively focused on early stages of psychosis or on schizophrenia-spectrum illnesses and had a dedicated section on early stages of/intervention for psychosis; iii) focused on either a province within Canada or all of Canada; and iv) were in English or French or both. When multiple versions were found for the same jurisdiction, the most recently dated guideline/standards were included.

Excluded were dissertations, literature reviews, informational reports, program descriptions/evaluations, publications exclusively centered on pharmacotherapy and drafts/summaries (e.g., quick reference guides).

Two trained reviewers screened titles and executive summaries; retained eligible documents; carried out deduplication; independently screened full texts; and made final selections. Decisions were based on consensus and discrepancies resolved by author SI.

2.3 Quality Appraisal

The Appraisal of Guidelines Research & Evaluation—Recommendation EXcellence (AGREE-REX) , a validated nine-item instrument developed in 2019, was used to assess the quality of recommendations in the included guidance documents[29]. AGREE-REX was chosen because it assesses rigor of evidence and methodology, as well as implementability of recommendations (e.g., were stakeholder preferences considered, adaptation to local context, etc.).

As recommended[29], three scores were derived for (a) items on a 7-point scale (1=lowest quality; 7 = highest quality) (b) domains by adding up scores for the three items each that fell under Clinical Applicability; Values and Preferences and Implementability; and (c) overall by adding up all item scores. Items 3 (Applicability to patients/populations), 5 (Values and Preferences of Patients/Populations) and 9 (Local Application and Adoption) were rated twice, for overall recommendations and for the cluster of family-focused recommendations. Domain and overall scores were converted into percentages and classified as >70% = high quality, <30% = low quality and 31% - 70% = moderate quality.

Four raters, with experience in early psychosis, independently appraised the documents using AGREE-REX and arrived at scores via consensus. For documents not exclusively early psychosis-focused, appraisal included reviewing the early psychosis, introductory and methodology sections.

2.4 Data Extraction and Management

Two authors independently extracted and discussed pertinent data from all included documents onto a predesigned MS Excel spreadsheet, resolved disagreements by consensus and documented decisions and received ongoing team feedback/guidance. Document characteristics were extracted including authors, publication year and type (guideline, standards, etc.), targeted age group, geographic scope, funding source, focus (early psychosis-focused or not), length and number of bibliographic references.

All family-focused recommendations (conceptualized broadly to include any family involvement in treatment and family interventions) were extracted separately into two categories (A) “Specific recommendations”, a specific recommendation/performance indicator (typically presented as a bullet point/box/numbered section) and (B) “General statements”, recommendations found in general sections but not explicitly labelled as a recommendation (e.g., a sentence in introduction “families should be considered key partners”). Clinical guideline developing bodies[30] typically focus on the first category of recommendations.

2.5 Data Synthesis

Themes reflected in the family-focused recommendations were identified using the directed content analysis approach where codes were defined before (using existing literature) and during (iterative process informed by data) analysis[31, 32]. Two raters independently categorized key elements into codes, code categories and finally into themes, through iterative discussion and refinement.

Specific family-focused recommendations were mapped using a patient and family co-designed multi-dimensional framework for patient and family engagement in healthcare[27]. Each recommendation was categorized as aligning with one of three options within the framework's "continuum for engagement"(consultation; involvement; and partnership and shared leadership); and "levels of engagement" (involvement in direct care; organizational design; and governance and policy-making). Increased engagement is indicated by moving to the right on the engagement continuum, for each of the levels. The framework also recognizes individual, organizational and systemic factors that influence engagement.

3. Results

3.1 Description of Included Documents

Seven documents (from 2009-2022) were included (Table 1). Two were peer-reviewed and the others were grey literature. Five documents were standards or guidelines for five specific provinces: New Brunswick (NB)[33], Nova Scotia (NS)[34], Quebec (QC)[19], Ontario (ON)[21], and British Columbia (BC)[20]. These were developed and funded by their respective provincial health ministries. Only one of these documents had a previous version (QC). Besides NS, the provincial documents exclusively focused on early psychosis. The NS guidelines were for mental health services in the province, with a specific section on early psychosis. The two peer-reviewed articles focused on schizophrenia-spectrum disorders, with specific sections on early stages of psychosis (Canada2017a and Canada2017b)[35, 36]. All documents covered recommendations for pharmacological and non-pharmacological treatments. The documents had various names, including guidelines, standards (in the case of two), guidelines and standards, practice guidelines, administrative guidelines, and *cadre de référence* (French terminology referring to guidelines). All early psychosis guidelines targeted adolescence and early adulthood, but no two documents stipulated the same age. Five were only in English; one was only in French (QC) and one in both English and French (NB).

A single methodological exercise resulted in the two peer-reviewed documents, one covering assessment and diagnosis, and the other covering community treatment of schizophrenia-related disorders. These methods were outlined in an additional publication[37], which we also used for extraction and quality appraisal. The Quebec guidelines referenced the government's overall mental health action plan[38], which was considered in extraction and appraisal.

3.2 Involvement of Families in Guidelines Development

The single methodological exercise resulting in the two Canadian peer-reviewed guidelines involved two named family caregivers as members of their national multidisciplinary team. The ON standards named one family member from a named family organization as having been involved. The BC document referred to an advisory council including members from family organizations (numbers and names not provided). The NS document referenced seeking consumer opinions, although it is unclear if this included families. The NB and QC documents have no information on whether families were involved (the QC document has a list of names with no additional details).

3.3 Themes

27 themes were identified from the literature and analysis of the extracted recommendations (Table 2). One theme identified as salient in the literature, "families involved during their ill family member's inpatient care" was not identified in any of the included documents. Supplement Y presents each recommendation against its corresponding theme.

3.3.1 Specific Family-Focused Recommendations

96 specific family-focused recommendations were identified from all seven documents, which covered 21/27 themes (Supplement Y). The number of recommendations (Table 3) varied from 40 (BC) to one (Canada2017b).

The topmost commonly endorsed recommendations (five/seven documents) pertained to involving families in developing patients' treatment/care plans (BC, Canada2017a, ON, NS, QC), and provision of family education/psychoeducation (BC, Canada2017b, ON, NB, QC). Four documents each recommended families' involvement in community outreach (BC, ON, NS, NB); providing other family supports such as community resources and self-care management (BC, ON NB, NS); and involving families in patients' assessments (NS, BC, ON, Canada2017a).

Recommendations pertaining to: involving families in seeking consent from patients (Canada 2017a, ON, NS); assessing family-focused domains such as needs/satisfaction (BC, ON, QC); type and modality of service delivery such as family-friendly environment (BC, ON, QC); and making description of services/program available to families (BC, ON, NS) were each found in any three documents.

Recommendations on family peer support (BC, ON); navigating patients' confidentiality vis-à-vis family member's needs and desire for information (ON); specific interventions other than family psychoeducation and peer support (BC, ON); different types and frequencies of contact/communications between families and treating teams (BC, ON); integrating clinician(s) with expertise in family approaches (NB, QC); involving families in relapse prevention (BC, ON) and patients' discharge planning (BC, ON); care plans to meet families' needs (BC, ON); involving families in program/service improvement/design (BC); provision of culturally sensitive care (ON) and description of families' roles and responsibilities (ON) were each found in any one-to-two of the seven documents.

3.3.2 General Statements

Five/seven documents (BC, Canada2017a, ON, NS, , QC,) contained 43 general statements, some of which were broad ("Services include crisis and emergency response service, and individual/group/family assessments and treatment services” in the NS document) whereas others referred to concrete practices (“In rural areas, peer linking may require creative and diverse strategies (e.g., family-to-family newsletters, secure web-based discussion groups, etc.)” in the BC document). These general statements spanned 24/27 themes. General statements in the QC document covered more themes than specific recommendations and, although not presented in a box such as their specific recommendations were, they were still worded as recommendations E.g., under addressing confidentiality, a general statement was “a young person whose family is already aware that he or she is being followed at PPEP may refuse to allow his or her parents to be met and involved in his or her follow-up, but these parents could still receive general psychological education about psychosis and its treatment.”[19] However, this theme was not covered in their specific recommendations.

3.4 Engagement Framework

Three out of 96 recommendations focused on clinicians' skillsets rather than tangible practices for families and were therefore not mapped against the engagement framework. Most recommendations (n = 72/93, 77.4%) fell under the "direct care" level of engagement, within which the highest number of recommendations reflected the lowest degree of the continuum of engagement i.e., consultation (30/72, 41.6%), followed by partnership and shared leadership (27/72, 37.5%) and then involvement (15/72, 20.8%) (Table 4). Only 21 recommendations from three jurisdictions (BC, ON, NS) had recommendations for involving families in organizational design and governance (n=21/93, 22.5%) that reflected lower degrees of the continuum of engagement (consultation = 14; involvement = 5; partnership and shared leadership = 2). There were no recommendations about involving families in policymaking. Supplement Y presents each recommendation by level and continuum of engagement.

3.5 Quality Appraisal

Only one document (BC) ranked high quality overall and for its three domains. One document (NB) ranked low quality in all three domains and overall. This was a brief document (seven pages which includes both English and French versions) which may have resulted in low scores. The remaining five documents were of moderate overall quality, with individual domains also ranked moderate quality except for the two peer-reviewed Canadian guidelines. These two documents ranked high quality in clinical applicability, scoring high in integrating “evidence” and "applicability to target users” given the use of detailed, rigorous methodology[37].

Table 5b shows that on the three pertinent items, family-focused recommendations were never rated higher than overall recommendations. On item 3 which assesses the extent to which relevant outcomes were considered in developing recommendations, how these were ascertained as relevant and whether recommendations were tailored to particular populations, five/seven documents scored lower for family recommendations than overall, with scores mostly in the low to low-moderate range, except for BC and ON which scored higher.

On item 5, nearly all guidelines performed similarly in the low to low-moderate range overall and for family-focused recommendations except for Canada 2017b and QC were slightly lower in family-focused recommendations, indicating that most had not elicited the values and preferences of families (and patients) in developing guidelines (or in reporting this if these were elicited), and in considering the acceptability of recommendations.

On Item 9 which focuses on “implementability” covering aspects like local applicability, how recommendations can be tailored to contexts/settings, costs, resources, training/competencies, etc., all guidelines consistently performed worse with respect to family-focused recommendations with generally low ratings, compared to overall recommendations with moderate to high ratings.

4. Discussion

4.1 Content of Family-Focused Recommendations

All extant Canadian guidance documents acknowledge “families” as a stakeholder group in the treatment of psychosis, as reflected in all documents having family-focused recommendations that covered a variety of themes. What is, however, concerning is that few recommendations featured consistently across all or most guidance documents. Also, most explicit recommendations were about involving families in “direct care”, with less than a quarter recommending their involvement in organizational design and governance and none recommending that they be involved in policymaking. Recommendations about involving families in design and governance also rarely saw them as partners with shared leadership. This may partially be attributable to increased breadth and depth of patient and family engagement becoming more prominently encouraged relatively recently in Canadian healthcare[39].

Most guidelines had an emphasis on family education/psychoeducation, aligning with the meta-analytic evidence for its benefits[40]. Most guidelines also had recommendation(s) around involving families in their loved one’s assessment and treatment planning, although these varied in number and level of detail. ON guidelines had nine explicit recommendations under these themes stating that families be involved in assessments, initial treatment planning, review of progress and so on. The QC document had one explicit recommendation under this theme about involving the family along with the patient in updating the intervention plan every 6 months. Given the increasing emphasis on measurement-based care and learning health systems[23], it is noteworthy that three/seven guidelines made explicit recommendations about assessing families’ needs and satisfaction with services, which could be considered in common measurement-based care protocols for early psychosis programs. The BC document provided 12 additional measurable family-focused indicators (e.g., number of care plans signed by families; number of families engaged, etc.) and the ON document additionally recommended assessing families’ goals and aspirations. These could be considered as candidates by future guidelines and measurement-based efforts in early psychosis.

With two exceptions (ON with an explicit recommendation, QC with general statements), there was no advice for navigating patients’ consent and confidentiality vis-à-vis involving families in treatment. This despite several studies identifying these as significant deterrents to family engagement in early psychosis intervention and mental healthcare[18,41]. While some authors have also proposed strategies to navigate disagreements around decision-making and confidentiality among patients, caregivers, and families[26, 41, 42], these were not featured in the recommendations. Encouragingly, both ON and QC provide clear, converging recommendations for when patients refuse consent for involving families, namely, that treating teams discuss the benefits of family involvement with the patient and if the patient still refuses, treating teams can listen to the family's concerns and provide them psychosocial support and education (while respecting patient's choice by not disclosing details about their care). Using these as examples and being guided by literature and stakeholder inputs, future guidelines must make recommendations for involving families when patients refuse consent, but that acknowledge consent as fluid (e.g., patients may consent but not want all information to be shared with families) and evolving (e.g., patients may refuse consent initially but shift over the course of treatment)[18, 26, 41, 42].

Beyond psychoeducation, most guidelines had relatively sparse recommendations about specific evidence-based family interventions. This despite a rich body of evidence for family-focused interventions (e.g., multiple family group therapy) and patient-focused interventions that involve families (e.g., cognitive-behavior therapy for psychosis)[43-45].

4.2 Quality and Implementability of Family-Focused Recommendations

Our analysis highlighted significant gaps in the quality of family-focused recommendations within Canadian early psychosis guidelines and these guidelines overall. The first pertains to the little attention paid to implementability and applicability considerations like training, resources, adaptations to local contexts, etc. which may help explain evidence/standards-practice gaps in early psychosis programs, and their poor and inconsistent implementation of family-focused recommendations[22, 46, 47]. Generally, there have been few applications of implementation science in early psychosis[48, 49]. Family work recommendations were much more likely to be formulated in ways that did not support their implementability, with generic statements or statements lacking information to operationalize them (e.g., In Canada2017b, "Individuals in the first episode of psychosis should receive treatment within the context of an evidence-based coordinated specialty service. This should be multidisciplinary and encompass the following: Family involvement and family interventions" (with 4 other listed treatments).

The second pertains to many guidelines not having - actively and systematically elicited the values and preferences of families; specified outcomes relevant for families; or clarified how listed outcomes were picked as relevant. Families were mentioned as having been involved in developing only two early psychosis-specific and the Canada-wide guidelines. Most documents and evidence informing them were created prior to the patient-oriented research push in Canada[39]. Low(er) ratings on this (and other AGREE-REX) item(s) may have also arisen because sufficient information (e.g., if families were included, how their opinions were considered) was not reported in the guidelines. Still, given that "engagement" is at the heart of early psychosis intervention[50], it is incumbent upon those developing guidelines that recommendations reflect the values and preferences of families (and patients) and that the strategies used to gather these are clearly outlined. Strategies could range from involving family members (with diverse lived experiences) during guidelines development, integrating literature on values and preferences of families, etc. These may be helpful in identifying and endorsing services/practices that may not as of yet have the highest levels of strength and consistency of evidence[51] but may be consistently valued and advocated for by lived experience stakeholders (e.g., peer support).

The third pertains to most guidelines not detailing how and when recommendations should be tailored to particular subsets of families based on age, ethnicity, etc. Equity considerations have increasingly become central in healthcare, but may not have been well integrated into these guidelines that were mostly published over five years ago. Definitions of "family" and familial values and views about mental illnesses and caregiving are influenced by social-cultural dimensions[52-54]). Factors like ethnicity have also been shown to impact uptake of family interventions[55] along with being associated with risk for psychosis and pathways to care[56, 57]. Early psychosis guidelines must provide guidance on when and how to adapt recommendations based on factors like ethnicity, disability, economic status and their intersectionalities.

5. Limitations and Strengths

Our review focused on family-focused recommendations in early psychosis guidelines, but the extent to which early psychosis programs are actually guided by guidelines developed in their own jurisdiction (and/or Canadian guidelines) is not clear. Nonetheless, because these guidelines enjoy the support of relevant ministries, they could be argued to be credible representations of minimally acceptable standards of early psychosis care in their respective jurisdictions.

On the AGREE-REX, a score of 1 (lowest quality) could either reflect poorest quality or that guideline developers undertook methods but failed to describe them. Our protocol did not allow us to distinguish these unless we contacted all developers, which we did not do. While the AGREE-REX developers provide thresholds for high, moderate and low quality for overall scores, they do not provide similar thresholds for individual items and domains. We used similar cutoffs for individual items and domains, along with detailed descriptions of their quality. Notwithstanding these limitations, AGREE-REX permits a comprehensive evaluation of recommendations in terms of their implementability and rigor, and should be used when developing future guidelines.

Our review also has noteworthy strengths. To our knowledge, this is the first literature review that analyzed the quality of family work recommendations in guidance documents for early intervention for psychosis in Canada, using a novel, validated quality appraisal tool[29]. Using a well-regarded engagement framework[27], we evaluated the level and continuum of engagement in family-focused recommendations, which allowed us to identify substantive (e.g., no involvement in policymaking) and process (e.g., families often involved not as partners, but consulted) gaps. Our review provides the first systematic collation and critical synthesis of family-focused recommendations across Canadian early psychosis guidance documents, which provides all jurisdictions and early psychosis programs a menu of strategies for family involvement and interventions and a list of convergent practices (e.g., psychoeducation) to be prioritized.

6. Implications

Our critical analysis using multiple methods – bottom-up content analysis, top-down mapping against an engagement framework and quality appraisal – yielded a thorough portrait of the state of family-focused recommendations in Canadian early psychosis guidelines. Given that guidelines provide directions to optimize and deliver high-quality patient and family care, it is critical that they are implementable in routine practice and provide the best possible evidence- and values-informed recommendations for direct care and for involving families (and patients) in services and policy design. Our work informs concrete recommendations for current practice and future efforts to develop/update guidelines (Table 6). Because AGREE-REX could be used as a methodological checklist to formulate and report the quality of recommendations, our results serve as a benchmark against which future early psychosis guidelines and recommendations can be measured.

Table 1 Description of included documents in chronological order

S.no	Document	Authors / Organization	Year	Province	Publication type	Funding	Focus	Target audience (age)	Volume (in pages)	No. of references listed
1	**Standards** for Mental Health Services in Nova Scotia	(Province of) Nova Scotia	2009	Nova Scotia (NS)	Standards	Not mentioned	Section on Early Psychosis	15 – 45 years	225	17*
2	**Standards and Guidelines** for Early Psychosis Intervention (EPI) Programs	Ministry of Health Services Province of British Columbia	2010	British Columbia (BC)	Guidelines and Standards	Ministry of Health Services	Early Intervention	early adolescence to mid-thirties	106	132
3	Early Psychosis Intervention Program **Standards**	Ontario Ministry of Health and Long-Term Care	2011	Ontario (ON)	Standards	Ontario Ministry of Health and Long-Term Care	Early Intervention	14 -35 years. *(exceptions assessed on an individual basis)*	36	21
4	Early Psychosis Services N.B. / Services d'intervention précoce en cas de psychose au N.-B.	Department of Health	2011	New Brunswick (NB)	Administrative guidelines	Not mentioned	Early Intervention	Up to 30 years	7	0
6	Canadian **Guidelines** for the Assessment and Diagnosis of Patients with Schizophrenia Spectrum and Other Psychotic Disorders	Donald Addington, Sabina Abidi, Iliana Garcia-Ortega, William G. Honer, Zahinoor Ismail	2017a	Canada (Canada 2017a)	Guidelines	Mathison Centre for Mental Health Research and Education, University of Calgary	Section on First Episode Psychosis	not mentioned	10	5*
5	Canadian **Practice Guidelines** for Comprehensive Community Treatment for Schizophrenia and Schizophrenia Spectrum Disorders	Donald Addington, Elizabeth Anderson, Martina Kelly, Alain Lesage, Chris Summerville	2017b	Canada (Canada 2017b)	Practice guidelines	Mathison Centre for Mental Health Research and Education, University of Calgary	Section on Early Intervention, First Episode Psychosis	not mentioned	11	18*
7	**Cadre de référence:** Programmes d'interventions pour premiers épisodes psychotiques (PIPEP) 2nd ed	Ministry of Health and Social Services#	2022	Quebec (QC)	Guideline# (Cadre de reference)	Ministry of Health and Social Services#	Early Intervention	12-35 years	54	77

Legend: *Only from early psychosis section; # Translated from French version

Table 2: Family work themes from specific recommendations and general statements (n=27)

Themes / Documents	NS	BC	ON	NB	Canada 2017a	Canada 2017b	QC
Families involved in patient's treatment plan development/ shared decision making with patient and clinician	x *	x *	x	-	x *	-	x *
Family education/psychoeducation	-	x *	x *	x	-	x	x
Other family supports (e.g., self-care, links to community services)	x	x	x *	x	-	-	*
Families involved in community outreach / referrals	x	x	x *	x	-	-	*
Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.)	x	x *	x	-	x *	-	-
Description of service/program given to families	x	x	x	-	-	-	*
Type of service delivery setting (e.g. family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	-	x *	x *	-	-	-	x *
Consent to treatment	x	-	x *	-	x	-	*
Assessing family-focused domains (e.g., Family satisfaction, needs assessment, socio-cultural context, illness explanatory models)	*	x *	x	-	-	-	x *
Family peer support	-	x	x *	-	-	-	*
Recommendation outlines prescribed frequency for treatment team to have communication/contact with family	-	x	x	-	-	-	*
Families involved in transition/ discharge planning	-	x	x	-	-	-	*
Families involved in relapse prevention	-	x *	x	-	-	-	-
Develop care plan for the family member	-	x	x	-	-	-	-
Family-focused psychosocial interventions (e.g., family therapy)	-	x *	x	-	-	-	*
Provision of family specialist in treatment team (e.g., based on illness phase, family approaches, peer support worker, cultural diversity)	-	-	-	x	-	-	x *
Addressing confidentiality issues (e.g., discuss confidentiality with patient and family)	-	-	x	-	-	-	*
Family involvement in program/ service improvement	*	x *	-	-	-	-	-
Culturally sensitive care for families	-	*	x	-	-	-	*
Description of families roles and responsibilities given to families	-	-	x	-	-	-	-
Families involved during their ill family member's inpatient care / hospitalization	-	-	-	-	-	-	
Families are partners in care/engage in meaningful collaboration/ engagement/ empowerment	-	*	-	-	*	-	-
Stigma prevention	-	*	*	-	-	-	-
Family's eligibility for services (e.g., All young people with a first episode of psychosis and their families should be eligible for EPI programs.)	-	*	-	-	-	-	-
Family involvement in advocacy activities	-	*	-	-	-	-	-
Families to be active partners in pharmacological treatment	-	*	-	-	-	-	*
Duration of services to families (e.g., Services are available to clients and families across all phases of recovery or relapse)	-	*	-	-	-	-	-
Themes from specific recommendations only n	5	7	12	4	1	1	1
Themes from general statements only n	2	7	1	0	1	0	11
Themes from both specific recommendations and general statements only n	1	8	6	0	2	0	4
Total themes n (out of 27)	8	22	19	4	4	1	16

Legends: x: specific recommendations; *: general statements, - :no information

Table 3: Heat-map showing an overview of AGREE-REX scores in chronological order

Document Label (see Table 1)	Total no. of specific recommendations (only EI section considered for docs. 1, 5 and 6)	No. of specific family recommendations (% of total recommendations)	Additional materials used for evidence appraisal	AGREE- REX Domain Scores (% out of 100)			AGREE-REX Overall Scores (% / 100)
				Domain 1	Domain 2	Domain 3	
				Clinical applicability (%)	Values and Preferences (%)	Implementability (%)	
NS*	26	4 (15)	No	**44.44**	**33.33**	**50.00**	**40.74**
BC	156	40 (26)	No	**72.22**	**70.83**	**83.33**	**74.07**
ON	83	39 (47)	No	**50.00**	**54.16**	**66.66**	**55.55**
NB	17	3 (18)	No	**22.22**	**20.83**	**25.00**	**22.22**
Canada 2017 a*	7	3 (43)	Yes #	**72.22**	**37.50**	**41.66**	**50.00**
Canada 2017 b*	3	1 (33)	Yes #	**77.77**	**58.33**	**50.00**	**59.25**
QC 2022	36	6 (17)	Yes	**61.11**	**54.16**	**66.66**	**59.25**
Total	328	96					

Legend:

EI = early intervention for psychosis

* Total number of recommendations combining those for EI and non-EI sections were 264, 22 and 33 in documents 1, 5 and 6.

#The same published peer-reviewed methods article was used for both (Pringsheim & Addington, 2017)

Low quality <30%	Moderate quality 31-70%	High quality >70%

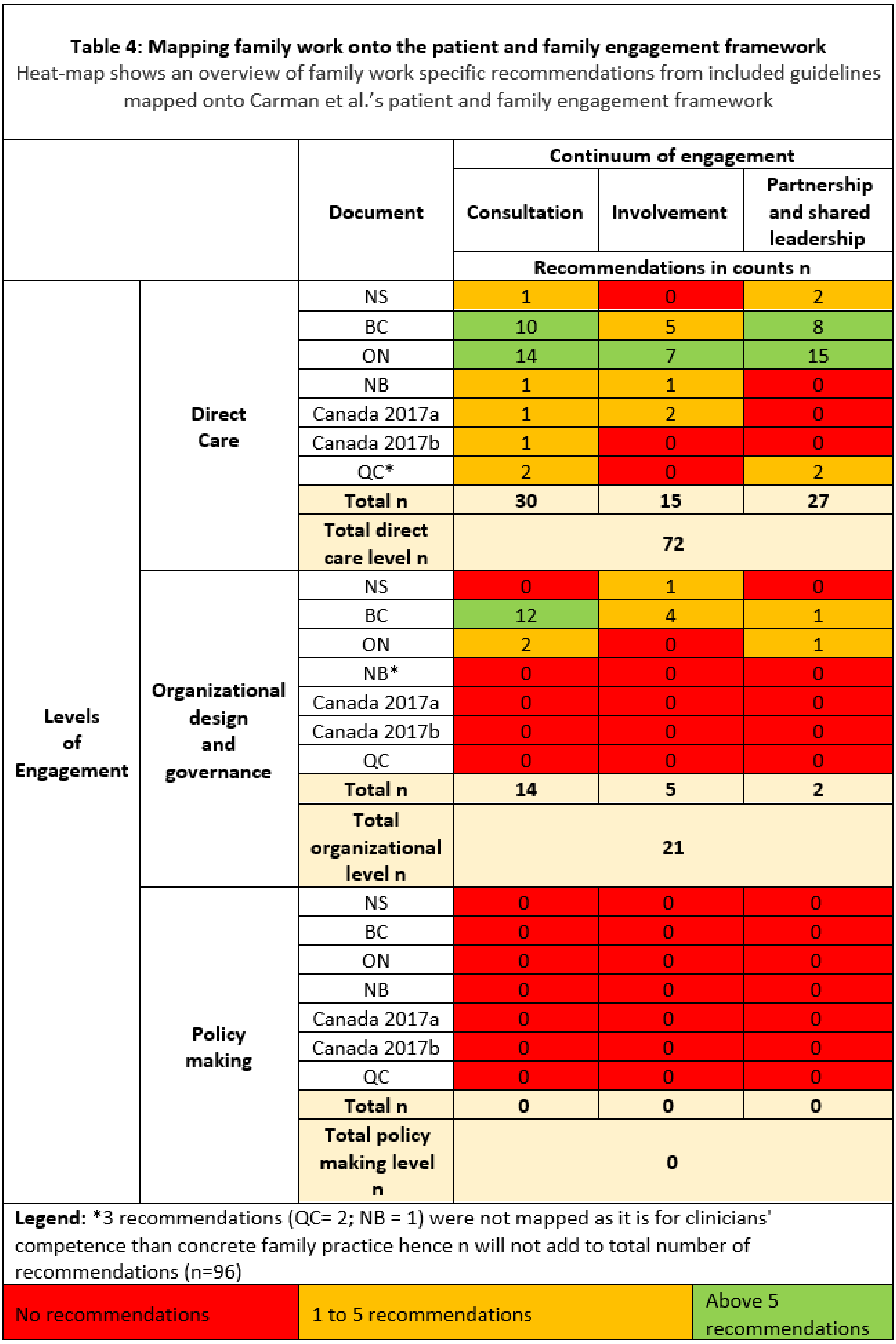


Table 4: Mapping family work onto the patient and family engagement framework

Heat-map shows an overview of family work specific recommendations from included guidelines mapped onto Carman et al.'s patient and family engagement framework

		Document	Continuum of engagement		
			Consultation	Involvement	Partnership and shared leadership
			Recommendations in counts n		
Levels of Engagement	Direct Care	NS	1	0	2
		BC	10	5	8
		ON	14	7	15
		NB	1	1	0
		Canada 2017a	1	2	0
		Canada 2017b	1	0	0
		QC*	2	0	2
		Total n	**30**	**15**	**27**
		Total direct care level n	**72**		
	Organizational design and governance	NS	0	1	0
		BC	12	4	1
		ON	2	0	1
		NB*	0	0	0
		Canada 2017a	0	0	0
		Canada 2017b	0	0	0
		QC	0	0	0
		Total n	**14**	**5**	**2**
		Total organizational level n	**21**		
	Policy making	NS	0	0	0
		BC	0	0	0
		ON	0	0	0
		NB	0	0	0
		Canada 2017a	0	0	0
		Canada 2017b	0	0	0
		QC	0	0	0
		Total n	**0**	**0**	**0**
		Total policy making level n	**0**		

Legend: *3 recommendations (QC= 2; NB = 1) were not mapped as it is for clinicians' competence than concrete family practice hence n will not add to total number of recommendations (n=96)

🟥 No recommendations	🟨 1 to 5 recommendations	🟩 Above 5 recommendations

Table 5a: AGREE-REX item scores

Items	NS	BC	ON	NB	Canada 2017a	Canada 2017b	QC
Domain 1: Clinical applicability							
Item 1: Evidence	4	5	3	1	6	6	4
Item 2: Applicability to target users	3	5	4	3	6	6	5
Item 3: Overall rating: Applicability to patients/populations	4	6	5	3	4	5	5
Item 3: Family rating: Applicability to families/populations	4	5	5	2	3	4	4
Domain 2: Values and preferences							
Item 4: Vaues and Preferences of target users	4	6	4	2	5	5	5
Item 5: Overall: Vaues and Preferences of patients/populations	2	4	4	2	3	5	4
Item 5: Family: Vaues and Preferences of families/populations	2	4	4	2	3	4	3
Item 6: Vaues and Preferences of policy/decision makers	3	6	5	3	2	3	4
Item 7: Vaues and Preferences of guideline developers	3	5	4	2	3	3	4
Domain 3: Implementability							
Item 8: Purpose	4	6	5	3	4	4	5
Item 9: Overall: Local application and adaptation	4	6	5	2	3	4	5
Item 9: Family: Local application and adaptation	2	4	3	1	2	2	3

Note 1: Item Scoring recommended by AGREE-REX (p. 8,9): **A score of 1** should be given if there is no information that is relevant to the AGREE-REX item's criteria or the item's criteria were not considered in the formulation of the guideline recommendations. **A score of 7** should be given if all the item's criteria have been carefully and thoroughly considered in the formulation of the recommendation(s). **A score between 2 and 6** should be given when some but not all of the item's criteria are considered in the formulation of the recommendation(s) and/or the link between the criteria and the recommendations is not optimal.

Note 2: Item Scoring 2-6 as determined by authors to match the scope of the study: Score of 2 should be given when a mere statement is given; score of 3 should be given when more than one of the criteria (but less than half) are fulfilled; score of 4 should be given when half of the criteria are partially fulfilled, there is less information; score of 5 should be given when half the criteria are completely fulfilled, there is more information; score of 6 should be given when every criteria is mostly fulfilled.

Table 5b: Comparison between overall recommendations vs family focused recommendations AGREE-REX item ratings

Items	NS	BC	ON	NB	Canada 2017a	Canada 2017b	QC
Domain 1: Clinical applicability							
Item 3-Overall rating: Applicability to patients/populations	4	6	5	3	4	5	5
Item 3-Family rating: Applicability to families/populations	4=	5↓	5=	2↓	3↓	4↓	4↓
Domain 2: Values and Preferences							
Item 5-Overall: Vaues and Preferences of patients/populations	2	4	4	2	3	5	4
Item 5-Family: Vaues and Preferences of families/populations	2=	4=	4=	2=	3=	4↓	3↓
Domain 3: Implementability							
Item 9-Overall: Local application and adaptation	4	6	5	2	3	4	5
Item 9-Family: Local application and adaptation	2↓	4↓	3↓	1↓	2↓	2↓	3↓

Note: Listed are ratings from 1 to 7 for each item; Higher ratings indicate better quality. Lower arrow ↓ indicates that rating was lower for family-focused recommendations than overall/patient-focused recommendations, and equal indicates ratings were the same.

Table 6: Recommendations for future development and update of guidelines for early intervention for psychosis, particularly with respect to family work practices

1) To achieve high quality, guideline developers must synchronize recommendations and clinical practice document development using guideline development metrics/reporting guidelines such as SIGN, GRADE, AGREE II, European Minimum Quality Standards (EQUS), etc.

2) To achieve better implementability of guidelines and their applicability to local contexts, guideline developers must synchronize recommendations and clinical practice document development using AGREE-REX. Guidelines should also pay greater attention to principles of equity, diversity, and inclusion, by ensuring that they cover how recommendations can be tailored to particular subsets of patient and family populations and particular contexts.

3) Recommendations should ensure that they span all levels of patient and family engagement (direct care, organization and governance, policymaking) and be attentive to the continuum of engagement, ensuring that engagement is not always at the lowest level of consultation.

4) All pertinent stakeholder groups (patients, families, clinicians, decision-makers, researchers and policy-makers) must be involved in the guidelines development process, including patients and families, paying attention to having a diversity of experiences among those involved; using evidence-based methods for co-designing guidelines with stakeholders; aligning stakeholder engagement practices with reporting guidelines such as AGREE and AGREE-REX. All published documents should explicitly outline how stakeholders were involved in the guideline's development process (using criteria outlined in AGREE II).

5) In addition to involving pertinent stakeholders in guidelines development, guidelines should be based on an extensive literature review and wide consultations. Specific recommendations should be anchored in evidence (paying attention to levels of evidence and grade of recommendation, as outlined in AGREE, GRADE, SORT, etc.). Evidence should be gathered and synthesized not only on interventions/practices that can be recommended but also on what outcomes should be focused on, why these outcomes are relevant, how these outcomes were chosen as relevant, and how the values and preferences of pertinent stakeholder groups were sought and integrated in prioritizing outcomes.

6) Evidence on implementation of best practices and existing guidelines should also be gathered and considered in developing guidelines, so that future efforts to develop and update guidelines can account for how guidelines can be applied and adapted, based on implementation factors such as resources, training, costs, etc. and contextual factors such as population characteristics, geography, health organizational type, etc.

SIGN: *Harbour, R., Miller, J., Grant, A. M., & Scottish Intercollegiate Guideline (2001). A revised method for the grading of guideline recommendations. British Medical Journal, 323(7308), 334-336. https://doi.org/10.1136/bmj.323.7308.334;* ***GRADE:*** *Guyatt, G. H., Oxman, A. D., Vist, G. E., Kunz, R., Falck-Ytter, Y., Alonso-Coello, P., & Schünemann, H. J. (2008). GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. Bmj, 336(7650), 924-926;* ***AGREE-REX:*** *Brouwers, M. C., Spithoff, K., Kerkvliet, K., Alonso-Coello, P., Burgers, J., Cluzeau, F., Férvers, B., Graham, I., Grimshaw, J., Hanna, S., Kastner, M., Kho, M., Qaseem, A., Straus, S., & Florez, I. D. (2020). Development and Validation of a Tool to Assess the Quality of Clinical Practice Guideline Recommendations. JAMA network open, 3(5), e205535. https://doi.org/10.1001/jamanetworkopen.2020.5535;* ***AGREE-II:*** *Brouwers, M. C., Kho, M. E., Browman, G. P., Burgers, J. S., Cluzeau, F., Feder, G., Fervers, B., Graham, I. D., Grimshaw, J., Hanna, S. E., Littlejohns, P., Makarski, J., Zitzelsberger, L., & AGREE Next Steps Consortium (2010). AGREE II: advancing guideline development, reporting and evaluation in health care. CMAJ : Canadian Medical Association journal = journal de l'Association medicale Canadienne, 182(18), E839–E842. https://doi.org/10.1503/cmaj.090449;* ***EQUS:*** *Schaub MP, Uchtenhagen A, EQUS Expert Group. Building a European consensus on minimum quality standards for drug treatment, rehabilitation and harm reduction. European Addiction Research. 2013 ;19(6):314-324. DOI: 10.1159/000350740. PMID: 23774998;* ***SORT:*** *Ebell, M. H., Siwek, J., Weiss, B. D., Woolf, S. H., Susman, J., Ewigman, B., & Bowman, M. (2004). Strength of recommendation taxonomy (SORT): a patient-centered approach to grading evidence in the medical literature. The Journal of the American Board of Family Practice, 17(1), 59-67.*

References

1. James B. Kirkbride, Ph.D. ,, Yasir Hameed, M.R.C.Psych. ,, Gayatri Ankireddypalli, M.D., M.R.C.Psych. ,, et al. The Epidemiology of First-Episode Psychosis in Early Intervention in Psychosis Services: Findings From the Social Epidemiology of Psychoses in East Anglia [SEPEA] Study. *American Journal of Psychiatry* 2017; 174: 143-153. DOI: 10.1176/appi.ajp.2016.16010103.
2. MacDonald K, Fainman-Adelman N, Anderson KK and Iyer SN. Pathways to mental health services for young people: a systematic review. *Social psychiatry and psychiatric epidemiology* 2018; 53: 1005-1038.
3. Claxton M, Onwumere J and Fornells-Ambrojo M. Do family interventions improve outcomes in early psychosis? A systematic review and meta-analysis. *Frontiers in Psychology* 2017; 8: 371.
4. Falloon IR, Held T, Coverdale JH, et al. Family interventions for schizophrenia: A review of long-term benefits of international studies. *Psychiatric Rehabilitation Skills* 1999; 3: 268-290.
5. Ma CF CW, Bressington DT. 2018 Aug;12(4):535-60. Family intervention for caregivers of people with recent-onset psychosis: A systematic review and meta-analysis. *Early intervention in psychiatry* 2018; 12: 535-560.
6. Falloon IR. Family interventions for mental disorders: efficacy and effectiveness. *World Psychiatry* 2003; 2: 20-28.
7. Oluwoye O, Stokes B, Stiles B, et al. Understanding differences in family engagement and provider outreach in New Journeys: A coordinated specialty care program for first episode psychosis. *Psychiatry Research* 2020; 291: 113286.
8. Iyer SN, Malla A, Taksal A, et al. Context and contact: a comparison of patient and family engagement with early intervention services for psychosis in India and Canada. *Psychological Medicine* 2022; 52: 1538-1547.
9. Nolin M, Malla A, Tibbo P, et al. Early intervention for psychosis in Canada: what is the state of affairs? *The Canadian Journal of Psychiatry* 2016; 61: 186-194.
10. Petrakis M, Hamilton B, Penno S, et al. Fidelity to clinical guidelines using a care pathway in the treatment of first episode psychosis. *J Eval Clin Pract* 2011; 17: 722-728. 2010/10/27. DOI: 10.1111/j.1365-2753.2010.01548.x.
11. Iyer SN, Loohuis H, Pawliuk N, et al. Concerns reported by family members of individuals with first-episode psychosis. *Early Intervention in Psychiatry* 2011; 5: 163-167.
12. Oluwoye O, Fraser ER and Kordas G. Taking a Look at How Family Member Engagement Influences Service User Engagement in New Journeys: a Coordinated Specialty Care Program. *The journal of behavioral health services & research* 2023; 50: 228-235.
13. Rodriguez-Meirinhos A, Antolin-Suarez L and Oliva A. Support needs of families of adolescents with mental illness: a systematic mixed studies review. *Archives of Psychiatric Nursing* 2018; 32: 152-163.
14. Dillinger RL and Kersun JM. Caring for caregivers: Understanding and meeting their needs in coping with first episode psychosis. *Early Intervention in Psychiatry* 2020; 14: 528-534.
15. Mui EYW, Chan SKW, Chan PY, et al. Systematic review (meta-aggregation) of qualitative studies on the experiences of family members caring for individuals with early psychosis. *Int Rev Psychiatry* 2019; 31: 491-509. 2019/09/25. DOI: 10.1080/09540261.2019.1659236.
16. Onwumere J, Shiers D and Chew-Graham C. Understanding the needs of carers of people with psychosis in primary care. British Journal of General Practice, 2016, p. 400-401.
17. Cree L, Brooks HL, Berzins K, et al. Carers’ experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. *BMC psychiatry* 2015; 15: 1-11.
18. Eassom E, Giacco D, Dirik A and Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ Open* 2014; 4: e006108. 2014/10/03. DOI: 10.1136/bmjopen-2014-006108.
19. Cadre de référence : Programmes pour premiers épisodes psychotiques (PPEP)
20. Standards and Guidelines for Early Psychosis Intervention (EPI) Programs
21. Early Psychosis Intervention Program Standard.
22. Durbin J, Selick A, Hierlihy D, et al. A first step in system improvement: a survey of Early Psychosis Intervention Programmes in Ontario. *Early Interv Psychiatry* 2016; 10: 485-493. 2016/10/21. DOI: 10.1111/eip.12201.
23. Ferrari M, Iyer S, LeBlanc A, et al. A Rapid-Learning Health System to Support Implementation of Early Intervention Services for Psychosis in Quebec, Canada: Protocol. *JMIR Research Protocols* 2022; 11: e37346.

24. Tricco AC, Zarin W, Clement F, et al. Introducing the Strategy for Patient Oriented Research (SPOR) Evidence Alliance: a partnership between researchers, patients and health system decision-makers to support rapid-learning and responsive health systems in Canada and beyond. *FACETS* 2022; 7: 639-653.

25. Iyer S, Jordan G, MacDonald K, et al. Early intervention for psychosis: a Canadian perspective. *J Nerv Ment Dis* 2015; 203: 356-364. 2015/04/23. DOI: 10.1097/NMD.0000000000000288.

26. Morin M-H, Bergeron A-S, Levasseur MA, et al. Family approaches in early intervention: Benchmarks to guide intervention and support families in first episode psychosis programs (FEPP). *Santé Mentale au Québec* 2021; 46: 139-159.

27. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health affairs* 2013; 32: 223-231.

28. Kredo T, Bernhardsson S, Machingaidze S, et al. Guide to clinical practice guidelines: the current state of play. *International Journal for Quality in Health Care* 2016; 28: 122-128.

29. Brouwers MC, Spithoff K, Kerkvliet K, et al. Development and validation of a tool to assess the quality of clinical practice guideline recommendations. *JAMA Network Open* 2020; 3: e205535-e205535.

30. Brouwers MC, Kho ME, Browman GP, et al. AGREE II: advancing guideline development, reporting and evaluation in health care. *Cmaj* 2010; 182: E839-E842.

31. Hsieh H-F and Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research* 2005; 15: 1277-1288.

32. Krippendorff K. Validity in content analysis. 1980.

33. Early Psychosis Services NB: Administrative Guidelines / Services d'Intervention Précoce en cas de psychose au N-B: Linges directrices administrative.

34. Standards for mental health services in Nova Scotia.

35. Addington D, Abidi S, Garcia-Ortega I, et al. Canadian guidelines for the assessment and diagnosis of patients with schizophrenia spectrum and other psychotic disorders. *The Canadian Journal of Psychiatry* 2017; 62: 594-603.

36. Addington D, Anderson E, Kelly M, et al. Canadian practice guidelines for comprehensive community treatment for schizophrenia and schizophrenia spectrum disorders. *The Canadian Journal of Psychiatry* 2017; 62: 662-672.

37. Pringsheim T and Addington D. Canadian schizophrenia guidelines: introduction and guideline development process. *The Canadian Journal of Psychiatry* 2017; 62: 586-593.

38. Gouvernement du Québec. *Syntheses Le Plan d'action en santé mentale 2005-2010*. 2017.

39. Canadian Institutes of Health Research. Canada's Strategy for Patient-Oriented Research. 2011.

40. Rodolico A, Bighelli I, Avanzato C, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. *The Lancet Psychiatry* 2022.

41. Johannes Hamann, M.D. , and and Stephan Heres, M.D. Why and How Family Caregivers Should Participate in Shared Decision Making in Mental Health. *Psychiatric Services* 2019; 70: 418-421. DOI: 10.1176/appi.ps.201800362.

42. Hansson KM, Romøren M, Pedersen R, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres–a nested qualitative study. *BMC Health Services Research* 2022; 22: 1-16.

43. Bighelli I, Rodolico A, García-Mieres H, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. *The Lancet Psychiatry* 2021; 8: 969-980.

44. Cormier H, Guimond G, Joncas G, et al. *Profamille, programme d'intervention de groupe auprès des familles de personnes atteintes de schizophrénie*. 1991.

45. Sin J and Norman I. Psychoeducational interventions for family members of people with schizophrenia: a mixed-method systematic review. *The Journal of clinical psychiatry* 2013; 74: 16055.

46. Vu N, Selick A, Volpe T and Durbin J. *Family Work in Four Early Psychosis Intervention Programs: An Exploratory Study*. 2016. Canada: CAMH and HSPRN.

47. Selick A, Durbin J, Vu N, et al. Barriers and facilitators to implementing family support and education in Early Psychosis Intervention programmes: A systematic review. *Early Interv Psychiatry* 2017; 11: 365-374. 2017/04/19. DOI: 10.1111/eip.12400.

48. Bertulies-Esposito B, Iyer S and Abdel-Baki A. The impact of policy changes, dedicated funding and implementation support on early intervention programs for psychosis. *The Canadian Journal of Psychiatry* 2022; 67: 585-597.

49. Lyles S, Khan Z, Qureshi O and Shaikh M. A systematic review of the effectiveness and implementation readiness of psychosocial interventions for psychosis in South Asia. *PLoS one* 2023; 18: e0283411.

50. McGorry PD. The recognition and optimal management of early psychosis: an evidence-based reform. *World Psychiatry* 2002; 1: 76-83.

51. Guyatt GH, Oxman AD, Vist GE, et al. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. *Bmj* 2008; 336: 924-926.

52. Jarvis GE, Iyer SN, Andermann L and Fung KP. Culture and psychosis in clinical practice. *A Clinical Introduction to Psychosis*. Elsevier, 2020, pp.85-112.

53. Lefley HP. Families, culture, and mental illness: Constructing new realities. *Psychiatry* 1998; 61: 335-355.

54. Snowden LR. Explaining Mental Health Treatment Disparities: Ethnic and Cultural Differences in Family Involvement. *Culture, Medicine and Psychiatry* 2007; 31: 389-402. DOI: 10.1007/s11013-007-9057-z.

55. Oluwoye O, Stiles B, Monroe-DeVita M, et al. Racial-ethnic disparities in first-episode psychosis treatment outcomes from the RAISE-ETP study. *Psychiatric Services* 2018; 69: 1138-1145.

56. Anglin DM, Ereshefsky S, Klaunig MJ, et al. From womb to neighborhood: a racial analysis of social determinants of psychosis in the United States. *American Journal of Psychiatry* 2021; 178: 599-610.

57. Morgan C and Hutchinson G. The social determinants of psychosis in migrant and ethnic minority populations: a public health tragedy. *Psychological Medicine* 2010; 40: 705-709.

Bridge 1

Manuscript I was a review of Canadian clinical guidance documents on early psychosis, with the goal of extracting and mapping family-focused recommendations, their implementability, and the level (direct care to policy making) and continuum (from consultation to partnership) of engagement of families reflected in the recommendations.

Findings from Manuscript I clarified the nature of Canadian clinical practice recommendations for offering family interventions and involving families in early intervention services for psychosis. These recommendations are generally overarching statements that are poorly operationalized and mainly concentrated around family interventions like family psychoeducation (group and/or individual) and the generic idea of families being involved. Furthermore, the assumption that families are care "recipients" than "partners" is evident from the nature of recommendations postulated in the clinical practice guidance documents, although more recent documents (ON, BC, QC) reflect a transition in outlook from recipients to partners.

We found that the implementability of the family recommendations were mostly of moderate quality. The preferences of the patients and families were either rarely systematically elicited (or reported) during the development of clinical practice recommendations. Along with policy makers and clinicians, the perspectives of patients and families are central to the formulation of clinical practice recommendations and guidelines.

Beyond this review, a majority of the family literature also investigates the efficacy and effectiveness of family interventions, and/or the experiences and needs of families in the caregiving role. Not much research has elicited the views and preferences of all pertinent stakeholder groups – patients, families, clinicians, and managers – regarding family involvement in early intervention services for psychosis and its actual operationalization and implementation. Gaps also remain about how these stakeholder perspectives converge and diverge, and the specific ways in which family involvement is navigated (e.g., around confidentiality, balancing competing priorities for clinicians, etc.).

An exploration of the preferences of multiple stakeholder groups for involving families in routine clinical care in early intervention services for psychosis was thus an evident next step. Innovatively, we undertook a single full day, consultation meeting involving representatives from all stakeholder groups (patients, families, case managers, decision-makers and psychiatrist) using a modified nominal group technique to elicit in-depth views and preferences regarding family involvement, followed by an e-survey to prioritize their preferences. Our discussion guide was informed by findings from the review (Chapter 3), as well as the literature on families in early psychosis (Chapter 1).

Modified nominal group technique methodology, like other consensus building techniques, includes using a group to make decisions, solve problems, and develop solutions. A distinct feature of this methodology is that each member of the group provides their perspective on the topic on their own, then duplicate answers are removed, and the remaining solutions are ranked in order of preference. More importantly, modified nominal group technique generates more ideas than typical group discourse and balances individual influence by reducing power imbalances. This technique reduces pressure to comply and the tendency that one or two people (e.g., established leaders) dominate the discussion.

In the following study, modified nominal group technique employed maximum discussion time, which yielded full development of ideas and nuanced insights. A follow-up e-survey prioritized strategies around the involvement of families in early intervention services for psychosis, which fit our objective of deriving an understanding of multiple stakeholders' preferences for family involvement that is at once rich and implementable. Such insights are critical for generating implementable recommendations for involving families in care, that are anchored in the preferences of patients, families, clinicians, and decision-makers, as well as informed by evidence and existing guidance/policy recommendations.

Chapter 4

Manuscript II

Exploring the Preferences of Multiple Stakeholder Groups for Family Involvement in Early Intervention Services for Psychosis Using Modified Nominal Group Technique

Helen Martin, Aarati Taksal, Mary Anne Levasseur, Srividya N Iyer

Prepared for submission, 2024

Abstract

Background: Families are involved in the care of their loved one(s) experiencing psychosis even before contact with healthcare services is made. There is consistent evidence that family involvement leads to improved outcomes and recovery in early intervention for psychosis. However, relatively less is known about how various stakeholders (patients, families, and clinicians) prefer that families get involved in early psychosis care. This study aims to understand patients', families', and clinicians' views about and preferences for involving families in care for youth experiencing early psychosis.

Methods: The study employed a modified nominal group technique and took place at an early intervention service for psychosis in Montreal. Nine participants including patients, family members, and clinicians participated in a one-day stakeholder consultation workshop. Informed by findings from this discussion, four questions with 10 statements/recommendations under each were generated and the same participants were asked to rank these statements/ recommendations in an e-survey. Data were analyzed in 3 stages (1) qualitative thematic analysis for the group discussion (2) content analysis of group discussion data to generate questions and associated statements/recommendations, (3) tabulation of ranks to identify the most important, moderately important, and least important statements for the whole group.

Results: Three themes were identified from the group discussion: Meaning and value of family involvement, Factors that influence family involvement (including a subtheme around consent and confidentiality), and Preferred ways and methods of family involvement. In the second stage, four questions were generated: (i) In what ways should families/ carers of persons with psychosis be involved in early intervention services? (ii) What influences the involvement of families/carers of persons with psychosis? (iii) How often should families/carers be involved? (iv) How should consent and confidentiality be dealt with in involving families/carers? Ten statements were also generated under each question, which were ranked from 1 (most important) to 10 (least important) by participants. In the third stage, an analysis of the ranking revealed that there was a consensus among stakeholders that: families be involved during crises and relapse; families keep the treating teams updated about the patient; maintaining contact with each other is the responsibility of both treating teams and families; there be common guidelines about involving families in treatment; and lack of patient consent need not prevent treating teams from receiving information from families and sharing general information with them. Finally, there was consensus that when patients were not inclined to involve their families in treatment, treating teams could have a dialogue with patients that family involvement in treatment could be helpful.

Conclusion: There is consensus among patients, families, and clinicians that contact between the family and the treating team needs to continue over the course of the treatment. However, there may be differences among them about the method, frequency, and content of such contacts, which are also seen as varying based on clinical, familial, and developmental factors. While all agree that consent and confidentiality are to be respected, there is also widespread consensus that these need not necessarily deter family involvement and that these aspects evolve and should therefore be revisited over the course of treatment. Our findings highlight the value of a trialogue between the patient, family, and the treating team regarding the nature of contact and family involvement in treatment. Future work can operationalize these findings into more concrete recommendations for family involvement in early intervention services for psychosis.

1. Introduction

Family involvement in early intervention services for psychosis has the potential to benefit patients, family members, clinicians, and society at large. There is a wealth of evidence for the substantial benefits of family interventions and family involvement in treatment for achieving better clinical, social, vocational, recovery and quality of life outcomes for patients with first-episode psychosis (1-6). Despite this, there are common challenges across early intervention services for psychosis such as poor and inconsistent implementation of recommendations around family involvement and interventions.

Although most early intervention services for psychosis in Canada and elsewhere offer family psychoeducation (7-9), few have reported on the level of their uptake among families. The few studies that have reported on this have shown that there is a substantial proportion of families (ranging from 30% to 50%) who do not participate in even a single psychoeducation session, with these percents rising when it comes to attending all offered sessions (10, 11). While treatment teams have contact with most families in the initial phases of treatment, this generally wanes as treatment progresses (3, 12). This is disconcerting because contact between families and treatment teams is at once the simplest and the most essential and foundational family work practice, as family contact with treatment team has been linked to a wide range of outcomes ranging from improved service engagement and medication adherence to reduced mortality rates (3, 13, 14).

Furthermore, uptake of more specialized family interventions (e.g., family psychoeducation, family therapy) may depend on families' trust and confidence, that regular contact between treatment teams and families is essential to build (15, 16). As is, specialized interventions may face an even higher level of implementation barriers (e.g., multiple family group therapy requires a closed group of family-patient dyads to meet over a period of six months) than just ensuring contact between families and treatment teams. Still, there are difficulties even in this regard, as is also evident from the fact that families themselves repeatedly discuss feeling poorly or inconsistently informed and excluded from treatment decision-making for their loved ones with psychosis (17, 18).

These implementation problems stand in sharp contrast to the widespread consensus among clinicians and decision- and policy makers regarding the importance of involving families in the care of young persons with psychosis, as reflected in most guidelines for early intervention services for psychosis (19-22).

Our review and critical appraisal of Canadian guidelines for early intervention services for psychosis revealed some important gaps that may be contributing to poor and/or inconsistent involvement of families in early intervention services for psychosis. Some of these gaps are also evident and have been pointed out in the literature on family involvement in psychosis, and barriers to such involvement (23, 24). Chief among these is that the views, values, and preferences of key stakeholder groups in the clinical encounter – families, patients and clinicians – have not always been systematically elicited and integrated in arriving at an understanding of what family involvement looks like and should look like in actual practice.

When stakeholders' views have been sought, this has often been in a siloed fashion with most studies focusing on select stakeholder groups, one at a time (25, 26). This may also explain at least partially why recommendations for family work in current guidelines are often generic and not "measurable", and provide little guidance on how these can be applied and adapted in real-world settings (22). Even when these generic actions and targets in guidelines may be informed by evidence and intuitively seem appropriate, they may not accurately reflect what is important, or what is most important, to key stakeholders, including patients, family members, and clinicians, particularly when they balance multiple priorities (e.g., valuing alliance with and confidentiality of patients vis-à-vis informing and involving families).

Across various fields of contemporary healthcare, it is widely recognized that incorporating the preferences of patients, family members, clinicians and other stakeholder groups is essential at all levels of decision-making (27-30). There has also been advocacy for the inclusion of different stakeholder voices and perspectives in early psychosis (31, 32). There are two primary justifications for incorporating patient and family preferences into the decision-making process in mental healthcare: ethical and outcomes-based. Attending to the preferences of those with lived experience aligns with ethical and rights-based principles that uphold dignity and inclusion (33), expressed in the idea of "nothing about us without us" (34).

Beyond this, evidence also suggests that individuals are more inclined to initiate and participate in treatments that align with their preferences, resulting in improved clinical outcomes (35).

To our knowledge, there is currently no evidence on the views and preferences of multiple stakeholders (patients; families; and clinicians and clinician-decision-makers/program leaders) regarding the specific topic of the involvement of families in early intervention services for psychosis, particularly in the Canadian context. Gaps also remain about how these stakeholders' perspectives converge and diverge; how stakeholders currently navigate family work and associated tensions and decision-points (e.g., around confidentiality, balancing competing priorities for clinicians, etc.); and how they think these should be effectively navigated (i.e., their preferences).

Addressing these gaps, we conducted a two-part study with two objectives (a) to explore in depth the views and preferences of all pertinent stakeholder groups regarding the involvement of families in early intervention services for psychosis; (b) to arrive at a concrete set of recommendations for how often families should be involved over the course of their loved one's follow-up and how patient consent and confidentiality vis-à-vis the involvement of their families should be navigated. We aimed to derive these recommendations, first by formulating specific statements arrived at based on the in-depth multi-stakeholder discussion in the first part, and then by asking the same set of stakeholders to rank these based on their preference. Along with these recommendations, we also sought to derive a triangulated, stakeholder-informed and actionable understanding of the various ways in which families are and could be involved, and the myriad factors that influence their level and nature of involvement.

2. Methods

2.1 Study Design and Setting

The study employed a cross-sectional design and qualitative research methodology, with the first part being a group discussion and consultation workshop, and the second being an e-survey. The data was collected using a modified Nominal Group Technique, a consensus-building method. The modified nominal group technique is a structured multi-step facilitated group meeting approach which requires various stakeholders to discuss and prioritize responses to specific questions (36). Refer to figure 1 for detailed modified nominal group technique process used in the current study.

The modified nominal group technique was carried out at a specialized early intervention service for psychosis in Montreal, Quebec, Canada (name of program [and cites] not provided to reduce identifiability of participants). The publicly funded, catchment-area based program is in a stand-alone building in a hospital with an academic affiliation. The program serves individuals between the ages of 14 and 35 who met DSM-IV-TR criteria (37) for a non-affective or affective psychotic disorder; had not been treated for more than 30 days; and did not have a pervasive development disorder, intellectual disability (i.e., intelligence quotient less than 70) or a primary substance use disorder at the time of admission.

The program provides a two-year treatment that includes case management, medication management and family psychoeducation. Additional psychosocial interventions (e.g., family peer support, cognitive-behavior therapy, etc.) are provided based on patient and family needs and preferences. Ethics approval was obtained from the research ethics board of the affiliated institution. All participants provided informed consent. The study was guided by the patient engagement framework of the Strategy for Patient-Oriented Research (SPOR), Canada (27) in that it was co-designed with inputs from a family peer support worker; focused on bringing all stakeholder group representatives together and eliciting all their perspectives; and aimed to yield findings with direct implications for improving services and policy.

2.2 Sampling Strategy and Recruitment

The same sample participated in both parts of the study. Our sample comprised individuals with first-episode psychosis and family members (could be parents, siblings, partners, spouses, etc.) of persons with first-episode psychosis who were currently receiving or had received services in the past five years from the participating early intervention service for psychosis, as well as clinicians with experience in the same program.

Potential participants were recruited using purposive sampling – to ensure that we recruited patients and families who were currently using and those who had completed the two-year program recently and who were of different genders and ethnicity to the extent possible; and clinicians who had only clinical and who had clinical and program coordination/administration roles and who were physicians (psychiatrist) and non-physicians (case managers). Information about the study was shared by clinicians and family peer support workers with patients and family members coming to the service and via a poster in the waiting area. While participants could speak in any language they preferred, we recruited those who were comfortable comprehending both languages (French and English) so they could understand and participate fully in the full-day consultation workshop. We did not recruit from patient-family dyads, i.e., patient and their own family member. We also ensured that the participating patients and families were not being currently followed by any of the participating clinicians.

In keeping with other studies using nominal group technique in health services research (38-41), we targeted a sample size of 9 to facilitate meaningful exchange and ensured an equal representation from the three stakeholder groups – patients, families and clinicians-team leads.

2.3 Study Materials

Participants completed socio-demographic information such as age, gender, sex (male, female, etc.), education (high school, CEGEP, Bachelor, Masters', Ph.D., etc.), employment, relationship status, living situation, ethnicity, whether they were currently or previously followed by the early psychosis program, and type of clinician role (social worker, occupational therapist, psychiatrist, etc.).

The modified nominal group technique discussion was guided by a discussion guide comprised of broad, open-ended questions about family involvement, what forms it takes, what factors influence it, how families are involved at different stages of the illness (e.g., acute phase, recovery, relapse), views on patient consent vis-à-vis family involvement, and what supports families may require. The development of the discussion guide was informed by existing literature reviews on family work in psychosis, the experiential knowledge of the authors both of whom had clinical and pertinent research experience in early intervention services for psychosis (SNI & HM), and inputs from a family peer support worker with experience participating in research. As per Krueger's (42) recommendations, the discussion questions and later, survey questions were pilot tested with members of the senior author's larger research team, as it was not feasible to test it in similar conditions as a focus group.

2.4 Data Collection

Data were collected sequentially in two phases: Phase 1 consisted of a one-day group discussion and consultation workshop (approx. 6hrs plus breaks for food and rest/casual interactions) that centred on family involvement. While the guide was generally used to organize the session, the facilitators explored additional themes and topics that came during the discussion. Authors SNI and HM served as moderators for the workshop, while AT assumed the role of an observer and note taker. None of them had clinical roles in the setting where recruitment took place.

For each of the key questions, some similar steps were followed: firstly, participants were given time to think about their responses and to note down written responses; a round-robin presentation of ideas was conducted during which each participant's responses were written down on a large sheet (during this time, the rest of the group remained quiet and did not react to ideas being generated, to allow participation from all members of the group); and finally, a non-evaluative discussion was held. The discussion helped clarify the responses, and also allowed further in-depth discussion, exchange and probing regarding additional topics that came up during the workshop.

The entire workshop was recorded with consent and transcribed verbatim. The facilitators (especially SNI) have significant experience with similar multi-stakeholder groups and was particularly attentive to mitigating power imbalances, ensuring that people felt safe to express their ideas and that they felt engaged and respected (e.g., by setting up ground rules for exchange, by sitting in a circle, by allowing people to generate their ideas and share it before group exchange happened, being attentive to group dynamics, etc.). Participants had also been prepared for the meeting by HM.

Phase 2 encompassed the development and implementation of an electronic survey (via Microsoft Forms) that comprised of statements organized under four themes pertaining to family involvement in early intervention services for psychosis. The themes, which were framed as questions, along with the 10 statements under each theme, were both derived from the analysis of Phase 1 data. The same nine participants from Phase 1 were asked to rank each of the ten statements within a designated theme based on their individual preferences, assigning a numerical value of 1 (indicating the highest level of importance) to 10 (indicating the lowest level of importance).

2.5 Data Analysis

Data collected from the two phases were analyzed sequentially in three stages. The workshop discussion was professionally transcribed and verified by the first author (HM). Qualitative data from Phase 1 was analyzed in phases, as recommended by Braun and Clarke (43). Three team members (HM, AT and SNI) were involved in this analysis. First, they familiarized themselves with the data by reading and re-reading the transcripts and noting initial thoughts. Secondly, they independently generated initial codes and thirdly, the codes were collated under themes. An initial list of themes was generated deductively based on the questions to guide the discussion. The team had agreed upon generating additional themes if needed. Fourthly, they reviewed and discussed the coded extracts and the themes, and grouped themes if needed, to ensure coherence of themes. The fifth phase was focused on naming themes and the sixth on writing the findings, which allowed further consolidation of the themes in relation to the study's objectives, existing literature and plans for Phase 2.

In Stage 2, an iterative content analysis approach (44) was used to develop statements pertinent for stakeholder prioritization (survey development). Phase 1 resulted in four themes that were then formulated as questions, and statements generated as answers/responses to each of these questions. HM and SI were involved in this stage, and first independently generated and then iteratively discussed and refined the statements under each of the four themes, to finally arrive at an agreed-upon set of 10 statements under each of the four question-themes. This exercise took several rounds of exchange and refinement to arrive at 10 statements that (a) were congruent with findings from Phase 1; (b) were distinct from each other so they could be ranked (c) articulated clearly in one sentence (d) articulated as actionable "recommendations" (i.e., should statements) for questions that were the involvement of families within early psychosis programs (45, 46) and the 10 statements under each question that were finally arrived at (See Supplemental)). The e-survey itself was also pilot tested within the authors' larger research team, with small modifications made before emailing it to study participants.

In Stage 3, the responses from the e-survey were downloaded into Microsoft Excel for analysis. At the individual level, all statements ranked between 1-3 were deemed "most important"; 4-7 were considered as "moderately important"; and those ranked 8-10 were deemed as "least important" for the respondent stakeholder. We computed, for each of the 40 statements, how many participants out of nine deemed them as most, moderately, and least important. As is often employed by nominal group technique studies, statements on which there was a "consensus" around their importance were considered as "most important", "moderately important" and "least important" for the group, as a whole (47).

There is no fixed standard for defining "consensus" in employing nominal group technique with small groups with multiple stakeholders. For instance, some studies have used 70% agreement on assigned level of importance among participants as the threshold for consensus (48). However, these thresholds have typically been used in studies that focused on outcomes (e.g., what outcomes should be prioritized for assessment in arthritis) (49, 50) rather than on understanding or exploring phenomena such as the involvement of families such as in our case. Therefore, the rule of thumb for this study was that if five or more participants ranked a statement within a given importance category, we considered it as the opinion of the entire group. For example, "The need for and frequency of family contact depends on the phase of recovery, (e.g., more contact when there is a crisis or relapse and less contact when the person is doing well)" was ranked most important by one participant, moderately important by seven, and least important by one participant. Using our rule of thumb, we concluded that the group had deemed this specific aspect of family involvement "moderately important". The cut-off of five allowed us to also ensure that at least two stakeholder groups had endorsed the statement at the same level.

In other words, since we had three participants in each stakeholder group for a total of nine participants, there was no way to arrive at the threshold of five without at least members from two (if not more) stakeholder groups endorsing the statement at that level. Beyond using this rule of thumb, we also descriptively noted salient patterns (e.g., if a statement was ranked by any one stakeholder group as "least important" but at least five members from the remaining two groups ranked it as "most important", we described this). Finally, we decided *a priori* that those statements that did not meet the threshold (i.e., were not assigned the same level of importance by at least five people) would not be completely disregarded because they were still generated based on the group discussion and because our sample size was small for the ranking exercise. In this regard, we see results from Stage 3 as needing to be further ascertained with a larger sample size across all three stakeholder groups.

2.6 Rigour and Trustworthiness

We strove for rigour and trustworthiness in stages 1 and 2 by adapting the well-established nominal group technique; frequent debriefing during data collection and analysis; having three researchers involved in data collection and analysis, and reflexivity. Reflexivity is the practice where researchers acknowledge the influences their positions and identities have on their research. In this case, the authors include a family member partner with lived experience of caring for someone who received services in an early intervention service for psychosis with experience of peer support and partnering on research (MAL). MAL was born in and has lived all her life in Quebec. MAL provided inputs at various stages during the project, including on the interview guide, recruitment process and methodology. The team also included three female first-generation immigrants (HM, AT, and SNI) who have clinical and research experience in early intervention for psychosis (but no lived experience as persons with psychosis or families of persons with psychosis). The senior author also has experience administering and coordinating an early intervention service for psychosis. Discussions involved careful reflections on how their positions and cultural backgrounds possibly influenced their views on the findings, and the authors sought feedback from their larger team to ensure that the way they analyzed the data did not only reflect their own assumptions and lenses. Stage 1 was thematically analyzed to generate statements for the e-survey, which was shared with the same participants, and served as a form of member check-in.

3. Results

Nine individuals provided written consent to participate in the workshop: three patients, three carers, and three clinicians. All nine participants completed and returned the demographic questionnaire before the workshop, attended the consensus workshop, and completed the electronic survey. Table 1 provides demographic characteristics of the participants (some responses, e.g., ethnicity, were collapsed into "minoritized" to reduce identifiability). Three individuals from the patient and family groups were currently seeking services at the participating early intervention service for psychosis, and three had within the past five years.

3.1 Stage 1: Thematic Analysis

Stakeholders' perspectives on family involvement in the lives of young persons with first-episode psychosis and their treatment were reflected in three themes: *Meaning and value of family involvement, factors that influence family involvement, and preferred ways and methods of family involvement*.

3.1.1 Theme: Meaning and Value of Family Involvement

All three stakeholder groups opined that generally, family involvement in the life and the treatment of young persons with early psychosis was important and beneficial. They described a myriad of ways in which families are involved in the lives and treatment of their young, loved ones with psychosis. Families were meaningfully involved by providing emotional support, practical support (transportation, housing, and day-to-day supports), and "*being there*" for the loved one. Listening or attuned listening (sometimes listening "quietly", particularly during sessions where families were present with the clinician and the patient) and accepting the changing situation (that is, experience of psychosis in a loved one, with its vicissitudes and sequelae) were also considered as valuable aspects of the family role.

"Because if you ask me in what way can families, caregivers be involved, I would say like be there all the time and be present. Okay, this would be my first answer. Be involved 100 percent." (Family member 1)

"…support [the young person] in a generic way, be there. I put it in a very simple word, you know, be there, that's what it is for me." (Clinician 1)

"So being there, even if you're just sitting there listening, you can understand what's going through your child's mind to then better deal with them at home, and like avoid certain topics and things like that." (Patient 2)

"I think parents should be involved in the emotional supporting aspect of it, whereas the technical more what to do to get a job, there are a lot of resources here at [name of clinic] clinic for that. So, they don't necessarily need to get the parents involved for that. But to just have the parents just like you said, to just be there, even if you're 35 to just support you and your goals and stuff." (Patient 2)

From the patient perspective, the family's presence while meeting the treating team was comforting as they faced a series of evaluative questions and felt judged. Families reported that their presence in the sessions was important so they could provide information and facts which could help with the diagnosis or the treatment plan. Clinicians felt that families played a pivotal role as a link between them and the patient and could intervene and be valuable allies during crises.

"I could tell him [the psychiatrist] specific facts which helped and the psychiatric diagnosis, the psychosis right away and he [the patient] took medication after two weeks of symptoms. So the fact that I was there because my son at first told the psychiatrist, "No, it's real." So the fact that I was involved ASAP was a good thing." (Family member 2)

"I think the biggest thing for me is I feel like as a [clinician], families are a big tool for me...So having a family member there that knows what to do if there's suicidal ideas or if there's a

crisis or if something's wrong with the medication or whatever situation is tough, I feel like it's good to have that link with the family, so the family can kind of intervene when we're not available." (Clinician 2)

Families reported that their involvement was restricted when their loved one was admitted to the hospital when symptoms were exacerbated. Because patients get admitted alone and do not have frequent contact with the family, families and patients reported feeling anxious and uncertain during inpatient hospitalizations. Visiting the hospital to ensure that the patient did not feel alone or scared during hospitalization was a stressful part of being involved for families, but often also reassuring and anchoring for their admitted loved ones who were otherwise in unfamiliar contexts (particularly as for some, their hospitalization at the time of entering the early intervention program was also their first hospitalization ever or first hospitalization in a psychiatric unit).

"She (daughter) called in the morning around 6. She said, "Mom, they took me somewhere. I don't know where I am. I don't know why they took me here. They put me in a room alone." Because in the emergency, she had other people in the room. So she said, "I really don't know if you're going to ever find me." I say, "Don't worry, I know exactly where you are." I didn't know where she was…I came straight to the emergency. I said, "I left my daughter here. So where is she?" They told me [name of inpatient unit]. I go to her and then this is also my first experience. I go to [name of inpatient unit], I ring the doorbell, nobody comes. I ring the doorbell, nobody comes…" (Family member 2)

"I'd encourage case managers and psychiatrists to encourage parents to visit while people are hospitalized because sometimes, I felt that I couldn't really have contacted a lot with some people because it would make my mental state worse. Some people are very wild in those places. I mean you can relate to those people sometimes and it can help but also sometimes it can make your situation worse. So being in contact with somebody that has a correct mental state or that is in ease with its mental state is helpful." (Patient 3)

Overall, the rationale for family involvement was succinctly put across by a patient, *"I like two general things. Like the first one would be trying to get them [patients] to understand that involving their family would bring their family more understanding about their situation and teach them, not necessarily teach them, but tell them how to better support them [patients]. So that could be a good thing and then another point in letting them [patient] know that involving their family could help improve their relationship. Like if they don't want to involve their family because they have like relationship problems, then they can just make the point that well, if they know more about you, maybe your relationship is going to get better."* (Patient 2)

3.1.2 Theme: Factors that Influence Family Involvement

Participants discussed various factors that influenced the extent to which and how families got involved. These factors were not consistently only "barriers" or "facilitators" and played out or were perceived differently at different times or in different contexts. For instance, treating teams could act in ways that could be seen as promoting and hindering the involvement of families, with the same treating team being seen differently at different junctures by different stakeholders. Broadly, factors influencing family involvement fell into two broad categories that interacted with each other - those pertaining to the familial and developmental context and those pertaining to the treatment context (relationship between family and treatment team, patient's mental health state and consent and confidentiality). "Consent and confidentiality" were the focus of detailed exchange and is presented separately as an important sub-theme.

3.1.2.1 Familial and Developmental Context and Family Involvement

Many participants felt it important to consider the developmental context (adolescence and young adulthood) of persons being served by early intervention services for psychosis when considering family involvement. For adolescents, for instance, there may be a need for greater and regular family involvement in treatment, compared to younger adults. Furthermore, participants also spoke about "autonomy" and establishing independence often being valued developmental goals for adolescents and young adults. Persons with psychosis, their families and clinicians may sometimes all be struggling to negotiate young people's pursuit of these developmental goals, within the context of psychosis, which may necessitate greater family involvement and "shared" decision-making. Stakeholders acknowledged that for families, this may also mean thinking through how the way they always related and desired to relate to their loved one shifts to integrate their loved one's experience of psychosis.

"I think I mean, that speaks a bit to the situation or to the phase of age that we are dealing with. So most of the time, the young are very much dependent on their parents. And in the same time, they want to have their autonomy compared to parents. And most of the time, you know, people are caught in this ambiguity, "I want to have the help of my parents and I want to live in the house and I want that they contribute to my education, and this and this. But I don't want them to be involved with in all the aspects." (Clinician 1)

"It's hard for parents sometimes to juggle like treating your child as if they're just your child and not treating your child as if they have like a mental illness. It's hard sometimes because they don't want to like offend you but they also like to know something's wrong. Sometimes it's hard to separate." (Patient 2)

Families reported that the larger culture they belonged to and the culture of the family, both influenced their involvement in the life and care of their loved one. Compared to the Canadian mainstream, some other cultures were seen as encouraging parents to be involved in the lives of adult children and for adult children to respect their parents' advice. Thus, participants pointed out that there were cultural norms about parental involvement.

"Now, my child consenting to me going into the room. Is it because of the way she was raised by me that the elders are involved in your life to guide you? Okay. So she always says, "Yeah, I want my mom to be in the room." In this society [Canada], it's not. It feels like I'm forcing myself onto her. So we've been struggling since 2014 and fast forward, recently, she had an episode a few months ago." (Family member 3)

For many minoritised families, there is a clash between the norms of parenting of the heritage and the host cultures, which can also get reflected in the struggle between them and the treating team about how involved they get to be in the care.

"First in each family, each family is different and there's a family culture. With mental health issues or not, some parents will be more involved in the life of their children and some won't. For example, like my wife is calm as a European background. My in-laws are involved a lot in the support, education of our three sons." (Family member 1)

"Some people think it's important that their sons leave home at 18 or 20 or 21 and as soon as possible because that's what they think. And this becomes also the desire on the side of the kids. So the development, the involvement will differ depending on the family culture." (Family member 1)

Further, for families, practical issues such as low financial capacity, presence of family stressors, long distance from the clinic/ hospital and their own employment reduced their involvement in the life and treatment of their loved one with psychosis.

Participants felt that the patient-parent relationship in general also influenced family involvement. In general, if the patient-parent relationship was good and they had trust between them then they would want their family to be actively involved throughout the program or treatment. Family members expressed that it was their responsibility to foster that relationship with their loved ones. Participants, especially patients and clinicians, felt that a young person's experience within the family (protected and supportive versus traumatic and violent) would also influence if families get involved in care, if their loved ones desire such involvement and if clinicians perceive family involvement as "helpful".

"I'd have them in specific cases, sometimes parents that are abusive shouldn't be implicated because the service can be an escape. We have to like still try to differentiate symptomatic abuse [referring to delusions, suspiciousness as part of the illness] and physical like real abuse because sometimes those things are very complicated. So just to like make sure that if the children is trying to escape from a troubled family, not implicate the parents to that because that's why he's here." (Patient 2)

3.1.2.2 Treatment Context and Family Involvement

Overall, when families had a positive relationship with the treating team, this resulted in greater family involvement in the care of the young person. As acknowledged by families and clinicians, clinicians also helped the family to learn about the illness and its course and treatment and be open to newer perspectives and encouraged a change in attitudes (e.g., acceptance, patience).

"Also, I was very involved with the social worker, he gave me his phone number. If I had worries about suicidal thoughts or something about my son, you know, because sometimes when the positive symptoms were like diminished but as he was down, I could right away text my worries to the social worker and he intervene the same day." (Family member 2)

"…the thing I appreciated the most and what changed my perception of the situation the most is when somebody here [the clinic] said the simple phrase that from that from now on in the life of your son, you have to redefine success...it means his whole life will change and at the same time, our whole life will change. And it's after I heard this, took me maybe a year to accept this. And since then, since I accepted this thing, I felt a lot better." (Family member 1)

"There is a family that really was extremely happy with one single word that I said. The first time I met with a patient, I said, "How can we help you?" And that remained in the mind of the mother." (Clinician 1)

Families' level of involvement also changed depending on how their loved one was doing functionally and with respect to their mental health.

"For me, I was able to take time off from work for one year when it began, but when she started stabilizing, I started understanding more what the situation was, I was able to only come on whenever I was needed." (Family member 2)

"The other thing is really step up and down the intensity depending on the situation... Sometimes the things are going very well, why should you come and leave your job for half a day and things are okay. So if there is no need for that, there is no need for that. If the situation

changes, then then you can negotiate again with your child and ask for more involvement." (Clinician 1)

3.1.2.3 Treatment Context and Family Involvement: Consent and Confidentiality

Importantly, all stakeholder groups agreed that how much families get involved in care (not necessarily in the life) of their loved one with psychosis is influenced by the consent given by the patient and confidentiality issues.

At least one patient shared a clear opinion that families need not get involved in care if they (patients) did not present any danger to self or others AND if the patient did not "want the parents to be involved". Further, another patient drew on their own experience to talk about how it would be hard to involve parents who did not believe in the concept of mental illness or mental healthcare. Interestingly, this same individual who had experienced a delay in getting help for their psychosis because their family saw "prayer" as the solution, had now, "over time, they (family) started getting more supportive about it. And I find like, I think educating them is really important on the topics." This highlights not only the importance of psychoeducation but also that families' views can evolve over time, and that treating teams may need to account for the potential for such change.

Among the stakeholder groups, clinicians expressed the most concerns around consent and confidentiality followed by patients. Clinicians reported that the primary challenge for family involvement is consent and confidentiality; even though families can share their concerns regarding the patient, clinicians were limited or not allowed to share information if the client refused consent. Clinicians reported that there were occurrences where the treatment team considered that involving families will assist patient recovery but since the client had refused consent, they were unable to involve families. In other instances, clinicians spoke about helping clients who refuse consent to see the value of family involvement.

"And then there's kind of grey zone where… the family might not be as supportive as we want them to be and the client doesn't feel they're supportive. So initially, the client is saying I don't want my family involved and what we do is try to work on that consent to try to explain to the

client that the more your family is aware of the situation, the more they're informed, the better they are to support you. And we can help with that to help, kind of improve that communication and improve that relationship. And in the end, it benefits everybody. And so it's important not to just kind of like right away be like, "Oh, we don't want to involve that family because they're problematic", we want to try as much as possible to work with everybody on that to see if that family can actually become more supportive." (Clinician 3)

Consent was also seen as evolving over the course of treatment (i.e., dynamic) depending on multiple factors (e.g., acute phase vs remission phase) thus revealing the complex nature of this process. In addition, there could also be several levels of consent which can include or exclude or shape family involvement.

"There are several grey zones in family involvement - the toughest one is when a client refuses any form of family involvement." (Clinician 1)

"So just to inform you that the work we have done is also to make sure that we have this kind of information systematically included in our files or that the patient initially agreed to contact with family or not and we need to revisit that from time to time." (Clinician 1)

"I can start with the preferences. So I put them in order of so not the worst case scenario but the most extreme scenario would be no knowledge at all about me participating in any treatment. And the second one would be no contact at all. So like knowledge but no involvement at all. Then there would be like no sharing information but there's still contact with the parents. "Oh, they're doing okay or they're doing so-so" And then like a sharing of information and action." (Patient 1)

"Confidentiality" and respecting the patient's confidentiality when sharing information with the family was not merely connected with patients' consenting for their families to receive information about and be involved in their care. Even after generally consenting, patients sometimes put limits on what could or could not be shared with their families. Some patients spoke about preferring to be present when their clinicians and families met, particularly in the initial phases of treatment.

"… if they were to meet up separately, I know at the time, I would have been convinced that they were like conspiring against me and something like that. So meeting together… shows that the parents is there for you to understand what you're going through….And to help in decision making for treatment." (Patient 1)

Clinicians also spoke about needing to sensitively navigate sharing information with families, and sometimes even receiving information from them, and shared examples of when such situations became tricky or difficult.

"It's kind of touches into the idea of consent is that sometimes family will call the clinician and say, "I want to share information with you, but I don't want you to tell my son or daughter." And that puts us in a really difficult position." (Clinician 3).

On a positive note, members from all three stakeholder groups spoke of successfully handling such situations, giving examples. Handling such situations often entailed clinicians communicating with families and patients to help them understand better the clinician's stance or view. In the instance below, the family member shared how the case manager had explained that he would share with the patient that their parent had called and the rationale for it. Hearing and understanding this, the family member chose to let their son know on their own that they had called the case manager.

"*It happened to me and [case manager's name] told me like, … "I can talk to [patient's name] about this but I have to tell him where it comes from or else he's going to be like what?" But I was okay, so when he came home, I was transparent. I was like, "I had to call [case manager's name] because I was worried." He's like, "It's okay mom." So it was all good."* (Family member 2)

Families spoke about their own journeys understanding and accepting patient's desires for privacy and limits they posed to their clinicians sharing information, which at times, was a difficult journey. At other times, families understood their loved one's desire for and limits to privacy as being part of their larger developmentally appropriate quest for autonomy. On their part, patients also spoke of their journeys becoming more accepting and appreciative of the involvement of their families in their care. This not only entailed time but also clinicians, families and patients negotiating and re-negotiating ways for families to be involved that resonated with all three stakeholders, but especially the patient.

"Privacy was a big word for me as a parent, which I had to accept." (Family member 2)

“And also for parents, it can be very reassuring to be in contact with the people that support their children like knowing what's happening. I was very private about it. My parents were stressed out like what's going on? What are you doing? And when they started being more involved to really help them to like understand more and help me…” (Patient 1)

Importantly, consent and confidentiality were seen by clinicians as multifaceted, having legal, ethical, social, and pragmatic dimensions, which they often juggled in their day-to-day practice.

“I think the privacy is a social institution. So, people take it as a social institution. It's something that is very much emphasized, very much put out there. And that's a piece of what you have as a right and you grab it and you run with it. So, this is mine. Don’t think that I am going to lose that even to my mom ... That’s my right, that's something that I have. And then I can play with it the way I want. But coming and depriving me from this, no, I don't accept it.” (Clinician 1)

“Because I think, obviously, there's the legal thing, but I want them to also understand that maybe there's consequences to themselves [referring to patients] too, if they don't share with the family.” (Clinician 2)

“But you know what, I mean I think we've all been in that situation [referring to situations where young people may have started using substances again or stopped taking medication, but have asked this to not be shared with families]. And I mean, what's the confidentiality about talking about confidentiality? So sometimes I will tell them an answer, but I will say, sometimes, not in all situation…I might say that and remind them that you know that it’s

something we continue to work on with clients. But in the meantime, if ever you have a concern, you can call me, but we might not be able to share everything that I'm aware of, but I'm really happy to hear your information and remind them that they can do that." (Clinician 3)

3.1.3 Theme: Preferred Ways and Methods of Family Involvement

We identified two sub-themes – the first around contact between the family and treatment team over the course of treatment and the second around interventions and supports for families – under this third larger theme.

3.1.3.1 Contact Between the Family and Treatment Team

There was agreement between stakeholders that the frequency of contact between the family and the treating team be high at the beginning of the treatment and then be tapered down over time. However, even during the later phases of treatment, periodic contact between them was seen as important, including when the patient was doing well.

"So I think it's very important to have frequent contacts in the beginning, once a week, after two weeks to like diminish the frequency, you know gradually diminish…" (Family member 1)

"Like in the beginning, when it's like really crisis mode for the parents to be there at every appointment, which is usually like once a week like you were saying. And then after that, maybe the month of second and third months, maybe just once a month.. Once the person is stabilized, I think it's a really good idea to have like a family meeting after the third or like fourth month. Because the last time my parents were here was like six months ago when it first happened, and they haven't been here." (Patient 2)

"I think it's still really important to make a point to touch base with families, even when things are going well...it helps to maintain the alliance with the family, it helps to maintain a comfort between —for the family members. And that way if ever concerns do start to arise, they don't hesitate as much to call the treatment team." (Clinician 3)

Although the need for periodic contact was agreed upon by most stakeholders, clinicians acknowledged contact with families sometimes "not being a priority when things are going well" and/or when they got "busy". On their part, families discussed their experience of trying unsuccessfully to get in touch with the treating team.

"Because we're often we often have these priorities that end up taking all the place and then you … I end up finishing my day. And I love speaking to families… but then it ends up that a million things happen and then oh, it's already 5pm. I was supposed to call the family and I had a million other texts and meetings. It ends up taking a lot of place, you know, so it's tough." (Clinician 2)

"*It may be difficult sometimes, me as a parent, I may try to contact the case manager say, "Oh, this is what has happened because we haven't had an appointment recently." I don't reach the case manager, I reach a voicemail or I send an email and it doesn't reply at the moment that I'm sending it. I'm sending because there's a crisis or I'm sending just to give an update or to ask a question about something. And then the case manager tries to reach me 3-4-5 days later but that crisis is over*." (Family member 3)

There were differing perspectives on how the contact between the family and the treating team should happen, that is, who should initiate the contact. One possible solution that was discussed was to have a fixed schedule of meetings with the family. Others felt that the frequency of contact could not be strictly prescribed as it depended on various factors.

"I feel like maybe it would be easier for me if the family kind of took that responsibility of if I want an update, I'm going to call the case manager. So that way, I don't have to like keep it in the back of my mind and make a note that I have to call every month like if the parents want an update, send me a text, we'll make an appointment also. I feel like we often just do a family meeting when things aren't doing…it's a bit tougher. But let's say we say every three to six months, we make sure that there's a family meeting and we put like an hour in the schedule instead of a 30 minute." (Clinician 2)

"*…the frequency and intensity of the family involvement should be flexible and adjust to the situation, the phase, the stage, and the need.”* (Clinician 3)

Stakeholders opined that texting or email could be less time-intensive ways for treating teams and families to be in touch with each other, particularly during later phases of treatment.

“But I like your idea. And also, the way of maybe, you know, it's maybe like it's email, call or meeting depending on the client situation. I think if everything goes well, sometimes me and [case manager] are texting and how's everything? Good. Okay, I'm happy. For me, it’s just a way to just relieve my worries and that's it.” (Family member 2)

“I know it's [referring to texting] not appropriate for every single situation. But I feel like it's very helpful as a case manager because sometimes I don't have the time to like spend 30 minutes on the phone and if I can just get like a quick answer and just, you know, get straight to the point, I feel like it's very helpful.” (Clinician 2)

Collaboration and partnership were seen as important elements of family involvement. Clinicians and patients reported that families could share responsibilities with the treatment team as partners in care, particularly during occasions involving difficult decisions and transitions/changes and provide moral support. On the other hand, families reported that they wanted to be involved throughout their loved one’s treatment and be included in the treatment decision-making process, which did not always happen.

“Once a week, first month, maybe and after, like maybe once a month, depending on everybody's agreement. I think participating in the intervention plan. To be honest, I would have liked to participate in the intervention plan of my son but I wasn't a part of it.” (Family member 2)

“…very often that after few months of treatment, the patient feels that he or she does not need medication anymore. We need to negotiate that to involve the family in that context and to see how they can have either to maintain the situation or if there is a decision to reduce the

medication and to have a closer eye on how things are going, then to involve the family in that context." (Clinician 1)

"But I wish all the parents..... sometimes they blame the system. It's not people's fault in the system, there is no money involved. They [clinicians] won't stay until 8 o'clock if they have two kids, okay? So we need to just stop blaming each other and work as a team." (Family Member 2)

3.1.3.2 Interventions and Supports for Families

The need for families having more information and education about the illness, its treatment and long-term outcomes was emphasized strongly by stakeholders.

"You're speaking to a person who comes from a culture that we don't believe in no [sic] medication at all. But I informed myself when I was in this situation, I said, "Okay, this is happening to me. I don't care what other people are saying. If this doctor says this medication is good, I'm reading on it." (Family member 3)

"I think the message that should be given to the parents is that there's definitely hope for recovery, but also prepare them for like a long-term thing because it does happen there is like relapse and things like that." (Patient 3)

Some of the preferred ways of family involvement in care were sitting in the follow-up sessions, family psychoeducation and family peer support group.

"There's a project somewhere in Montreal, I don't know which hospital where as soon as there's somebody comes to the emergency, there's peer support. Well, I believe this would be a very good tool" (Family member 1)

"…if they [the government] put money at the right places, maybe we could have a family therapy group also offered." (Family member 2)

3.2 Stage 2: Content Analysis: Identification of Themes for E-Survey

Four themes were identified for the survey based on the findings from the thematic analysis in Stage 1, i.e., types of family involvement, factors influencing family involvement, frequency of and responsibility for contact between treatment team and family contact and navigating consent and confidentiality. Each theme was then articulated as a question for the e-survey, namely, (i) In what ways should families/ carers of persons with psychosis be involved in early intervention services? (ii) What influences the involvement of families/carers of persons with psychosis? (iii) How often should families/carers be involved? (iv) How should consent and confidentiality be dealt with in involving families/carers? Again, informed by findings from our thematic analysis, we crafted ten statements under each of the four questions for the survey (Supplementary table).

In going from the themes identified in Stage 1 to the themes for the e-survey, we focused on identifying *concrete* expressions (in the case of types of family involvement), factors (in the case of influences on family involvement) and care practices (in the case of how often families should be involved or should involve themselves in treatment, and how patient consent and confidentiality should be navigated vis-à-vis involving their families). We were particularly interested in identifying points of tension or divergence that we could present to stakeholders to reflect on individually and using a different methodology (ranking) that necessitates weighting options against each other. Some key points of tension or divergence that we identified from Stage 1 data for the e-survey were around whether or not there should be a minimum prescribed frequency of contact between treating teams and families and what that should be if there is a minimum; who should be responsible for initiating and maintaining contact; and whether and what contact should be had with families when patients do not consent.

For questions 3 and 4 that pertain to clinical practices, we re-formulated responses identified from Stage 1 data in the form of "recommendation" statements, e.g., "Families and the treating team should have contact with each other at least once a month throughout treatment.", with the aim of deriving recommendations that reflected stakeholders' preferences and that could directly inform clinical practice.

3.3 Stage 3: Ranked Preferences on the E-Survey

Table 3 presents statements that were deemed as most, moderate, and least important under each of the four themes, based on the cut off of 5 or more respondents assigning a rank within that category of importance. For example, under Theme 1, three family members, two patients and two clinicians assigned a ranking between 1-3 (i.e., most important) to the statement, “Families can support during crises, relapses, or hospitalizations.” The statement was therefore deemed as “most important” for the group as a whole. Table 4 presents the statements on which there was no consensus (i.e., 5 or more respondents did not assign same level of importance).

The number of times each of these statements was assigned “most”, moderately” and “least” important is presented in Table 4, along with indicating which stakeholders assigned these ranks. Table 5 presents all statements under each theme, with their rankings for each participant. It should be noted that the statements that did not get assigned an importance level based on consensus are not to be automatically disregarded – they may represent statements whose importance may depend more on context or the particular situation, compared to the statements on which there was consensus which may have been seen as more generally most or least or moderately important. An example is the statement “Families can have the young person with psychosis live with them” under Theme 1, which was endorsed in all three categories of importance.

3.3.1 Theme 1: Types of Family Involvement

As Table 3a shows, there was consensus on the importance of seven of 10 statements (two most important, four moderately important and one least important). All statements that reached consensus were endorsed in the same category of importance by at least one member of all three stakeholder groups. The statements endorsed as most and moderately important highlight the many important ways that families are involved in the treatment of young persons with psychosis, with the family’s role during crises or relapses (7/9 ranked it most important) and in keeping the treatment team updated about progress and concerns

(7/9 moderately important) being endorsed strongly, as well as the need for families to be educated about the illness (5/9 most important).

3.3.2 Theme 2: Factors Influencing Family Involvement

As Table 3b shows, there was consensus on the importance of only five of 10 statements (two most important, two moderately important and one least important). Four of the statements that reached consensus were endorsed in the same category of importance by at least one member of all three stakeholder groups. Interestingly, although the statement "The young person's consent is necessary for families/carers to be involved in treatment" was "most important" for at least 5 respondents, this did not include a single family member, all of whom saw this as moderately important. While patient consent is seen as important by all stakeholder groups, it may have primacy for clinicians and patients.

Although the statement, "The frequency and types of involvement of families should be discussed jointly by patients, families and treating teams" (Table 4b) did not get endorsed in any one category of importance by at least five stakeholders, it was seen as most or moderately important by almost all stakeholders (only one respondent saw it as least important). This is a concrete practice point for early psychosis services and clinicians. Interestingly, five stakeholders (from all three stakeholder groups) endorsed "The frequency and types of involvement of families should be set based on patients' preferences" as moderately important. For only two people, there was more than a 3-point discrepancy between their scores for these two statements, suggesting that stakeholders think it possible to at once honour patient's preferences, and also arrive at decisions about family involvement in treatment via joint discussions involving all three key stakeholders.

3.3.3 Theme 3: Contact Frequency for Family Involvement

As Table 3c shows, there was consensus on the importance of only five of 10 statements (four moderately important and one least important). Four of the statements on which consensus was reached were endorsed in the same category of importance by at least one member of all three stakeholder groups. No statement was ranked as "most important" by at least five respondents. However, the statement, “Families and treating teams should be jointly responsible for maintaining contact with each other” could be considered as being generally important for most respondents as four ranked it “most important” and five as “moderately important” and no one as “least important”.

Interestingly, the statement “Maintaining contact with the family should be the primary responsibility of the treatment team (with families having the option of initiating contact)” was endorsed as “moderately important” by five people (all three family members and two patients), but as “least important” by three respondents, including two clinicians and one patient. This reflects that there may be confusion or lack of congruence in the views of different stakeholders about who is responsible for contact being sustained between families and treating teams. Such confusion could lead to inconsistent or reduced contact between families and treating teams, and potentially also ruptures in alliance if families feel disappointed when treating teams do not initiate contact, while the treating team may instead think of this as a joint responsibility.

That the statement, “Because each person’s situation is different, there cannot be any common guidelines about involving families in treatment” was ranked least important by six respondents suggests that there may be consensus among many stakeholders that there should be some common standards guiding programs on how families can be involved in treatment. Another area where there may be both convergence and divergence of opinions is around the minimum frequency of contact between families and treating teams. All statements around this – no minimum frequency but guided by needs, contact at least once a month, contact at least once a week – were endorsed in all three categories of importance, with 4-5 votes in the moderate level of importance for all three ways to organize contact (Tables 3c and 4c). On the one hand, this may reflect that stakeholders may have chosen a frequency that resonated with them based on their own experience, reflecting the heterogeneity that exists in needs and perhaps consequently preferences. On the other hand, this also reflects a potential point of tension if three stakeholders – the patient, family, and clinician – within the same triad have varying preferences for the frequency of contact.

3.3.4 Theme 4: Dealing with Consent and Confidentiality of Family Involvement

As Table 3d shows, there was consensus on the importance of only five of 10 statements (one most important, two moderately important and two least important). All five statements for which consensus was reached were endorsed in the same category of importance by at least one member of all three stakeholder groups.

Two statements, "If the patient does not consent to their treatment provider sharing information with families/carers, the treating team can still receive information or updates from families and can share general information about the illness and treatment if families contact them" and "When a patient does not consent to involving families/carers, treating teams should try to convince them that family support can be helpful and discuss their concerns about family involvement" were endorsed as important by all nine respondents (5 most important, 4 moderately important for the first statement; and 5 moderately important and 4 most important for the second statement).

Aligned with these preferences, the statement, "If the patient does not consent to their treatment provider sharing information with families/carers, the treating team should not have any contact with families/carers" was rated by seven out of nine respondents as least important (and never rated "most important") suggesting that lack of consent is not seen as automatically precluding contact between treatment teams and families. These are concrete practice points that can therefore be relatively confidently disseminated via guidelines and other methods to early psychosis programs and clinicians, as ways to navigate situations where the patient does not consent for their families to receive information about their treatment.

Despite some clear consensus on key issues that may be tricky to navigate (such as patients refusing consent), there were other points under this theme that reflected varying opinions. A noteworthy one is the statement, "Even when patients consent for families to be involved, patients themselves should make key treatment decisions" which did not get endorsed in any one category of importance by at least five people (Table 4d). Responses were spread out on this. Notably, two clinicians thought that the primacy of the patient in decision-making was most important, but no family members or patients endorsed it at that level of importance (their responses were spread out between moderately and least important). This example may illustrate that principles of recovery-oriented practice like agency and autonomy may be valued by all stakeholders but be weighted differently in the context of other factors or choices, an area that deserves more attention in future research.

4. Discussion

The aims of our study were to conduct an in-depth examination of stakeholder views and preferences regarding family involvement in early intervention services for psychosis using a modified nominal group technique, starting with an in-depth exploration of views in a group discussion and ending with an e-survey where participants ranked concretely worded statements/recommendations that had emerged from the in-depth group discussion. Patients, family members, and clinicians took part in this study. While the results of the study were presented in two parts (qualitative thematic analysis and quantitative results from the electronic survey), we discuss the findings cohesively in this section.

4.1 Family Involvement

All stakeholders identified that families played a vital role in the lives and care of young persons with early psychosis. As has been found earlier too (51, 52), providing emotional support ("being there", "listening", not using "trigger words", emotional acceptance of the changing situation) and practical day-to-day, tangible support were some of the ways families mentioned as being part of how they saw themselves involved in care. This is an important reminder about how families are almost always inevitably involved in their loved ones' recovery, beyond their direct involvement with the treating team. Additionally, the support of families during moments of transition, crises, hospitalizations, and relapses were considered as most important for all stakeholders (53, 54). However, participants shared that in moments when families were most needed (such as during hospitalization), their contact with patients could be hindered by barriers imposed by the healthcare structures themselves.

Sharing information with the treating team, accompanying the patient to appointments, and helping the patient stay engaged with treatment were also described as important ways of involving families (55). However, different stakeholders also pointed out that the way family is involved depends on family dynamics, phase of recovery, age of the patient, cultural context of the family and the broader cultural milieu in which the healthcare system exists (56). Different complexities with regards to understanding and integrating mental illness in a given family context were mentioned as shaping family involvement, such as tensions between autonomy and dependence, parenting and caregiving and different ways of acting on different roles at different times and from different cultural standpoints.

4.2 Family Involvement Through Contact with Treating Team

The findings indicated that all three stakeholder groups felt that channels of communication involving the family, the patient and the clinicians were essential and a core component of family involvement in early intervention services for psychosis. It is important to note that this contact was seen as possible not only in the form of meeting but also through calling/texting/emailing similar to a previous study (3, 55). Contact with families could serve the purpose of exchanging information as needed regarding the patient's health status, for regular updates, or simply as a means to show openness and availability from the treatment team. Previous studies show that increased contact between families and treating teams improve patients' engagement with services (55, 57, 58). Family involvement in treatment has been shown to yield a number of benefits in early psychosis, with family involvement at first contact even being linked with reduced risk of unnatural-cause mortality (59).

It appears that all three stakeholder groups prefer to have open channels of communication with each other, and having contact with the treating team ensures that. It also may help families feel validated in their efforts and part of a joint effort between all parts to help patients through their recovery journey. Indeed, Hem et al. (60) discussed in their scoping review on confidentiality that a lack of communication between these stakeholders can be an important obstacle in the treatment process. The maintenance of this contact was deemed to be a joint responsibility of the family and the team.

Nonetheless, there was no agreement on who should initiate the contact. The challenge with this is that different stakeholders may find themselves waiting for someone else to initiate contact. This kind of miscommunication or disconnect may hinder therapeutic alliance, cause delays in modification of treatment (if needed), and important information could simply be lost. Moreover, it can possibly hinder concerted efforts towards common goals.

A recent study examining Canadian policy documents for family involvement in early intervention services (22) reported that there are few standards or guidelines for how (format and frequency) the contact between families and treating teams should take place. Possible forms of structured contact include psychoeducation sessions where families can obtain information about early psychosis, learn about how to engage with their loved one with psychosis, learn problem solving and communication skills (61, 62). Importantly, psychoeducation sessions are also opportunities to meet with other families going through similar journeys and build peer support. The importance of both psychoeducation (at different stages and in different formats) and peer support was brought up by the participants in this study.

Overall, we found that a good relationship between the patient, the family, and the treating team from a stance of openness, respect and honesty were the basic facilitating factors in family involvement in early psychosis treatment. It was considered helpful by families to discuss expectations with the treating team regarding treatment and long-term outcomes in psychosis. As mentioned before, communication and support from the treating team were considered key for family involvement. Therapeutic alliance is very often conceptualized as in dual relationships in training for mental health professionals. But our findings highlight that in mental healthcare (particularly early psychosis programs), clinicians are building individual alliances with the patient and the family member, as well as a joint alliance that clarifies the relationship, they all share together (as well as its scope). Mental healthcare clinicians may need additional training and supervision for family work. Beyond training in specific family interventions which may be applicable to particularly to clinicians, all clinicians should be trained and supported in initiating, maintaining and (re)negotiating the involvement of families during the entire course of treatment.

Surprisingly, none of the stakeholders suggested that families could be involved in early psychosis treatment by engaging at a service, organisational or policy development level (63). While it is possible that patients and families were not even aware of this possibility, it is important to note that clinicians also did not suggest this kind of involvement in the current study. The study by Martin et al. (22) reported that very few family members were involved in the development of practise guidelines for early psychosis and that these guidelines showed low implementability. Therefore, we argue that families should be made aware by treatment teams that along with participating in the treatment at the individual level, they can also have an impactful role in their loved one's lives and recovery through advocacy and by helping shape services, policies, standards, and guidelines.

4.3 Navigating Consent and Confidentiality

Obtaining consent and maintaining patient confidentiality are crucial aspects of healthcare (64). Some scholars have written about the multifaceted nature of these concepts that include but go beyond the narrow view of these as legal concepts (65, 66). In our study too, we found that stakeholders acknowledge the various dimensions - moral, ethical, legal, social, cultural, pragmatic and developmental – of consent and confidentiality. A significant finding was that consent and confidentiality were understood as evolving, changing, context-dependent and overall, a possible object of (re)negotiation. It was suggested that consent should be thoroughly discussed (along with its implications), and frequently revisited. For instance, it was posited that treating teams could provide families general information about psychosis, interventions and resources (education and psychoeducation) even if the patient refused consent for the family to participate in their specific treatment. This may help families feel better equipped to support their loved one, work on family relationships, communication, and overall feel more informed, empowered and validated (23).

Interestingly, participants also found important for both family members and patients to be informed and discuss the benefits of family involvement for recovery, as something that should be taken into account when discussing issues of consent and confidentiality. Overall, practising consent and confidentiality as clinicians in early intervention services seems to involve artfully navigating between the legal and pragmatic through relationality, even making room for what one clinician calls, “forgiveness” if ever more is shared with a family member than was intended by a consenting patient.

5. Strengths and Limitations

The key strengths of our study are embedded in the methodology that we used to generate the data. The use of the modified nominal group technique enabled us to collect data in two ways. While the discussion stage of the modified nominal group technique generated rich qualitative data and creation of recommendations for family involvement, the e-survey method allowed us to examine how important these recommendations were to the stakeholders. While previous studies have explored stakeholder preferences for family involvement in a siloed manner by engaging with one stakeholder group at a time, the modified nominal group technique brought all of them on one platform which enabled a rich discussion and exchange of views (67-70). In contrast to existing studies, we also generated recommendations which can be concretely implemented in early intervention services for psychosis (71, 72).

Nonetheless, our study has important limitations. Despite efforts to elicit participation from all stakeholders and to create a safe space, having all stakeholders present together might have challenged some contributions due to relationships of power and role expectations. For example, clinicians may have felt uncomfortable to articulate barriers to family involvement and negative or difficult experiences with families in front of families and patients. Similarly, family members may have hesitated to more strongly share experiences where they felt excluded from care.

Also, families may not seek involvement because it can be hard for them to deal with their loved one’s mental illness and caregiving can entail burnout and burden. But families in our group made little mention regarding their own burden, contrarily to other studies (73, 74). This could either reflect these particular families’ journeys or that they may not have felt comfortable to describe these feelings in front of patients and families. Several points of divergence still remain. While these are expectable, our study design did not allow us to explore these further. We could have employed a longitudinal qualitative design and/or integrated other methods such as observation of actual encounters and individual interviews towards this end.

While our e-survey served as a member check-in for some key findings derived from the thematic analysis, we did not do a more elaborate process of member check-in after the thematic analysis and after the ranking exercise. This study included stakeholders from a single early psychosis clinic in a Canadian city which limits the applicability of our findings to other contexts where different organizational and societal factors may influence the experiences of young people, families, and clinicians. Further, our study only included consenting patients and families who were or had been engaged in care in the early psychosis program. A study on this topic may also have been more likely to attract patients who had some level of contact with their families. A limitation therefore is that it does not include the perspectives of those who disengaged from treatment and/or those who did not want their families to be involved at all in their care.

6. Conclusion and Implications

Family involvement is an essential component of treatment in early intervention services for psychosis. Families contribute immensely to facilitate the recovery of their loved one. Patients, families, and clinicians agree that the contact between the family and the treating team needs to continue over the course of the treatment. However, the method, frequency and content of the contact can vary depending upon various clinical, familial, developmental factors. There may also be differences in opinions about these within specific triads of patients, families, and clinicians. Finally, there is general consensus that consent and confidentiality, and privacy and autonomy/agency of the patient have to be respected. However, these need not necessarily deter family involvement.

Consent and confidentiality evolve over the course of treatment and need to be revisited from time to time. Our recommendations could be used as a starting point for a trialogue between the patient, family, and the treating team to decide the nature of contact and family involvement in treatment, and how to navigate issues of consent and confidentiality (see Table 6). Future research could examine in greater detail how points of divergence or of greater nuance could be approached in clinical practice and how these aspects could be operationalized as concrete recommendations while simultaneously giving space for treating teams to adapt their intervention to a given context and keep the needed flexibility in their approach throughout the follow-up.

Figure 1

modified Nominal Group Technique Process m(NGT)

Step 1

Silent generation of ideas

Step 2

Round-robin to share responses

Step 3

Clarification and grouping of ideas

Step 4

Transcription and Qualitative Data analysis

Step 5

Development of prioritization e-survey

Step 6

Administration of e-survey

Step 7

Quantitative data analysis

Note: Traditional NGT process: Silent generation of ideas, round-robin to share responses, clarification and grouping of ideas, voting and ranking, and discussion

Table 1: Participant demographics (n=9)

Characteristics	Patients (n=3)	Families (n=3)	Clinicians (n=3)	Total n
Mean age (SD) (min:max)	22.3 (2.08) (20-24)	53 (9.64) (42-60)	41 (17.09) (25-59)	38.8 (16.63) (20-60)
Gender				
Female	1	2	2	5
Male	2	1	1	4
Education				
CEGEP	3	0	0	3
Undergraduate	0	3	0	3
Postgraduate	0	0	2	2
Doctor of Medicine	0	0	1	1
Employment				
Part-time	3	0	0	3
Full-time	0	2	3	5
Retired	0	1	0	1
Relationship status (n=6)				
Single	3	0	NA	3
Separated	0	1	NA	1
Married	0	2	NA	2
Living situation (n=6)				
Parents	2	0	NA	2
Partner/children	0	3	NA	3
Friends	1	0	NA	1
Ethnicity				
White	1	2	2	5
Minoritized	1	1	1	3
Prefer not to answer	1	0	0	1
Birthplace				
Born in Canada	3	2	2	7
Outside Canada	0	1	1	2
Treatment status (n=6)				
Current user	2	1	NA	3
Past user	1	2	NA	3
Relationship with client (n=3)				
Child	NA	3	NA	3
Provider role (n=3)				
Program director/ Psychiatrist	NA	NA	1	1
Clinical coordinator/ social worker	NA	NA	1	1
Case Manager/ Occupational therapist	NA	NA	1	1

Table 2: List of themes and sub-themes

Themes	Sub-themes
Meaning and value of family involvement	No sub-themes
Factors that influence family involvement	Familial and developmental context and family involvement
	Treatment context and family involvement
	Treatment context and family Involvement: consent and confidentiality
Preferred ways and methods of family involvement	Contact between the family and treatment team
	Interventions and supports for families

Table 3: Statements based on importance categories (n=22)

3a: Theme 1: Types of family involvement

Statements	Votes (out of 9)	Stakeholder endorsement
Families can support during crises, relapses, or hospitalizations.	7 most important	3FM+2PT+2CL
Families can educate themselves about the illness.	5 most important	2PT+2FM+1CL
Families can accompany the young person during appointments at the clinic.	5 moderately important	2FM+2CL+1PT
Families can update the treating team about progress and concerns such as changes in young family member's behavior, so that treatment can be adjusted.	7 moderately important	3PT+3FM+1CL
Families can help the young person to stay in treatment and be in contact with the treating team.	5 moderately important	2CL+2PT+1FM
Families can offer emotional support.	5 moderately important	3FM+1PT+1CL
Families can support the young person with their work or school.	7 least important	3FM+2PT+2CL

3b: Theme 2: Factors influencing family involvement

Statements	Votes (out of 9)	Stakeholder Endorsement
There should always be some involvement of families/carers in treatment, except when the families/carers are unhelpful or harmful.	5 most important	2FM+2CL+1PT
The young person's consent is necessary for families/carers to be involved in treatment.	5 most important	3PT+2CL
The need for and frequency of family contact depends on the phase of recovery, e.g., more contact when there is a crisis or relapse and less contact when the person is doing well.	7 moderately important	3CL+2FM+2PT
The frequency and types of involvement of families should be set based on patients' preferences.	5 moderately important	2FM+2CL+1PT
When patients are doing well, it is okay for busy treating teams to not contact families.	7 least important	3PT+2FM+2CL

3c: Theme 3: Contact frequency for family involvement

Statements	Votes (out of 9)	Stakeholder Endorsement
Over the course of two years, **there should not be** a minimum number of times that treatment teams should contact families. Instead, they should contact families as and when needed.	5 moderately important	2CL+2PT+1FM
Families and treating teams should be jointly responsible for maintaining contact with each other.	5 moderately important	2SP+2PT+1FM
Maintaining contact with the family should be the primary responsibility of the treatment team (with families having the option of initiating contact).	5 moderately important	3FM+2PT
Programs like * should systematically record presence or absence of contact with families in each patient's chart.	5 moderately important	2PT+2FM+1CL
Because each person's situation is different, there cannot be any common guidelines about involving families in treatment.	6 least important	3FM+2CL+1PT

3d: Theme 4: Dealing with consent and confidentiality of family involvement

Statements	Votes (out of 9)	Stakeholder Endorsement
If the patient does not consent to their treatment provider sharing information with families/carers, the treating team can still receive information or updates from families and can share general information about the illness and treatment if families contact them.	5 most important	2FM+2CL+1PT
Even if the patient has consented for families to be involved, treatment providers should always check with patients before disclosing any specific information.	6 moderately important	2FM+2PT+2CL
When a patient **does not consent to** involving families/carers, treating teams should try to convince them that family support can be helpful and discuss their concerns about family involvement.	5 moderately important	2PT+2FM+1CL
If the patient does not consent to their treatment provider sharing information with families/carers, the treating team should not have any contact with families/carers.	7 least important	3CL+2PT+2FM
Laws and regulations around consent and confidentiality make it difficult to involve families.	6 least important	3PT+2CL+1FM

Legend
PT = Patient; FM = Family member; CL = Clinician
*Name of program redacted for confidentiality purposes

Table 4: Statements that did not qualify under any of the importance categories based on themes (n=18)

Statements	
4a. Theme 1: Types of family involvement	**Stakeholder Endorsement (n= 9)**
Families can have the young person with psychosis live with them.	2FM+1PT = Most important 1CL+1PT = Moderately important 2CL+1FM+1FM = Least important
Families can develop emotional acceptance and adjust their expectations from their young family member.	2CL = Most important 1CL+2FM+1PT = Moderately important 2PT+1FM = Least important
Families can be aware of and be involved in developing treatment plans.	2PT+1CL+1FM = Most important 1CL+1FM = Moderately important 1CL+1FM+1PT = Least important
4b. Theme 2: Factors influencing family involvement	**Stakeholder Endorsement (n= 9)**
Involvement is influenced by the resources of families such as finances, accessibility of the clinic, time available based on job and other commitments, etc.	1PT+1FM+1CL = Most important 2PT = Moderately important 2CL+2FM = least important
Involvement is influenced by each family's culture around autonomy and support.	2FM = Most important 2CL+1PT = Moderately important 2PT+1FM+1CL = Least important
Involvement is influenced by the age or development of patients (e.g., adolescents versus young adults versus adults).	1FM+1CL = Most important 1PT+1FM+2CL = Moderately important 2PT+1FM = Least important
There should always be some involvement of families/carers in treatment.	2FM = Most important 2PT+1FM = Moderately important 3CL+1PT = Least important
The frequency and types of involvement of families should be discussed jointly by patients, families and treating teams.	2CL+1PT+1FM = Most important 2PT+1FM+1CL = Moderately important 1FM = Least important
4c. Theme 3: Contact frequency for family involvement	**Stakeholder Endorsement (n= 9)**
Families should be present at every point in treatment.	1PT+1FM+1CL = Most important 1FM+1CL = Moderately important 2PT+1FM+1CL = least important
Families and the treating team should have contact with each other at least once a week for the first month.	2PT+2FM = Most important 2CL+1FM+1PT = Moderately important 1CL = Least important
Families and the treating team should have contact with each other at least once a month throughout treatment (which is usually for 2 years at *).	2FM+1CL+1PT = Most important 2PT+1FM+1CL = Moderately important 1CL = Least important
Over the course of two years, **there should be** a minimum number of times that treatment teams should contact families. Beyond this minimum, treatment teams can also increase contact depending on patients' needs.	2CL+1FM+1PT = Most important 1CL+1PT+1FM = Moderately important 1PT+1FM = Least important
There should be guidelines about involving families for treatment teams to follow.	2CL+1FM = Most important 1CL+1FM+1CL = Moderately important 2PT+1FM = Least important
4d. Theme 4: Dealing with consent and confidentiality of family involvement	**Stakeholder Endorsement (n= 9)**
If a patient is not a threat to himself or others, there should be no insistence on involving families/carers if the patient does not desire such involvement.	2PT+1FM = Most important 1PT+1CL = Moderately important 2FM+2CL = least important
When the patient has consented for families to be involved, treatment providers should use their judgment in deciding what information should and should not be disclosed to families.	2CL+1PT+1FM = Most important 1CL+1FM+1PT = Moderately important 1PT+1FM = Least important
It is possible to involve families/carers and also respect patient consent and confidentiality.	2PT+1CL+1FM = Most important 2CL+1PT+1FM = Moderately important 1FM = Least important
Even when patients consent for families to be involved, patients themselves should make key treatment decisions.	2CL = Most important 2FM+1PT+1FM = Moderately important 2PT+1FM = Least important
When patients consent for families to be involved, key treatment decisions should involve both the patient and the family.	2FM+1PT = Most important 2CL+1FM+1PT = Moderately important 1CL+1PT = Least important

Legend:
Ranks 1-3 = Most important, Ranks 4-7 = Moderately important, Ranks 8-10 = Least important
PT = Patient; FM = Family member; CL = Clinician
*Name of the early psychosis intervention program redacted for confidentiality purposes

Table 5: Statements based on themes (as questions) and individual ranks of all participants

5a. In what ways should families/ carers of persons with psychosis be involved?	**PT1**	**PT2**	**PT3**	**FM1**	**FM2**	**FM3**	**CL1**	**CL2**	**CL3**
Families can have the young person with psychosis live with them.	5	2	10	1	1	10	9	4	9
Families can support during crises, relapses, or hospitalizations.	1	5	2	2	2	3	1	3	4
Families can accompany the young person during appointments at the clinic.	9	10	5	4	10	6	7	10	6
Families can support the young person with their work or school.	6	9	9	10	9	9	10	5	10
Families can update the treating team about progress and concerns such as changes in young family member's behavior, so that treatment can be adjusted.	4	4	6	5	4	4	3	8	5
Families can educate themselves about the illness.	3	1	7	3	5	2	8	7	2
Families can develop emotional acceptance and adjust their expectations from their young family member.	7	8	8	7	8	5	4	2	1
Families can help the young person to stay in treatment and be in contact with the treating team.	8	7	4	8	6	1	6	6	3
Families can be aware of and be involved in developing treatment plans.	10	3	3	9	3	8	2	9	7
Families can offer emotional support.	2	6	1	6	7	7	5	1	8
5b. What influences the involvement of families/carers of persons with psychosis?	**PT1**	**PT2**	**PT3**	**FM1**	**FM2**	**FM3**	**CL1**	**CL2**	**CL3**
Involvement is influenced by each family's culture around autonomy and support.	7	8	9	1	8	2	7	9	4
Involvement is influenced by the resources of families such as finances, accessibility of the clinic, time available based on job and other commitments, etc.	5	2	4	3	10	8	8	8	3
Involvement is influenced by the age or development of patients (e.g., adolescents versus young adults versus adults).	6	9	10	2	9	6	6	4	2
There should always be some involvement of families/carers in treatment.	8	5	7	4	1	3	10	10	9
There should always be some involvement of families/carers in treatment, except when the families/carers are unhelpful or harmful.	9	6	1	6	2	1	3	2	6
The young person's consent is necessary for families/carers to be involved in treatment.	3	3	2	7	6	5	1	1	8
The need for and frequency of family contact depends on the phase of recovery, e.g., more contact when there is a crisis or relapse and less contact when the person is doing well.	4	1	6	5	4	9	5	7	5
The frequency and types of involvement of families should be discussed jointly by patients, families and treating teams.	1	4	5	8	3	4	2	5	1
The frequency and types of involvement of families should be set based on patients' preferences.	2	7	3	9	7	7	4	3	7
When patients are doing well, it is okay for busy treating teams to not contact families.	10	10	8	10	5	10	9	6	10
5c. How often should families/carers be involved?	**PT1**	**PT2**	**PT3**	**FM1**	**FM2**	**FM3**	**CL1**	**CL2**	**CL3**
Families should be present at every point in treatment.	1	9	9	1	8	4	3	10	7
Families and the treating team should have contact with each other at least once a week for the first month.	6	3	3	7	3	1	5	9	6
Families and the treating team should have contact with each other at least once a month throughout treatment (which is usually for 2 years at *).	7	1	5	3	7	2	2	8	5
Over the course of two years, there should be a minimum number of times that treatment teams should contact families. Beyond this minimum, treatment teams can also increase contact depending on patients' needs.	8	2	7	2	4	8	4	2	2
Over the course of two years, there should not be a minimum number of times that treatment teams should contact families. Instead, they should contact families as and when needed.	3	7	4	9	6	9	7	5	10
Families and treating teams should be jointly responsible for maintaining contact with each other.	5	5	2	4	2	3	6	4	3
Maintaining contact with the family should be the primary responsibility of the treatment team (with families having the option of initiating contact).	4	8	6	6	5	5	8	3	8
Programs like * should systematically record presence or absence of contact with families in each patient's chart.	9	6	8	5	9	6	10	1	4
There should be guidelines about involving families for treatment teams to follow.	10	4	10	10	1	7	1	7	1
Because each person's situation is different, there cannot be any common guidelines about involving families in treatment.	2	10	1	8	10	10	9	6	9
5d. How should consent and confidentiality be dealt with in involving families/carers?	**PT1**	**PT2**	**PT3**	**FM1**	**FM2**	**FM3**	**CL1**	**CL2**	**CL3**
If a patient is not a threat to himself or others, there should be no insistence on involving families/carers if the patient does not desire such involvement.	1	7	1	2	8	7	9	6	8
If the patient does not consent to their treatment provider sharing information with families/carers, the treating team can still receive information or updates from families and can share general information about the illness and treatment if families contact them.	6	6	3	3	4	3	10	5	1
If the patient does not consent to their treatment provider sharing information with families/carers, the treating team should not have any contact with families/carers.	7	10	10	8	7	10	2	9	10
Even if the patient has consented for families to be involved, treatment providers should always check with patients before disclosing any specific information.	3	5	4	4	10	4	8	7	5
When the **patient has consented f**or families to be involved, treatment providers should use their judgment in deciding what information should and should not be disclosed to families.	5	1	8	5	1	9	5	2	3
Laws and regulations around consent and confidentiality make it difficult to involve families.	8	9	9	1	9	6	7	10	9
When a patient **does not consent to** involving families/carers, treating teams should try to convince them that family support can be helpful and discuss their concerns about family involvement.	4	2	7	7	3	5	1	3	7
It is possible to involve families/carers and also respect patient consent and confidentiality.	2	4	2	9	5	2	4	4	2
Even when patients consent for families to be involved, patients themselves should make key treatment decisions.	9	8	5	10	6	8	3	1	4
When patients consent for families to be involved, key treatment decisions should involve both the patient and the family.	10	3	6	6	2	1	6	8	6

Legend:
PT-Patient, FM-Family Member, CL-Clinician
*Name of the early psychosis intervention program redacted for confidentiality purposes

Table 6 – List of recommendations for family involvement in early intervention services for psychosis

S. No	Recommendations
1	Families can support during crises, relapses, or hospitalizations.
2	Families can educate themselves about the illness.
3	Families can accompany the young person during appointments at the clinic.
4	Families can update the treating team about progress and concerns such as changes in young family member's behavior, so that treatment can be adjusted.
5	Families can help the young person to stay in treatment and be in contact with the treating team.
6	Families can offer emotional support.
7	Families can be aware of and be involved in developing treatment plans.
8	Families can help the young person to stay in treatment and be in contact with the treating team.
9	When a patient **does not consent to** involving families/carers, treating teams should try to convince them that family support can be helpful and discuss their concerns about family involvement.
10	Families should receive adequate information and education about psychosis, interventions, community resources, and long-term outcomes.
11	Families should be allowed to continue remain involved during hospitalisation, i.e., be able to contact the and visit the patient, communicate with the treating team.
12	Inpatient treating teams should explain hospitalisation procedures and processes clearly to the patient and the family to assuage their anxiety and worry.
13	Families and treating teams should be jointly responsible for maintaining contact with each other.
14	Early intervention service for psychosis programs should systematically record presence or absence of contact with families in each patient's chart
15	Even if the patient **does not consent** to their treatment provider for sharing information with families/carers, the treating team can still receive information or updates from families and can share general information about the illness and treatment if families contact them.
16	The frequency and types of involvement of families should be discussed jointly by patients, families and treating teams

Considerations: *Factors such as patient's age, cultural context of the family, the larger service context etc. will influence the uptake of these recommendations. These recommendations are based on data that emerged from both, Stage 1 and Stage 3 of the study.*

References

1. Correll CU, Galling, B., Pawar, A., Krivko, A., Bonetto, C., Ruggeri, M., ... & Hui, C. L. . Comparison of early intervention services vs treatment as usual for early-phase psychosis: a systematic review, meta-analysis, and meta-regression. JAMA psychiatry. 2018.
2. Cowman M, Donohoe G, Frawley E, Lepage M. Social and occupational recovery in early psychosis: a systematic review and meta-analysis of psychosocial interventions. 2021.
3. Iyer SN, Malla A, Taksal A, Maraj A, Mohan G, Ramachandran P, et al. Context and contact: a comparison of patient and family engagement with early intervention services for psychosis in India and Canada. Psychological Medicine. 2022;52(8):1538-47.
4. Malla A, Iyer SN, Rangaswamy T, Ramachandran P, Mohan G, Taksal A, et al. Comparison of clinical outcomes following 2 years of treatment of first-episode psychosis in urban early intervention services in Canada and India. The British Journal of Psychiatry. 2020;217(3):514-20.
5. Cohen AN, Pedersen ER, Glynn SM, Hamilton AB, McNagny KP, Reist C, et al. Preferences for family involvement among veterans in treatment for schizophrenia. Psychiatric Rehabilitation Journal. 2019;42(3):210.
6. Malla A, Payne J. First-episode psychosis: psychopathology, quality of life, and functional outcome. Schizophrenia bulletin. 2005;31(3):650-71.
7. Bertulies-Esposito B, Nolin M, Iyer SN, Malla A, Tibbo P, Otter N, et al. Ou en sommes-nous? An Overview of Successes and Challenges after 30 Years of Early Intervention Services for Psychosis in Quebec: Ou en sommes-nous? Un apercu des reussites et des problemes apres 30 ans de services d'intervention precoce pour la psychose au Quebec. The Canadian Journal of Psychiatry. 2020;65(8):536-47.
8. Nolin M, Malla A, Tibbo P, Norman R, Abdel-Baki A. Early intervention for psychosis in Canada: what is the state of affairs? The Canadian Journal of Psychiatry. 2016;61(3):186-94.
9. Ma CF, Chien WT, Bressington DT. Family intervention for caregivers of people with recent-onset psychosis: A systematic review and meta-analysis. Early Intervention in Psychiatry. 2018;12(4):535-60.
10. Iyer SN, Loohuis H, Pawliuk N, Joober R, Malla AK. Concerns reported by family members of individuals with first-episode psychosis. Early Intervention in Psychiatry. 2011;5(2):163-7.
11. Oluwoye O, Kriegel L, Alcover KC, Compton MT, Cabassa LJ, Mcdonell MG. The impact of early family contact on quality of life among non-Hispanic Blacks and Whites in the RAISE-ETP trial. Schizophrenia Research. 2020;216:523-5.
12. Oluwoye O, Stokes B, Stiles B, Monroe-DeVita M, McDonell MG. Understanding differences in family engagement and provider outreach in New Journeys: A coordinated specialty care program for first episode psychosis. Psychiatry Research. 2020;291:113286.
13. Leclerc E, Noto C, Bressan RA, Brietzke E. Determinants of adherence to treatment in first-episode psychosis: a comprehensive review. Braz J Psychiatry. 2015;37(2):168-76.
14. Reininghaus U, Dutta R, Dazzan P, Doody GA, Fearon P, Lappin J, et al. Mortality in schizophrenia and other psychoses: a 10-year follow-up of the ÆSOP first-episode cohort. Schizophrenia bulletin. 2015;41(3):664-73.
15. Bucci S, Berry K, Barrowclough C, Haddock G. Family interventions in psychosis: a review of the evidence and barriers to implementation. Australian Psychologist. 2016;51(1):62-8.
16. Marshall M, Lockwood A, Lewis S, Fiander M. Essential elements of an early intervention service for psychosis: the opinions of expert clinicians. BMC Psychiatry. 2004;4:17.
17. Doody O, Butler MP, Lyons R, Newman D. Families' experiences of involvement in care planning in mental health services: an integrative literature review. J Psychiatr Ment Health Nurs. 2017;24(6):412-30.
18. Dillinger RL, Kersun JM. Caring for caregivers: Understanding and meeting their needs in coping with first episode psychosis. Early Intervention in Psychiatry. 2020;14(5):528-34.
19. QC. Cadre de référence : Programmes pour premiers épisodes psychotiques (PPEP) Quebec, Canada2022.
20. ON. Early Psychosis Intervention Program Standard. Retrieved from Ontario, Canada2011.

21. BC. Standards and Guidelines for Early Psychosis Intervention (EPI) Programs Retrieved from British Columbia, Canada2010.

22. Martin H, Pawliuk N, Valle R, Iyer SN. A critical appraisal of Canadian guidelines for family work recommendations in early intervention services for psychosis. . Manuscript under preparation. 2024.

23. Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres–a nested qualitative study. BMC Health Services Research. 2022;22(1):1-16.

24. Rose LE, Mallinson RK, Walton-Moss B. Barriers to family care in psychiatric settings. Journal of Nursing Scholarship. 2004;36(1):39-47.

25. Susanti H, Brooks H, Keliat B-a, Bradshaw T, Wulandari D, Fadilah R, et al. Stakeholder perspectives of family interventions for schizophrenia in Indonesia: a qualitative study. BMC psychiatry. 2024;24(1):59.

26. Landeweer E, Molewijk B, Hem MH, Pedersen R. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. BMC Health Services Research. 2017;17(1):1-10.

27. Canadian Institutes of Health Research. Canada's Strategy for Patient-Oriented Research. 2011.

28. Guinaudie C, Mireault C, Tan J, Pelling Y, Jalali S, Malla A, et al. Shared decision making in a youth mental health service design and research project: insights from the Pan-Canadian ACCESS open minds network. The Patient-Patient-Centered Outcomes Research. 2020;13:653-66.

29. Zarin W, Lunny C, Chaudhry S, Thomas SM, LeBlanc A, Clement F, et al. A Canadian model for providing high-quality, timely and relevant evidence to meet health system decision-maker needs: the SPOR Evidence Alliance. FACETS. 2022;7(1):420-34.

30. Swartz MS, Swanson JW, Wagner HR, Hannon MJ, Burns BJ, Shumway M. Assessment of four stakeholder groups’ preferences concerning outpatient commitment for persons with schizophrenia. American Journal of Psychiatry. 2003;160(6):1139-46.

31. Ferrari M, Pawliuk N, Pope M, MacDonald K, Boruff J, Shah J, et al. A scoping review of measures used in early intervention services for psychosis. Psychiatric Services. 2023;74(5):523-33.

32. McGorry PD, Ratheesh A, O'Donoghue B. Early intervention—an implementation challenge for 21st century mental healthcare. JAMA psychiatry. 2018;75(6):545-6.

33. Ford S, Schofield T, Hope T. What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. Social science & medicine. 2003;56(3):589-602.

34. Charlton JI. Nothing about us without us: Disability oppression and empowerment: Univ of California Press; 1998.

35. Street RL, Elwyn G, Epstein RM. Patient preferences and healthcare outcomes: an ecological perspective. Expert review of pharmacoeconomics & outcomes research. 2012;12(2):167-80.

36. Gallagher M, Hares T, Spencer J, Bradshaw C, Webb I. The nominal group technique: a research tool for general practice? Family practice. 1993;10(1):76-81.

37. First MB. Structured clinical interview for DSM-IV-TR axis I disorders, research version, non-patient edition.(SCID-I/NP). (No Title). 2002.

38. Jones J, Hunter D. Consensus methods for medical and health services research. Bmj. 1995;311(7001):376-80.

39. Cantrill J, Sibbald B, Buetow S. The Delphi and nominal group techniques in health services research. International Journal of pharmacy practice. 1996;4(2):67-74.

40. Kleiner-Fisman G, Gryfe P, Naglie G. A patient-based needs assessment for living well with Parkinson disease: implementation via nominal group technique. Parkinson’s disease. 2013;2013.

41. Locke JE, Qu H, Shewchuk R, Mannon RB, Gaston R, Segev DL, et al. Identification of strategies to facilitate organ donation among African Americans using the nominal group technique. Clinical Journal of the American Society of Nephrology: CJASN. 2015;10(2):286.

42. Krueger RA. Developing questions for focus groups: Sage publications; 1997.

43. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

44. Krippendorff K. Content analysis: An introduction to its methodology: Sage publications; 2018.

45. Robinson VA, Hunter D, Shortt SE. Accountability in public health units: using a modified nominal group technique to develop a balanced scorecard for performance measurement. Canadian Journal of Public Health. 2003;94:391-6.

46. Thier M, Mason DP. Breaking ranks? Differentiating nominal group technique scoring approaches for consensus and prioritization. International Journal of Research & Method in Education. 2019;42(4):428-41.

47. Rubin G, Wit ND, Meineche-Schmidt V, Seifert B, Hall N, Hungin P. The diagnosis of IBS in primary care: consensus development using nominal group technique. Family practice. 2006;23(6):687-92.

48. Mallett R, McLean S, Holden MA, Potia T, Gee M, Haywood K. Use of the nominal group technique to identify UK stakeholder views of the measures and domains used in the assessment of therapeutic exercise adherence for patients with musculoskeletal disorders. BMJ Open. 2020;10(2):e031591.

49. Kremer IE, Evers SM, Jongen PJ, van der Weijden T, van de Kolk I, Hiligsmann M. Identification and prioritization of important attributes of disease-modifying drugs in decision making among patients with multiple sclerosis: a nominal group technique and best-worst scaling. PLoS One. 2016;11(11):e0164862.

50. Madden L, Bojko MJ, Farnum S, Mazhnaya A, Fomenko T, Marcus R, et al. Using nominal group technique among clinical providers to identify barriers and prioritize solutions to scaling up opioid agonist therapies in Ukraine. International Journal of Drug Policy. 2017;49:48-53.

51. Claxton M, Onwumere J, Fornells-Ambrojo M. Do family interventions improve outcomes in early psychosis? A systematic review and meta-analysis. Frontiers in Psychology. 2017;8:371.

52. Sadath A, Muralidhar D, Varambally S, Jose JP, Gangadhar B. Family intervention in first-episode psychosis: a qualitative systematic review. Sage Open. 2015;5(4):2158244015613108.

53. Bighelli I, Rodolico A, García-Mieres H, Pitschel-Walz G, Hansen W-P, Schneider-Thoma J, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2021;8(11):969-80.

54. Allan S, Bradstreet S, McLeod HJ, Gleeson J, Farhall J, Lambrou M, et al. Perspectives of patients, carers and mental health staff on early warning signs of relapse in psychosis: a qualitative investigation. BJPsych Open. 2020;6(1):e3.

55. Polillo A, Voineskos AN, Foussias G, Kidd SA, Bromley S, Soklaridis S, et al. Disengagement from early psychosis intervention services: an observational study informed by a survey of patient and family perspectives. Schizophrenia. 2022;8(1):94.

56. Zhang Y. Family functioning in the context of an adult family member with illness: A concept analysis. Journal of clinical nursing. 2018;27(15-16):3205-24.

57. Kline ER, Thibeau H, Davis BJ, Fenley A, Sanders AS, Ipekci B, et al. Motivational interviewing for loved ones: Randomized controlled trial of brief training for first episode psychosis caregivers. Schizophrenia Research. 2022;250:43-9.

58. Mascayano F, van der Ven E, Martinez-Ales G, Henao AR, Zambrano J, Jones N, et al. Disengagement from early intervention services for psychosis: a systematic review. Psychiatric Services. 2021;72(1):49-60.

59. Reininghaus U, Dutta R, Dazzan P, Doody GA, Fearon P, Lappin J, et al. Mortality in schizophrenia and other psychoses: a 10-year follow-up of the SOP first-episode cohort. Schizophr Bull. 2015;41(3):664-73.

60. Hem MH, Molewijk B, Weimand B, Pedersen R. Patients with severe mental illness and the ethical challenges related to confidentiality during family involvement: A scoping review. Frontiers in Public Health. 2023;10:960815.

61. Falloon IR. Family interventions for mental disorders: efficacy and effectiveness. World Psychiatry. 2003;2(1):20-8.

62. Falloon IR, Held T, Coverdale JH, Roncone R, Laidlaw TM. Family interventions for schizophrenia: A review of long-term benefits of international studies. Psychiatric Rehabilitation Skills. 1999;3(2):268-90.

63. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health affairs. 2013;32(2):223-31.

64. Roberts LW, Geppert CM, Bailey R. Ethics in psychiatric practice: essential ethics skills, informed consent, the therapeutic relationship, and confidentiality. Journal of Psychiatric Practice®. 2002;8(5):290-305.

65. Noroozi M, Zahedi L, Bathaei FS, Salari P. Challenges of confidentiality in clinical settings: compilation of an ethical guideline. Iranian Journal of Public Health. 2018;47(6):875.

66. Wadman R, Thul D, Elliott AS, Kennedy AP, Mitchell I, Pinzon JL. Adolescent confidentiality: Understanding and practices of healthcare providers. Paediatrics & Child Health. 2014;19(2):e11-e4.

67. Jones N, Basaraba C, Piscitelli S, Jewell T, Nossel I, Bello I, et al. Clients' preferences for family involvement and subsequent family contact patterns within OnTrackNY early psychosis services. Psychiatric Services. 2021;72(4):399-407.

68. Cohen AN, Drapalski AL, Glynn SM, Medoff D, Fang LJ, Dixon LB. Preferences for family involvement in care among consumers with serious mental illness. Psychiatric Services. 2013;64(3):257-63.

69. Byrne R, Reeve S, Bird J, Jones W, Shiers D, Morrison A, et al. Clinicians' views of treatment types for first episode psychosis delivered in a randomized controlled trial (MAPS). EClinicalMedicine. 2020;24.

70. Chisholm J, Hope J, Fossey E, Petrakis M. Mental health clinician attitudes about service user and family agency and involvement in recovery-oriented practice. International Journal of Environmental Research and Public Health. 2023;20(18):6787.

71. Lucksted A, Stevenson J, Nossel I, Drapalski A, Piscitelli S, Dixon LB. Family member engagement with early psychosis specialty care. Early Interv Psychiatry. 2018;12(5):922-7.

72. Selick A, Durbin J, Vu N, O'Connor K, Volpe T, Lin E. Barriers and facilitators to implementing family support and education in Early Psychosis Intervention programmes: A systematic review. Early Interv Psychiatry. 2017;11(5):365-74.

73. Koutra K, Simos P, Triliva S, Lionis C, Vgontzas AN. Linking family cohesion and flexibility with expressed emotion, family burden and psychological distress in caregivers of patients with psychosis: A path analytic model. Psychiatry Research. 2016;240:66-75.

74. Ruggeri M, Lasalvia A, Santonastaso P, Pileggi F, Leuci E, Miceli M, et al. Family burden, emotional distress and service satisfaction in first episode psychosis. Data from the GET UP Trial. Frontiers in Psychology. 2017;8:721.

Bridge 2

As noted in Chapter 1, and subsequently established in Manuscripts 1 and 2, there is a paucity of research on family involvement in early intervention services for psychosis, particularly from the perspectives of all pertinent stakeholder groups – patients, clinicians, and families. In the psychosis field more broadly too, the focus has often been on specific family interventions (e.g., family psychoeducation, multiple family group therapy; 8, 86) and constructs like family support and expressed emotion (36, 276), which while helpful leave many even simple questions unanswered (e.g., what is the level of contact between families and treating teams over the course of a follow-up?).

Chapter 3's thematic analysis highlighted the multiple ways in which families get involved in the lives and care of their young, loved ones with psychosis. Yet, most quantitative research in early psychosis has focused on a binary indicator of whether families are involved in care. While our study and other qualitative studies highlight that families often extend concrete support like reminding their loved ones regarding appointments and accompanying them during appointments, this has not been systematically documented in early psychosis research. Our next paper addresses this gap. Triangulated knowledge through qualitative and quantitative methods can yield a rich comprehensive understanding of complex phenomena such as family involvement and help design strategies for improved engagement of families in early psychosis services.

This dissertation also argues that knowledge generated from single or dual stakeholder perspectives can be limiting and therefore, it may be very important to examine phenomena from the perspective of multiple stakeholders. Chapter 3 highlighted areas of within- and between-group convergence and divergence among patients, clinicians, and service providers in their views about and preferences for family involvement in early intervention services for psychosis. Beyond a handful of qualitative studies (12, 26), to our knowledge, most research on family involvement has often focused on one stakeholder group at a time. Our work (Chapter 3) suggested that in general, all stakeholder groups value family involvement, but it is not known if they differ in how helpful they find family involvement. Similarly, there has been no examination of what patients, families, and clinicians report in terms of frequencies of concrete forms of involvement of families. Our next paper undertakes such an examination. This work will help document concrete forms of family involvement in treatment, as well as attitudes towards such family involvement, and how these vary across stakeholder groups. Such knowledge is essential before we seek to improve dialogue and practices around family involvement in early psychosis services.

The following manuscript has been prepared for submission.

Chapter 5

Manuscript III

Real-World Evidence for Family Involvement in Treatment in Early Intervention Services for Psychosis In Canada – a Multi-Stakeholder Perspective

Helen Martin, Aarati Taksal, Daniel Rabouin, Srividya N. Iyer

Prepared for submission, 2024.

Abstract

Background: Most research on family support in early psychosis has focused on a high-level indicator of presence or absence of family contact in treatment, often upon entry. Few studies have examined concrete forms of family involvement in treatment (e.g., reminders to take medication), how these evolve over the course of the follow-up and what factors predict these forms of involvement. Little is also known about how different stakeholders – patients, families, and clinicians – report on the same forms of family involvement, as well as how they perceive its helpfulness. Addressing these gaps, this study examined concrete aspects of and attitudes towards family involvement as reported by patients, families, and clinicians over a two-year period of early intervention for psychosis.

Methods: The study was conducted in two McGill university-affiliated early intervention services for psychosis in Montreal, Canada. The sample comprised of patients with a first episode of psychosis (n=139 at baseline; n=82 for at least two time points during the follow-up), their families (n=113 at baseline; n=100 for at least two time points during the follow-up), and their treating clinicians. In addition to socio-demographic and clinical data, patients, families and clinicians responded to six items regarding family involvement at Month 1, Month 12, and Month 24 after entering treatment. Items pertained to frequencies of medication reminders, appointment reminders, accompaniment to appointments, and family contact with treating team; and desired level and helpfulness of the family's involvement in treatment. Generalized estimating equations (GEE) and proportional odds models were used to examine whether reported frequencies of and attitudes towards family involvement changes over time and based on the stakeholder reporting (patient, family, or clinician), while accounting for relevant covariates.

Results: Over time, families are reported to issue fewer medication and appointment reminders, and to accompany their loved ones to appointments and have contact with their treating team less often. Family involvement is also seen as less helpful over the course of follow-up. Clinicians perceive families as issuing fewer medication and appointment reminders to their loved ones, compared to families themselves. They also see the

involvement of families as less helpful than families and patients themselves, although all stakeholders still generally view family involvement positively. Families also reported that they had accompanied their loves ones to appointments and had contact with their treating teams more often than patients themselves did. Compared to patients, families also desired a higher level of involvement in treatment than currently and found family involvement to be more helpful. A higher frequency of family involvement in treatment was also reported for younger patients.

Conclusion: We found that family involvement in the treatment of young persons with early psychosis evolves over the course of treatment. The general trend is that it decreases with time and is higher for younger patients. Further, even on concrete aspects of family involvement, there is considerable variation between different stakeholders. This implies that there needs to be more communication between the patient, family, and the clinician to avoid misalignment and miscommunication. Also, that families were seen as less involved and less helpful in treatment by patients and clinicians than families may explain why families feel not adequately included as key partners in early psychosis care.

1. Introduction

Given that they are often young (adolescents or young adults) at the time of the onset of their psychosis, many individuals with first-episode psychosis are often living with and/or in regular contact with their families(1, 2). Families are also often the first ones to initiate help-seeking (3-6) and are usually, also involved in treatment, often providing critical information to treating teams to support diagnosis and treatment planning; liaising with teams and supporting at the time of crises or relapses; and more generally, supporting the recovery journeys of their loved ones (7-10).

There is strong evidence on the benefits of family involvement in early psychosis for a range of outcomes including relapse reduction (11), medication adherence (12), service engagement (1), social and functional outcomes (13, 14), and quality of life (15). Despite this, there are some critical knowledge gaps with respect to the involvement of families in early psychosis. In general, there have been less than a handful of studies that have examined how family involvement and attitudes associated with it evolve over the course of a follow-up in early psychosis.

Nuttall et al. (16) examined family burden, patient quality of life and positive symptoms over a 24-month course of follow-up in the RAISE-ETP study in the United States. They found that initially, levels of positive symptoms and levels of family burden were associated; later, as patients' quality of life improved, family burden reduced. In a cross-cultural study involving Montreal, Canada and Chennai, India, Iyer et al. (1) case managers tracked their contact with patients' families over a 24-month period and found significantly higher levels of contact with families in India compared to Montreal. More recently, Oluwoye et al. (2) reported that families were more likely to attend appointments during the first seven months if they had been initially engaged in treatment, highlighting that it was important that treating teams ensured a connection with families earlier during the follow-up.

Little is known about how different stakeholders – patients, families, and clinicians – report on the same forms of family involvement, as well as how they perceive its helpfulness. To our knowledge, no studies in early psychosis have elicited the same quantitative data (e.g., desired level of involvement of families in treatment, how often families accompany their loved ones to appointments) from all three stakeholder groups. This may be important because there are some indications that stakeholders' perspectives can often vary, even about the same phenomena (17, 18). For instance, clinician-rated and patient-reported quality of life and medication adherence ratings can vary (19, 20).

When it comes to family involvement, we know from qualitative studies (21-23), including our own (Martin et al., in preparation, Chapter 4) that there may be some critical ways in which stakeholders differ in their views and preferences regarding family involvement in treatment. With few exceptions, even these studies have generally interviewed one stakeholder group at a time. Nonetheless, they have yielded some important insights, and highlighted the need to consider the perspectives of the three key stakeholders in the clinical encounter at once – the patient, the family and the clinician. Patient's consent and confidentiality are brought up by all stakeholders as a barrier to family involvement in treatment (24, 25). But the extent to which this is an actual barrier is not clear (e.g., the percent of patients refusing consent for their families to be involved in early intervention services).

Families tend to prefer to receive continuous support from, and consistent contact with, mental health services, and often report several barriers to participating in their loved one's treatment such as their own work schedules, power imbalances with clinicians, clinicians not keeping them informed, clinicians disregarding their knowledge or not being aware of appreciative of their role and context, etc. (26-29). On their part, clinicians, treatment structures and policymakers generally endorse families as important in treatment, as also reflected in most clinical practice guidelines for early psychosis (Martin et al., in preparation/Chapter 3; (30, 31)).

Clinicians may also perceive some families as cooperative and others as disengaged or harmful (32, 33). Both patients and clinicians value patient autonomy and agency, which may at times hinder them from involving families in care or from seeing it positively (34). Cameron et al.'s (26) systematic review of mental health service users' perspectives of family involvement found that service users can view family involvement positively (e.g., because it provides comfort and practical support) and negatively (e.g., because of problematic relationships with families, or feeling excluded from decisions made by families and clinicians working together).

Most quantitative research on family support in early psychosis has focused on a high-level indicator of presence or absence of family contact in treatment, often upon entry (35, 36). Few, if any, quantitative studies have examined concrete forms of family involvement in early psychosis treatment (e.g., reminders to take medication, families helping their loved ones to get to appointments, etc.), how these evolve over the course of the follow-up, and what factors predict these forms of involvement, even though multiple qualitative studies highlight that families often support their ill family member's treatment through practical or instrumental means such as housing, transport to appointments, encouraging medication adherence, etc. (37, 38). Addressing these gaps, this study examined concrete aspects of and attitudes towards family involvement as reported by patients, families, and clinicians over a two-year period of early intervention for psychosis. Our specific questions were (A) How do concrete aspects of and attitudes towards family involvement change over the course of a follow-up? (B) Are there any differences between patients, families and clinicians in their reports of concrete aspects of and attitudes towards family involvement?

2. Methods

The study had a quantitative longitudinal design and was a part of a larger study examining outcomes and family factors in first-episode psychosis. Institutional ethics boards in Montreal approved the study. All participants provided informed consent. Participants younger than 18 provided assent, and their parents/guardians gave consent.

2.1 Setting

This study was conducted in two early intervention services for psychosis affiliated with McGill University, Montreal, Canada (both called PEPP): the Prevention and Early Intervention Program for Psychosis at Douglas Mental Health University Institute and the Prevention and Early Intervention Program for Psychosis at McGill University Health Centre. Both services are publicly funded programs and have an open-referral system. Both provide services to young people experiencing their first episode of psychosis. Treatment is characterized by early, phase-specific, and recovery-oriented approaches provided by a multidisciplinary team (case managers, psychiatrists, occupational therapists, etc.) over two years. Treatment consists of assertive case management, family psychoeducation, flexible administration of antipsychotic medication, and, if necessary, other individual and family psychosocial interventions (1, 13, 39).

2.2 Inclusion and Exclusion Criteria

This study included three stakeholder groups at PEPP: patients with first-episode psychosis receiving services, families of patients with first-episode psychosis, and clinicians. Patients were eligible for the study if they were between 16 and 35 years old; had a primary diagnosis of schizophrenia-spectrum disorder or affective psychosis as per the DSM-IV-TR criteria (63); had not been previously treated with antipsychotics for more than 30 days; and could communicate in French and/or English. Those with organic or substance-induced psychosis, an IQ<70 or a pervasive developmental disorder were excluded. Those with co-occurring substance use were included. Family members recruited for this study were parents, spouses/partners, grandparents, extended family members, and friends of patients followed at PEPP. Clinicians were case managers (i.e., counsellors, social workers, occupational therapists, psychiatric nurses) who worked with patients and families at PEPP.

2.3 Assessments

All assessments were administered by trained research staff and completed in French or English, depending on participants' preferences. Socio-demographic data for all participants and clinical data for patients were obtained at entry into the study. Diagnoses were based on the Structured Clinical Interview for DSM-IV (SCID) (40). Age at onset of psychosis and duration of untreated psychosis were ascertained through the Circumstances of Onset and Relapse Schedule (CORS) (41). Duration was defined as the number of weeks between the onset of psychosis and the commencement of treatment (typically, initiation of antipsychotic treatment).

The Scale for Assessment of Positive Symptoms (SAPS) and the Scale for Assessment of Negative Symptoms (SANS) (42, 43) were used to rate the severity of positive and negative symptoms at baseline. The latter excluded scores on the items of ‘inappropriate affect’ and ‘poverty of content of speech’ and items for the ‘attention’ subscale, as these have been shown not to be part of the negative symptoms’ domain (39). Positive symptom remission was achieved if patients obtained a rating of 2 or lower (indicating mild severity) on global scores for hallucinations, delusions, bizarre behaviour, and formal thought disorder using the SAPS. Negative symptom remission was defined as ratings of 2 or lower on affective flattening, alogia, avolition, apathy, and anhedonia using the SANS (44). Furthermore, remission, defined similarly, within the initial three months was categorized as "early remission." (45).

Assessment of family involvement: Participants responded to six items regarding family involvement in the beginning of treatment (Month 1), in the middle (Month 12 after entry or Month 6 if Month 12 was not available) and near the end of treatment (Month 24 after entry or Month 18 if Month 24 was not available). Items were rated on a scale of 1 to 6, or 0 to 5, where higher ratings indicated more family involvement or more positive attitudes towards family involvement in the treatment. All respondents answered the same six items at all timepoints, with minor changes in wording (e.g., “My family reminded me to take my medication” versus “I reminded my family member to take his/her medication” versus “The patient’s family reminded the patient to take his/her medication” in the patient, family, and case manager versions, respectively). See supplemental Table 1 for all items. Four items were about concrete forms of family involvement (Items 1-4) and two about attitudes towards family involvement (Items 5 and 6).

Item 1: frequency of medication reminders given by the family to the patient (never, once every few months, monthly, weekly, more than once per week, daily), scored on a 6-point scale.

Item 2: frequency of appointment reminders given by the family to the patient (none, 1 out of 5 appointments, 2 out of 5 appointments, 3 out of 5 appointments, 4 out of 5 appointments, all appointments), scored on a 6-point scale.

Item 3: frequency with which family accompanied patients to their PEPP appointments (none, 1 out of 5 appointments, 2 out of 5 appointments, 3 out of 5 appointments, 4 out of 5 appointments, all appointments), scored on a 6-point scale.

Item 4: frequency of family's contact with the treatment team (Never, once every few months, monthly, weekly, more than once per week, daily), scored on a 6-point scale.

Item 5: desired level of family involvement in treatment (not at all, a lot less than now, a bit less than now, to the same extent as now, a little more than now, a lot more than now) scored on a 6-point scale.

Item 6: perceived helpfulness of family's involvement in patient treatment (very unhelpful, unhelpful, neither helpful nor unhelpful, helpful, very helpful) scored on a 5-point Likert scale.

2.4 Data Analysis

Statistical analyses were computed using SPSS version 29 for descriptive analyses and R statistical package (version 4.3.2) for Windows for question-driven analyses. Group data were represented as means, standard deviations (SDs), median, range, frequency, and percentages, and compared using chi square and independent samples t-tests. Effect sizes were computed using Cohen's d and interpreted as small (0.2), medium (0.5) and large (0.8 and above) (46).

Data for Items 1,2, 5, and 6 (ordinal data) from different stakeholders, at Time 1 (Month 1), 2 (Month 12) and 3 (Month 24) were analyzed using generalized estimating equation (GEE). For Items 3 and 4, whose response categories enquired about the number of occurrences (frequency of medication reminders and accompanying patients to appointments), a Poisson distribution with a log link functionwas used. We examined the effects of stakeholder group (patient, family, clinician) and time on outcomes assessed by each of the six family involvement items. Time was the repeated measure with the correlation structure as independence (47). Time was treated as a continuous variable because the time graphs of the raw data for each stakeholder showed a clear linear trend. To estimate the rate at which events were occurring, the coefficients were exponentiated to obtain the odds ratio. The family stakeholder was the reference group in our models, which were also adjusted using covariates.

We initially ran univariate analyses with variables that could be potentially associated with family involvement (based on previous literature(48-50)) - age at entry, gender, ethnicity (visible minority or not), education level (high school completed or not), occupational status (employed/student or not employed/not in school), duration of untreated psychosis, substance use diagnosis (yes/no), positive and negative symptoms severity at baseline, and early positive remission and early negative remission. Only those covariates which were significant at p<0.1 for each item were selected to be entered in the final models for each of the six items.

3. Results

3.1 Descriptive Statistics

3.1.1 Respondents vs non-respondents

Of the consenting 165 patients and 128 family members, 139 (84%) patients and 113 (88%) families responded to the family involvement items at least once during their follow-up. A comparison of patient respondents versus non-respondents indicated that at baseline, the two groups were comparable on variables of age at entry, gender, education, employment status, relationship status, living situation, diagnosis and substance use, age at onset of current psychosis episode, DUP, and positive symptom severity. However, the respondents had significantly higher negative symptom severity (23.24, 12.85) compared to non-respondents (18.48, 9.37) (t=1.766, df=158, p=0.40, Cohen's d=0.384). Family respondents and non-respondents were comparable on gender, relationship with the patient, education, and age.

3.1.2 Respondents

In this section, we present socio-demographic and clinical characteristics of participants who responded to the family involvement items *at least once* during their follow-up. Results (Tables 1, 2 and 3) indicate that at entry into the study, patients were in their mid-twenties. A majority were men, white, were single, were unemployed, resided with their family, had more than high school education, were diagnosed with schizophrenia-spectrum disorder, and had no co-occurring substance use. The average age at onset was 23 years and the median DUP was 10 weeks. The majority of family members were 51-60 years old, white, women, parents and had a university-level education. All the clinicians were case managers, with the majority being women, social workers, and were either 31-40 or 51-60 years old.

3.2 Family Involvement in Treatment: Effects of Time and Stakeholder Group

Data were analyzed separately for each of the six family involvement items presented in Tables 4a-f; with means and SDs for each item presented in supplementary tables 2a-f. The analyses included only those who had data for at least two of the three time points, which was approximately 100 patients, 82 families, and 147 patients for whom clinicians rated these items, with Ns varying between items due to missing data. Data from families who had filled out the questionnaire but whose patients had not consented to research (n=19) was also removed for this analysis.

<u>Item 1 (frequency of medication reminders given by families):</u> The effects of time (OR = 0.78, 95% CI [0.65, 0.93], p=0.007), stakeholder group (OR = 0.38, 95% CI [0.25, 0.57], p<0.001; families compared to clinicians) and age (OR = 0.95, 95% CI [0.90, 0.99], p=0.029) were significant. Overall, as reported by all stakeholders, the frequency of medication reminders being given to patients significantly decreased over the duration of the follow-up. For every one unit increase in months, the frequency of medication reminders decreased by 1.28 times. The means at entry, year 1 and year 2 (i.e., the three time points) indicate that there was wide variation in the frequency with which families were reported as giving medication reminders to their loved ones. Clinicians estimated that families gave medication reminders to patients 2.63 times less frequently than did families. For every one unit decrease in age (years), the frequency of medication reminders given by families increased by 1.05 times. Other covariates (education, occupational status, early positive emission) were not significant.

<u>Item 2 (frequency of appointment reminders given by families):</u> The effects of time (OR = 1.27, 95% CI [1.07, 1.51], p=0.006), stakeholder group (OR = 1.74, 95% CI [1.12, 2.71], p=0.014; families compared to clinicians) and age (OR = 0.94, 95% CI [0.90, 0.98], p=0.002) were

significant. Overall, as reported by all stakeholders, frequency of appointment reminders being given to patients significantly increased over the duration of the follow-up. For every one unit increase in months, the frequency of appointment reminders increased by 0.78 times. The means at entry, year 1 and year 2 (i.e., the three time points) indicate that there was wide variation in the frequency with which families were reported as giving appointment reminders to their loved ones. Clinicians estimated that families gave appointment reminders to patients 0.57 times more frequently than did families. For every one unit decrease in age (years), the frequency of medication reminders given by families increased by 1.06 times. Other covariates (education, substance use) were not significant.

Item 3 (number of appointments for which the family accompanied the patient): The effects of time (OR = 0.68, 95% CI [0.57, 0.82], p<0.001), stakeholder group (OR = 2.22, 95% CI [1.58, 3.12], p<0.001; families compared to patients) and age (OR = 0.94, 95% CI [0.90, 0.98], p=0.002) were significant. Overall, as reported by all stakeholders, the number of appointments during which patients were accompanied by their families significantly decreased over the duration of the follow-up. For every one unit increase in months, the number of accompanied appointments decreased by 1.47 times. The means at entry, year 1 and year 2 (i.e., the three time points) indicate that there was wide variation in the number of times that families were reported as having accompanied their patients for appointments. Patients estimated that families accompanied them for appointments 0.45 times more than families did. For every one unit decrease in age (years), the number of appointments that families accompanied patients increased by 1.06 times.

Item 4: (frequency of contact between families and treating team): The effects of time (OR = 0.55, 95% CI [0.46, 0.65], p<0.001), stakeholder group (OR = 0.59, 95% CI [0.40, 0.86], p=0.006; families compared to patients) and age (OR = 0.94, 95% CI [0.90, 0.97], p=0.001) were significant. Overall, as reported by all stakeholders, the frequency of contact between families and treating teams significantly decreased over the duration of the follow-up. For every one unit increase in time (months), the frequency of contact decreased by 1.81 times. The means at entry, year 1 and year 2 (i.e., the three time points) indicate that there was wide variation in the frequency of contact between families and treating teams. Patients estimated that families had 1.69 times less contact with treating teams than families did. For every one unit decrease in age (years), as reported by all stakeholders, the frequency of contact between families and treating teams increased by 1.06 times.

Item 5 (desired level of family involvement in treatment than now): There was a significant main effect of stakeholder group (OR = 0.21, 95% CI [0.11, 0.37], p<0.001; families compared to patients) and age (OR = 1.04, 95% CI [1.01, 1.07], p=0.021). The effect of time was not significant. Compared to families, patients reported that they would desire a lower level (by 4.76 times) of involvement than now. Interestingly, with every one unit increase in age of patients, the desired level of involvement from families increased by 0.96 times. Other covariates (gender, DUP, early negative remission, and negative symptom severity at baseline) were not significant.

Item 6 (perceived level of helpfulness of family involvement in treatment): Results indicated that there was a significant main effect of time (OR = 0.84, 95% CI [0.72, 0.98], p=0.025); of stakeholder group (OR = 0.42, 95% CI [0.25, 0.70], p=0.001; patients compared to families and OR = 0.30, 95% CI [0.19, 0.46], p<0.001; clinicians compared to families). For every one unit increase in time (months), the perceived level of helpfulness of family involvement decreased by 1.19 times. Compared to families, patients rated family involvement as 2.38 times less helpful and clinicians as 3.33 times less helpful. The means (see supplementary table 2f) indicate that while families generally rated their own involvement in treatment as being between “helpful” and “very helpful”, other stakeholders rated the involvement of families as being between “neither helpful not unhelpful” and “helpful”. Other covariates (age and negative symptom severity at baseline) were not significant.

4. Discussion

Our study examined four concrete forms of and two attitudes towards the involvement of families in early intervention services for psychosis, with respect to their evolution over a two-year course and how they vary between patients, families and case managers. At the outset, it is important to note that there is significant heterogeneity on nearly all items but few to no scores at the extreme ends, suggesting that at least when families are involved (which is the case for this sample), there is variability in the extent to which they are involved and how it is perceived. This aligns with previous quantitative and qualitative research, including our own (Martin et al., in preparation/Chapter 4) and underlines the myriad patient-level, family-level, program-level and societal factors that shape family involvement (24, 51).

The general pattern in terms of a lack of extreme scores highlights that at least in high-income contexts like Montreal, families are rarely *always* present or extending support and *never* present or extending support (when they are aware of their loved one's treatment or their loved one has consented, the sample in our study). This is unlike contexts like India where families engaged in treatment generally tend to be *always* present (1). Still, these concrete supports like reminders regarding medication or appointments and accompanying during appointments are important ways that families support the engagement of their loved ones.

Indeed, a recent study from Toronto, Canada (52) found 25.7% of service users with first-episode psychosis identified, "I forgot appointments or lose track of time" as a barrier to service engagement". Conversely, 14.4% of service users in the same study identified "My family member helps get me there" as a facilitator to service engagement. Encouragingly, our findings also highlight that there were few stakeholders who saw family involvement as "very unhelpful" (no families or case managers and only 3 patients). This too aligns with previous qualitative literature in psychosis that most stakeholders generally value family involvement (53, 54). This is reassuring because family involvement has consistently shown to improve various outcomes in psychosis, such as remission, hospitalization, relapse, quality of life, medication adherence, and social and occupational functioning (1, 39, 48, 55-57).

4.1 How Do Concrete Forms of And Attitudes to Family Involvement Change Over Time?

With respect to our first research question, we found that with one exception, all examined aspects of family involvement shifted significantly over the course of a follow-up, highlighting the importance of studying family involvement using a longitudinal perspective, something that is still rare in early psychosis research. Overall, the frequencies of medication reminders given by families to patients, contact between family and treating team, and families accompanying patients to their appointments reduced over the two-year period.

To our knowledge, previous research in first-episode psychosis has not looked at frequencies of and evolution in families issuing medication reminders and accompanying their patients during appointments. Congruent with our finding, one study (from our group in the same setting) found that contact between treating teams and families (as recorded in these studies by clinicians) reduces over the course of a follow-up in early intervention (1, 2) and another that attendance in family psychoeducation reduces over the course of time (58). It is understandable that generally, as patients become functionally and symptomatically better, they may need a reduced frequency of concrete involvement of their families in their treatment.

Interestingly, an opposite pattern was found with family reminders for attending appointments increasing over time. This may be related to the parallel trend of reducing the frequency of families accompanying their loved ones to appointments. Also, as patients may become better, they may not feel the need for going for sessions, and may need more reminders for appointments, and thus continuing treatment. In terms of attitudes, the preference for family involvement in treatment remained stable over time, but there was a decrease (albeit small) in the perceived helpfulness of family involvement in treatment over time. This may have likely been driven by a shift in clinicians' and patients' attitudes, as our findings in relation to stakeholder effects indicate.

4.2 Views of Patients, Families, and Clinicians

Families' and patients' reports of frequencies of medication and appointment reminders converged but diverged with reference to frequency of contact between treating teams and families and patients being accompanied by their families, as well as on the two attitudinal items. Patients reported a far lower frequency of contact between families and their treating teams – this may be because they may not always be aware or present when there is such contact, which may happen by phone or text or email, particularly later during follow-up. Being the main units of therapeutic attention, patients may also tend to underestimate the contact that their families and treating teams have. They also desired a lower level of involvement from families than families did and found family involvement less helpful than their families did. While significant, one must not extrapolate this to infer that patients did not desire family involvement or that they found it unhelpful – these are differences in degrees of desired involvement and perceived helpfulness of family involvement. While this discrepancy in attitudes has not been examined earlier by quantitative studies in early psychosis, it aligns with previous qualitative studies of family involvement in treatment for schizophrenia-spectrum disorders (59, 60) . In first-episode psychosis, this discrepancy may also reflect the play of a normative developmental struggle between autonomy and independence versus relatedness and interdependence (8, 15) , overlaid over the push and pull between patients' agency and autonomy vis-à-vis treatment and family structures that can align with, hinder or facilitate such agency (61). Also, there was a marginal discrepancy (much smaller in size than the other ones) between patients and families with respect to how frequently they reported that their families accompanied them to appointments.

Families' and clinicians' reports of frequencies of patients being accompanied by their families and contact between treating teams and families, as well as preferred level of family involvement converged. But they diverged with respect to reports of medication and appointment reminders, and perceived helpfulness of family involvement. Our results suggest that even regarding somewhat tangible, concrete aspects of family involvement in treatment, stakeholders' reports do not always converge. For behaviours that usually take place at home (reminders for medication and appointments), patients and families' reports converged, but not those of families and clinicians. There was, however, convergence between families and clinicians for behaviours that are observable by clinicians (families accompanying patients to appointments; and contact between family and treating team), which may also be documented in clinical notes.

Clinicians perceived family involvement as substantially less helpful than did the families themselves. Even though this is still a difference in degrees, this is concerning because it may clarify why families feel excluded or their role and perspective not adequately considered in their loved one's treatment. While novel because of our study's multi-stakeholder, longitudinal and quantitative lens, our finding that both patients and clinicians see family involvement as less helpful (among the top differences between stakeholders that we found in terms of size) than families is striking, and somewhat congruent with findings from a recent survey (52) which found that families (8% of them), but no patients endorsed "My family does not want me to be as actively involved in care as I would like to be" as a barrier to service engagement. Earlier, Iyer et al. (62) found that when asked to assign responsibility for addressing the needs of persons with mental health problems, families assigned more responsibility to families (versus to persons with mental health problems themselves) than patients and clinicians. This was the case in early intervention services in Canada and India. This suggests that families may see themselves as having a bigger role in supporting their loved ones than other stakeholders (patients and clinicians) do.

Overall, our findings highlight that there may sometimes be communication and alignment gaps between clinicians and families (as well as between families and patients) with respect to family involvement. These gaps could be bridged (or their negative impacts mitigated even when attitudes are not shifted) by clinicians seeking more information from families and patients, as well as by clinicians creating more opportunities for triadic dialogue between patients, families, and clinicians. Moreover, opting for such an approach has also been deemed as convenient and user-friendly for clinicians (24, 27, 59, 63-65).

4.3 Other Influences

As expected, we found that families were reported to extend more concrete supports (all four items) to younger patients. This is understandable given that younger patients may require more parental support, and as they become young adults, strive towards more autonomy in their treatment (66, 67). This is congruent with a developmental viewpoint (8). Interestingly, older patients desired a slightly higher level of family involvement. This too may parallel developmental processes whereby adolescents and younger adults may be more centrally focused on the developmental task of individuation (albeit to varying degrees based on their sociocultural context) than their slightly older counterparts (e.g., between the ages of 25 and 35). Jones et al. (8) has also reported that preferences for family involvement varied by age of persons with early psychosis. Interestingly, no other factors (e.g., symptoms) shaped the six aspects of examined family involvement in multivariate analyses. However, we may have been underpowered to detect some of these differences.

5. Strengths and Limitations

This study adopts a multiple stakeholder perspective to studying family involvement in early intervention for psychosis. Along with its integration of a triadic and longitudinal perspective, the examination of attitudes towards family involvement is a novel contribution of the study. By focusing on concrete, simply worded items related to family involvement, we could gauge what patients, families, and clinicians reported about practical supports extended by families towards the ends of service and medication engagement. Asking the same questions of all three stakeholder groups yielded valuable insights about gaps in alignment in their views, that in turn help explain consistent findings from qualitative studies (e.g., families feeling excluded despite clinicians endorsing that they involve and value families) and have implications for improving family work in early psychosis services.

However, we acknowledge that the study was carried out in one specific city in Canada, and the study would need to be replicated with other samples from other early intervention services. We included participants who were engaged in care and willing to engage in research and filling out measures, which shapes and limits the generalizability of our results, particularly with respect to those young people and families who may have both difficult relationships with each other and/or difficult treatment journeys.

Our sample sizes were also modest and precluded the examination of all pertinent covariates in our models (resulting in us opting for the less ideal option of being guided in our choice of covariates to include by first running univariate analyses). Our small sample sizes also precluded more sophisticated analyses such as interaction and path effects (e.g., does change over time vary across stakeholder groups?) or whether specific events (e.g., relapses) are associated with changes in family involvement.

We also used only patient-related variables as covariates in our study, whereas literature indicates that family-related (including important cultural factors) and provider-related variables also impact family involvement in treatment (24, 68). Finally, a mixed methods approach with an in-depth qualitative component would have been helpful, as well as studying additional aspects of family involvement in treatment like attendance in family psychoeducation and family peer support.

6. Conclusion and Implications

The nature of family involvement changes over the course of a follow-up in early intervention services. There are differences in reports of concrete forms of and attitudes towards family involvement between them. Thus, open channels of communication are essential between patients, families, and clinicians. Clinicians should be trained and supported in facilitating such triadic communication at multiple junctures over the course of treatment. Assessment of family involvement need to be carried out periodically as a part of measurement-based care. Data collected this way can inform early intervention services as to how they are performing against policy guidelines or standards, as well as against the preferences of stakeholders. Research on engagement and involvement of patients and families in early psychosis should ideally involve all pertinent stakeholder groups.

Table 1: Baseline socio-demographic and clinical characteristics of patients who responded to at least one item at one timepoint during their follow-up (N=139)

Variable	N (%) | M (SD)	Test statistic
Age at entry (years) (n=139)	24.38 (5.39)	
Gender		X^2=91.40; df =2; **p=<0.001**
Men	93 (66.91)	
Women	46 (32.37)	
Transpersons	1 (0.7)	
Total	139 (100)	
Education		X^2=28.27; df =1; **p=<0.001**
Less than High School	37 (27.2)	
Completed high school or more	99 (72.8)	
Total	136 (100)	
Occupation Status		X^2=53.79; df =2; **p=<0.001**
Student	21 (15.8)	
Employed	28 (21.1)	
Unemployed	84 (63.2)	
Total	133 (100)	
Visible minority status		X2=66.60; df =2; **p=<0.000**
No (White)	77 (57.9)	
Yes (Minoritized)		
Indigenous	2 (1.5)	
Visible minority	54 (40.6)	
Total	133 (100)	
Relationship Status		
Single	125 (90.6)	
Married/ Common Law relationship	12 (8.7)	
Separated/ divorced / widowed	1 (0.7)	
Total	138 (100)	
Living Situation		X^2=208.85; df =3; **p=<0.001**
Alone	14 (10.4)	
With family	106 (78.5)	
With friend / roommate	13 (9.6)	
In residence, group home or homeless	2 (1.4)	
Total	135 (100)	
SCID Diagnosis		
Schizophrenia-spectrum Disorders	95 (69.3)	X^2=20.504; df =1; **p=<0.001**
Affective psychosis	42 (30.7)	
Total	137 (100)	
Substance Abuse or Dependence (SCID)		X^2=10.124; df =1; **p=0.001**
No	78 (64.5)	
Yes	43 (35.5)	
Total	121 (100)	
Age at onset of current psychotic episode (years) (n=135)	23.46 (5.80)	
DUP (weeks) to presenting episode (n=131)	44.51 (94.90) Median = 10 (0-684.29)	
Positive symptom severity at baseline (mean, S.D) (n=129)	35.29 (14.69)	
Negative symptom severity at baseline (mean, S.D) (n=135)	23.24 (12.85)	
Early positive remission		X^2=20.2; df =1; **p<0.001**
Yes	96 (69)	
No	43 (31)	
Early negative remission		X^2=6.05; df =1; **p=0.014**
Yes	55 (39.5)	
No	84 (60.5)	

Note: Total ns for each item may not match due to missing values.

Significance level set at < 0.05

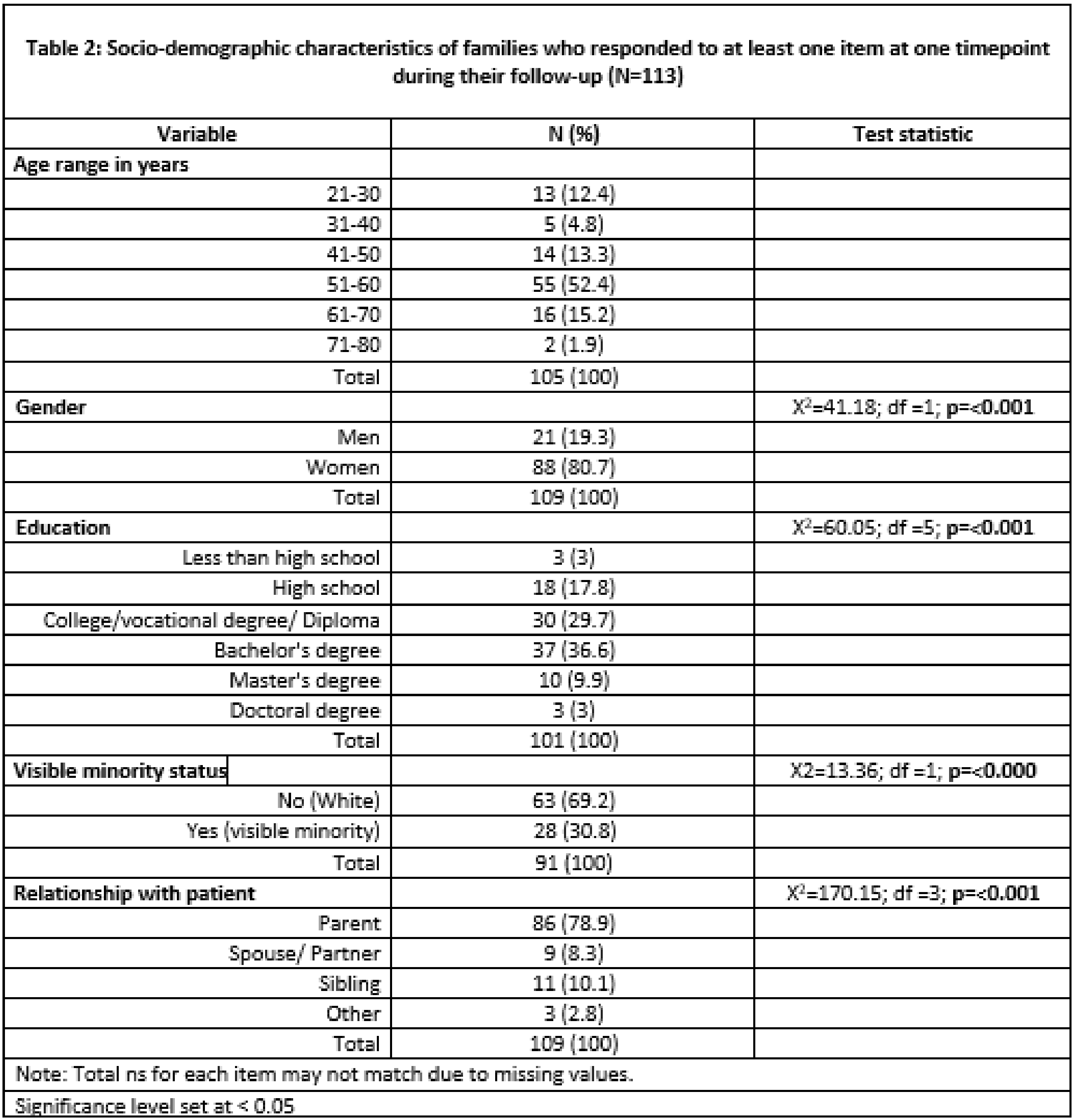


Table 2: Socio-demographic characteristics of families who responded to at least one item at one timepoint during their follow-up (N=113)

Variable	N (%)	Test statistic
Age range in years		
21-30	13 (12.4)	
31-40	5 (4.8)	
41-50	14 (13.3)	
51-60	55 (52.4)	
61-70	16 (15.2)	
71-80	2 (1.9)	
Total	105 (100)	
Gender		X^2=41.18; df =1; **p=<0.001**
Men	21 (19.3)	
Women	88 (80.7)	
Total	109 (100)	
Education		X^2=60.05; df =5; **p=<0.001**
Less than high school	3 (3)	
High school	18 (17.8)	
College/vocational degree/ Diploma	30 (29.7)	
Bachelor's degree	37 (36.6)	
Master's degree	10 (9.9)	
Doctoral degree	3 (3)	
Total	101 (100)	
Visible minority status		X2=13.36; df =1; **p=<0.000**
No (White)	63 (69.2)	
Yes (visible minority)	28 (30.8)	
Total	91 (100)	
Relationship with patient		X^2=170.15; df =3; **p=<0.001**
Parent	86 (78.9)	
Spouse/ Partner	9 (8.3)	
Sibling	11 (10.1)	
Other	3 (2.8)	
Total	109 (100)	

Note: Total ns for each item may not match due to missing values.

Significance level set at < 0.05

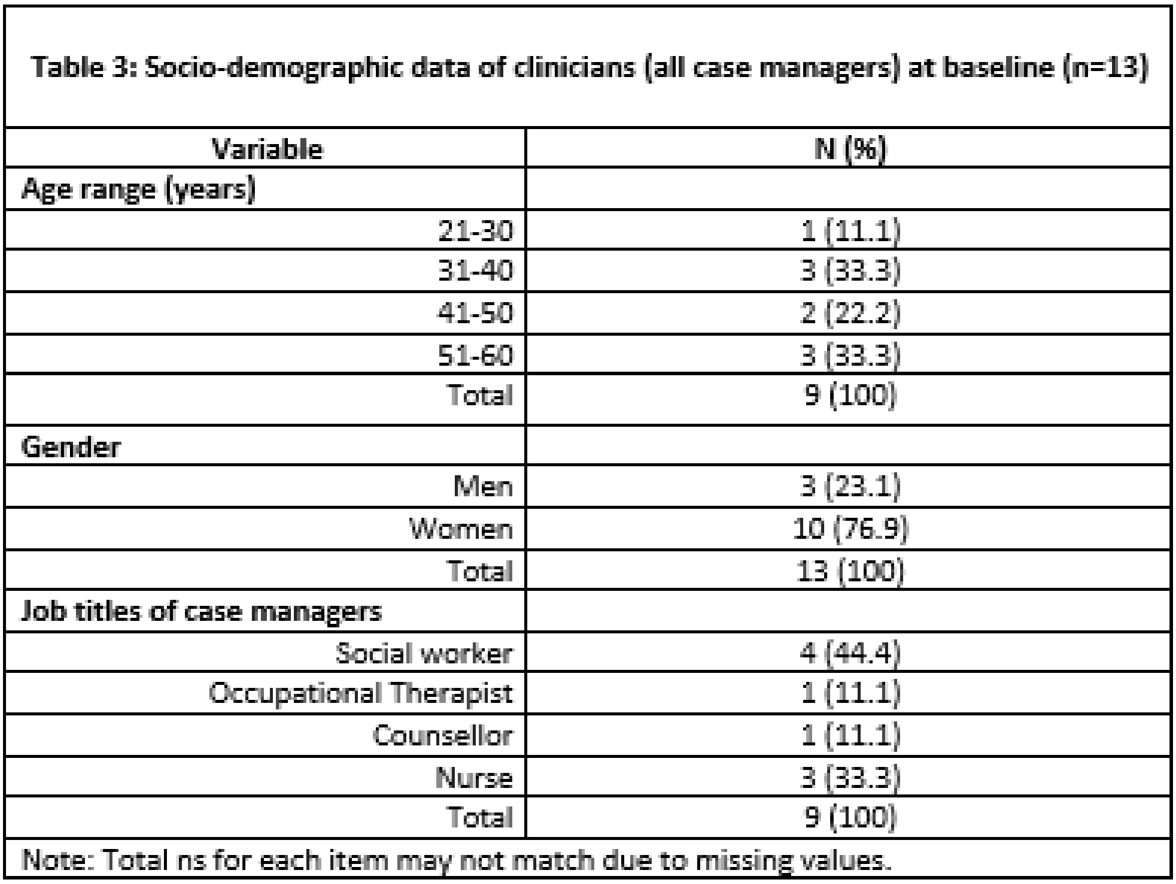


Table 3: Socio-demographic data of clinicians (all case managers) at baseline (n=13)

Variable	N (%)
Age range (years)	
21-30	1 (11.1)
31-40	3 (33.3)
41-50	2 (22.2)
51-60	3 (33.3)
Total	9 (100)
Gender	
Men	3 (23.1)
Women	10 (76.9)
Total	13 (100)
Job titles of case managers	
Social worker	4 (44.4)
Occupational Therapist	1 (11.1)
Counsellor	1 (11.1)
Nurse	3 (33.3)
Total	9 (100)

Note: Total ns for each item may not match due to missing values.

Table 4: Predictors of family involvement

4a. Item 1: Frequency of medication reminders given by the family to the patient

Predictors	Odds Ratios	95% CI	p
beta10	2.73	0.74 – 10.07	0.131
beta20	6.06	1.66 – 22.10	0.006
beta30	9.79	2.66 – 35.98	0.001
beta40	12.88	3.51 – 47.30	<0.001
beta50	19.42	5.40 – 69.85	<0.001
Time	**0.78**	**0.65 – 0.93**	**0.007**
Stakeholder Patient	1.07	0.68 – 1.66	0.774
Stakeholder Clinician	**0.38**	**0.25 – 0.57**	**<0.001**
Stakeholder Family (reference group)			
Patient age at entry	**0.95**	**0.90 – 0.99**	**0.029**
High school completed (yes)	0.88	0.51 – 1.50	0.633
Early positive remission (yes)	0.66	0.42 – 1.06	0.086
Occupation status	0.63	0.37 – 1.07	0.09
N pin	129		
Observations	636		

4b. Item 2: Frequency of appointment reminders given by the family to the patient

Predictors	Odds Ratios	95% CI	p
beta10	0.22	0.05 – 0.87	0.031
beta20	0.28	0.07 – 1.08	0.064
beta30	0.34	0.09 – 1.30	0.113
beta40	1.08	0.30 – 3.91	0.912
beta50	3.6	1.00 – 12.99	0.05
Time	**1.27**	**1.07 – 1.51**	**0.006**
Stakeholder Patient	1.07	0.65 – 1.77	0.787
Stakeholder Clinician	**1.74**	**1.12 – 2.71**	**0.014**
Stakeholder Family (reference group)			
Patient age at entry	**0.94**	**0.90 – 0.98**	**0.002**
High school completed (yes)	0.93	0.56 – 1.53	0.764
Substance use (yes)	1.45	0.92 – 2.30	0.113
N pin	133		
Observations	663		

4c. Item 3: Frequency with which family accompanied patients to their PEPP appointments

Predictors	Odds Ratios	95% CI	p
beta10	1.94	0.63 – 5.98	0.246
beta20	3.15	1.01 – 9.78	0.048
beta30	4.53	1.46 – 14.12	0.009
beta40	6.6	2.08 – 20.96	0.001
beta50	18.62	5.77 – 60.07	<0.001
Time	**0.68**	**0.57 – 0.82**	**<0.001**
Stakeholder Patient	**2.22**	**1.58 – 3.12**	**<0.001**
Stakeholder Clinician	1.15	0.88 – 1.49	0.309
Stakeholder Family (reference group)			
Patient age at entry	**0.94**	**0.90 – 0.98**	**0.002**
N pin	151		
Observations	760		

4d. Item 4: Frequency of contact between family and treating team

Predictors	Odds Ratios	95% CI	p
beta10	0.31	0.10 – 0.97	0.044
beta20	1.56	0.48 – 5.13	0.463
beta30	7.02	2.25 – 21.87	0.001
beta40	25.17	7.89 – 80.23	<0.001

beta50	105.79	31.84 – 351.47	<0.001
Time	**0.55**	**0.46 – 0.65**	**<0.001**
Stakeholder Patient	**0.59**	**0.40 – 0.86**	**0.006**
Stakeholder Clinician	0.77	0.56 – 1.05	0.094
Stakeholder Family (reference group)			
Patient age at entry	**0.94**	**0.90 – 0.97**	**0.001**
N pin	155		
Observations	789		
4e. Item 5: Desired level of family involvement in treatment			
Predictors	**Odds Ratios**	**95% CI**	**p**
beta10	0.04	0.01 – 0.12	<0.001
beta20	0.22	0.07 – 0.67	0.008
beta30	5.63	1.84 – 17.27	0.003
beta40	11.94	3.98 – 35.81	<0.001
beta50	15.66	5.03 – 48.72	<0.001
Time	0.98	0.82 – 1.17	0.83
Stakeholder Patient	**0.21**	**0.11 – 0.37**	**<0.001**
Stakeholder Clinician	1.35	0.86 – 2.12	0.193
Stakeholder Family (reference group)			
Patient age at entry	**1.04**	**1.01 – 1.07**	**0.021**
Gender (Woman)	0.81	0.58 – 1.15	0.244
DUP	1.23	0.99 – 1.52	0.063
Early negative Remission (Yes)	0.87	0.59 – 1.29	0.495
Negative symptom severity at baseline	1.01	0.99 – 1.02	0.447
N pin	131		
Observations	667		
4f. Item 6: Perceived level of helpfulness of family involvement in treatment			
Predictors	**Odds Ratios**	**95% CI**	**p**
beta10	0.24	0.07 – 0.88	0.031
beta20	2.47	0.69 – 8.84	0.164
beta30	9.35	2.50 – 34.88	0.001
beta40	13.62	3.62 – 51.29	<0.001
beta50	24.86	6.76 – 91.48	<0.001
Time	**0.84**	**0.72 – 0.98**	**0.025**
Stakeholder Patient	**0.42**	**0.25 – 0.70**	**0.001**
Stakeholder Clinician	**0.3**	**0.19 – 0.46**	**<0.001**
Stakeholder Family (reference group)			
Patient age at entry	1.04	1.00 – 1.08	0.052
Positive symptom severity at baseline	1.01	1.00 – 1.03	0.071
N pin	140		
Observations	703		
Note: Significance level set at < 0.05			

References

1. Iyer SN, Malla A, Taksal A, Maraj A, Mohan G, Ramachandran P, et al. Context and contact: a comparison of patient and family engagement with early intervention services for psychosis in India and Canada. Psychological Medicine. 2022;52(8):1538-47.
2. Oluwoye O, Fraser ER, Kordas G. Taking a Look at How Family Member Engagement Influences Service User Engagement in New Journeys: a Coordinated Specialty Care Program. The journal of behavioral health services & research. 2023;50(2):228-35.
3. Bergner E, Leiner AS, Carter T, Franz L, Thompson NJ, Compton MT. The period of untreated psychosis before treatment initiation:: A qualitative study of family members' perspectives. Comprehensive psychiatry. 2008;49(6):530-6.
4. Lucksted A, Stevenson J, Nossel I, Drapalski A, Piscitelli S, Dixon LB. Family member engagement with early psychosis specialty care. Early Interv Psychiatry. 2018;12(5):922-7.
5. Martin H, Xavier S, Taksal A, Levasseur M, Iyer SN. Family involvement in mental healthcare. In: Leclerc TLaC, editor. Manuel de réadaptation psychiatrique. 3rd ed. Quebec, Canada: Presses de l'Université du Québe; 2023.
6. Del Vecchio V, Luciano M, Sampogna G, De Rosa C, Giacco D, Tarricone I, et al. The role of relatives in pathways to care of patients with a first episode of psychosis. International Journal of Social Psychiatry. 2015;61(7):631-7.
7. Drapalski AL, Piscitelli S, Lee RJ, Medoff D, Dixon LB. Family Involvement in the Clinical Care of Clients With First-Episode Psychosis in the RAISE Connection Program. Psychiatr Serv. 2018;69(3):358-61.
8. Jones N, Basaraba C, Piscitelli S, Jewell T, Nossel I, Bello I, et al. Clients' preferences for family involvement and subsequent family contact patterns within OnTrackNY early psychosis services. Psychiatric Services. 2021;72(4):399-407.
9. Lakeman R. Family and carer participation in mental healthcare: perspectives of consumers and carers in hospital and home care settings. Journal of Psychiatric and Mental Health Nursing. 2008;15(3):203-11.
10. Cairns VA, Reid GS, Murray C. Family members' experience of seeking help for first-episode psychosis on behalf of a loved one: a meta-synthesis of qualitative research. Early Intervention in Psychiatry. 2015;9(3):185-99.
11. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2022.
12. Coldham E, Addington J, Addington D. Medication adherence of individuals with a first episode of psychosis. Acta Psychiatrica Scandinavica. 2002;106(4):286-90.
13. Iyer S, Jordan G, MacDonald K, Joober R, Malla A. Early intervention for psychosis: a Canadian perspective. J Nerv Ment Dis. 2015;203(5):356-64.
14. Early Psychosis Guidelines Writing Group, Asian Network of Early Psychosis Writing program, EPPIC National Support. Australian Clinical Guidelines for Early Psychosis, 2nd edition update. Melbourne: Orygen, The National Centre of Excellence in Youth Mental Health; 2016.
15. Oluwoye O, Kriegel L, Alcover KC, Compton MT, Cabassa LJ, Mcdonell MG. The impact of early family contact on quality of life among non-Hispanic Blacks and Whites in the RAISE-ETP trial. Schizophrenia Research. 2020;216:523-5.
16. Nuttall AK, Thakkar KN, Luo X, Mueser KT, Glynn SM, Achtyes ED, et al. Longitudinal associations of family burden and patient quality of life in the context of first-episode schizophrenia in the RAISE-ETP study. Psychiatry Research. 2019;276:60-8.
17. Tambuyzer E, Pieters G, Van Audenhove C. Patient involvement in mental healthcare: one size does not fit all. Health Expectations. 2014;17(1):138-50.
18. Wallcraft J, Amering M, Freidin J, Davar B, Froggatt D, Jafri H, et al. Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. World psychiatry. 2011;10(3):229.

19. Cassidy CM, Rabinovitch M, Schmitz N, Joober R, Malla A. A comparison study of multiple measures of adherence to antipsychotic medication in first-episode psychosis. Journal of clinical psychopharmacology. 2010;30(1):64-7.

20. Rabinovitch M, Cassidy C, Schmitz N, Joober R, Malla A. The influence of perceived social support on medication adherence in first-episode psychosis. Can J Psychiatry. 2013;58(1):59-65.

21. Aldersey HM, Whitley R. Family influence in recovery from severe mental illness. Community Mental Health Journal. 2015;51:467-76.

22. Banerjee D, Arasappa R, Chandra PS, Desai G. “Hear me out”: experiences of women with severe mental illness with their healthcare providers in relation to motherhood. Asian Journal of Psychiatry. 2021;55:102505.

23. Fisher A, Manicavasagar V, Sharpe L, Laidsaar-Powell R, Juraskova I. A qualitative exploration of patient and family views and experiences of treatment decision-making in bipolar II disorder. Journal of Mental Health. 2018;27(1):66-79.

24. Eassom E, Giacco D, Dirik A, Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open. 2014;4(10):e006108.

25. Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres–a nested qualitative study. BMC Health Services Research. 2022;22(1):1-16.

26. Cameron SL, Tchernegovski P, Maybery D. Mental health service users’ experiences and perspectives of family involvement in their care: A systematic literature review. Journal of Mental Health. 2023;32(3):699-715.

27. Doody O, Butler MP, Lyons R, Newman D. Families' experiences of involvement in care planning in mental health services: an integrative literature review. J Psychiatr Ment Health Nurs. 2017;24(6):412-30.

28. McCann TV, Lubman DI, Clark E. First-time primary caregivers' experience accessing first-episode psychosis services: Caregivers accessing FEP services. Early Intervention in Psychiatry. 2011;5(2):156-62.

29. Wainwright LD, Glentworth D, Haddock G, Bentley R, Lobban F. What do relatives experience when supporting someone in early psychosis? Psychology and Psychotherapy: Theory, Research and Practice. 2015;88(1):105-19.

30. QC. Cadre de référence : Programmes pour premiers épisodes psychotiques (PPEP) Quebec, Canada2022.

31. BC. Standards and Guidelines for Early Psychosis Intervention (EPI) Programs Retrieved from British Columbia, Canada2010.

32. Nicholls E, Pernice R. Perceptions of the relationship between mental health professionals and family caregivers: has there been any change? Issues Ment Health Nurs. 2009;30(8):474-81.

33. Rowe J. Great expectations: a systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. Journal of psychiatric and mental health nursing. 2012;19(1):70-82.

34. Glynn SM, Cohen AN, Dixon LB, Niv N. The potential impact of the recovery movement on family interventions for schizophrenia: opportunities and obstacles. Schizophrenia bulletin. 2006;32(3):451-63.

35. Conus P, Lambert M, Cotton S, Bonsack C, McGorry PD, Schimmelmann BG. Rate and predictors of service disengagement in an epidemiological first-episode psychosis cohort. Schizophrenia Research. 2010;118(1-3):256-63.

36. Stowkowy J, Addington D, Liu L, Hollowell B, Addington J. Predictors of disengagement from treatment in an early psychosis program. Schizophrenia Research. 2012;136(1-3):7-12.

37. Glick ID, Stekoll AH, Hays S. The role of the family and improvement in treatment maintenance, adherence, and outcome for schizophrenia. Journal of clinical psychopharmacology. 2011;31(1):82-5.

38. Tsai J, Stroup TS, Rosenheck RA. Housing arrangements among a national sample of adults with chronic schizophrenia living in the United States: A descriptive study. Journal of Community Psychology. 2011;39(1):76-88.

39. Malla A, Iyer SN, Rangaswamy T, Ramachandran P, Mohan G, Taksal A, et al. Comparison of clinical outcomes following 2 years of treatment of first-episode psychosis in urban early intervention services in Canada and India. The British Journal of Psychiatry. 2020;217(3):514-20.

40. First MB. Structured clinical interview for DSM-IV-TR axis I disorders, research version, non-patient edition.(SCID-I/NP). (No Title). 2002.

41. Norman RMG, Malla AK. Duration of untreated psychosis: a critical examination of the concept and its importance. Psychological medicine. 2001;31(3):381-400.

42. Andreasen NC. Negative symptoms in schizophrenia: definition and reliability. Archives of general psychiatry. 1982;39(7):784-8.

43. Andreasen NC. Scale for the assessment of positive symptoms. Psychiatrie & Psychobiologie. 1984.

44. Andreasen NC, Carpenter Jr WT, Kane JM, Lasser RA, Marder SR, Weinberger DR. Remission in schizophrenia: proposed criteria and rationale for consensus. American Journal of Psychiatry. 2005;162(3):441-9.

45. Malla A, Iyer SN, Joober R, Rangaswamy T, Ramachandran P, Schmitz N, et al. An observational study of antipsychotic medication discontinuation in first-episode psychosis: clinical and functional outcomes. Social Psychiatry and Psychiatric Epidemiology. 2022;57(7):1329-40.

46. Cohen J. Statistical power analysis for the behavioral sciences: Academic press; 2013.

47. Laird NM, editor Analysis of longitudinal and cluster-correlated data2004: IMS.

48. Claxton M, Onwumere J, Fornells-Ambrojo M. Do family interventions improve outcomes in early psychosis? A systematic review and meta-analysis. Frontiers in Psychology. 2017;8:371.

49. Lobban F, Postlethwaite A, Glentworth D, Pinfold V, Wainwright L, Dunn G, et al. A systematic review of randomized controlled trials of interventions reporting outcomes for relatives of people with psychosis. Clinical psychology review. 2013;33(3):372-82.

50. Onwumere J, Jansen JE, Kuipers E. family interventions in psychosis change outcomes in early intervention settings–how much does the evidence support this? : Frontiers Media SA; 2018. p. 406.

51. Bucci S, Berry K, Barrowclough C, Haddock G. Family interventions in psychosis: a review of the evidence and barriers to implementation. Australian Psychologist. 2016;51(1):62-8.

52. Polillo A, Voineskos AN, Foussias G, Kidd SA, Bromley S, Soklaridis S, et al. Disengagement from early psychosis intervention services: an observational study informed by a survey of patient and family perspectives. Schizophrenia. 2022;8(1):94.

53. Mui EYW, Chan SKW, Chan PY, Hui CLM, Chang WC, Lee EHM, et al. Systematic review (meta-aggregation) of qualitative studies on the experiences of family members caring for individuals with early psychosis. Int Rev Psychiatry. 2019;31(5-6):491-509.

54. Sin J, Norman I. Psychoeducational interventions for family members of people with schizophrenia: a mixed-method systematic review. The Journal of clinical psychiatry. 2013;74(12):16055.

55. Ma CF CW, Bressington DT. 2018 Aug;12(4):535-60. Family intervention for caregivers of people with recent-onset psychosis: A systematic review and meta-analysis. Early intervention in psychiatry. 2018;12(4):535-60.

56. Malla A, Payne J. First-episode psychosis: psychopathology, quality of life, and functional outcome. Schizophrenia bulletin. 2005;31(3):650-71.

57. Pharoah F, Mari JJ, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane database of systematic reviews. 2010(12).

58. Lucksted A, McFarlane W, Downing D, Dixon L. Recent developments in family psychoeducation as an evidence-based practice. Journal of marital and family therapy. 2012;38(1):101-21.

59. Cohen AN, Drapalski AL, Glynn SM, Medoff D, Fang LJ, Dixon LB. Preferences for family involvement in care among consumers with serious mental illness. Psychiatric Services. 2013;64(3):257-63.

60. Cohen AN, Pedersen ER, Glynn SM, Hamilton AB, McNagny KP, Reist C, et al. Preferences for family involvement among veterans in treatment for schizophrenia. Psychiatric Rehabilitation Journal. 2019;42(3):210.

61. Cowan T, Pope MA, MacDonald K, Malla A, Ferrari M, Iyer SN. Engagement in specialized early intervention services for psychosis as an interplay between personal agency and critical structures: A qualitative study. International Journal of Nursing Studies. 2020;108:103583.

62. Iyer SN, Malla A, Pope M, Mustafa S, Mohan G, Rangaswamy T, et al. Whose responsibility? Part 2 of 2: views of patients, families, and clinicians about responsibilities for addressing the needs of persons with mental health problems in Chennai, India and Montreal, Canada. International Journal of Mental Health Systems. 2022;16(1):1-16.

63. Doherty WJ. The why's and levels of collaborative family healthcare. Family Systems Medicine. 1995;13(3-4):275.

64. Guinaudie C, Mireault C, Tan J, Pelling Y, Jalali S, Malla A, et al. Shared decision making in a youth mental health service design and research project: insights from the Pan-Canadian ACCESS open minds network. The Patient-Patient-Centered Outcomes Research. 2020;13:653-66.

65. Huang C, Lam L, Plummer V, Cross WM. Feeling responsible: Family caregivers' attitudes and experiences of shared decision-making regarding people diagnosed with schizophrenia: A qualitative study. Patient Education and Counseling. 2021;104(7):1553-9.

66. Martin H, Taksal A, Levasseur MA, Iyer S, N. Exploring multiple stakeholder preferences for family involvement in early intervention services for psychosis using modified nominal group technique. Manuscript under peparation. 2024.

67. Arango C, Buitelaar JK, Correll CU, Díaz-Caneja CM, Figueira ML, Fleischhacker WW, et al. The transition from adolescence to adulthood in patients with schizophrenia: Challenges, opportunities and recommendations. European Neuropsychopharmacology. 2022;59:45-55.

68. Selick A, Durbin J, Vu N, O'Connor K, Volpe T, Lin E. Barriers and facilitators to implementing family support and education in Early Psychosis Intervention programmes: A systematic review. Early Interv Psychiatry. 2017;11(5):365-74.

Chapter 6: Discussion

Families play an integral role in caring for individuals experiencing the early stages of psychosis, by providing essential support, and advocating for their loved ones (269). There is also an abundance of consistent evidence that family support, family involvement in care, and family interventions are beneficial for a range of proximal (service engagement and medication adherence) and distal (relapses, hospitalizations, quality of life, recovery, work and social functioning and mortality) outcomes (140, 270, 271). Conversely, neglecting family involvement may result in fragmented care, decreased treatment adherence, poor quality of life, service disengagement and heightened risk of relapse among young individuals with early psychosis. Therefore, integrating families into early psychosis care is crucial for achieving better long-term outcomes and enhancing the overall quality of mental health services. Despite this, qualitative studies in psychosis indicate that families often report feeling not adequately informed and excluded from decision-making processes about treatment and discharge (264, 272). Although not extensively investigated, there is also evidence for inconsistent implementation and uptake of best practices around family involvement, family psychoeducation, and other family interventions (245, 250, 258). Various knowledge gaps contribute to these evidence-practice gaps with respect to family involvement and family interventions.

Despite their influential role in shaping and regulating practices, there has been no systematic examination of what early psychosis guidelines recommend with respect to family work and the quality of these recommendations. Do guidelines make a range of family-focused recommendations that reflect both the state of the evidence and stakeholders' preferences? Are these recommendations formulated clearly and in a way that allows programs in diverse contexts to apply them? There is also a lack of in-depth knowledge concerning the views and preferences of various stakeholder groups (patients, families, and clinicians) regarding the role of families in early intervention services for psychosis, including various types of family involvement, and the navigation of consent and confidentiality (273) . By addressing these knowledge gaps, the larger aim of this doctoral research was to advance our understanding regarding family involvement in the treatment of young individuals with first-episode psychosis within early intervention services in the Canadian context, with a view to informing policy and clinical service recommendation and facilitating a collaborative, family-friendly delivery of early psychosis care in Canada.

Aligned with this larger aim, this dissertation addressed three specific objectives in three separate studies. Firstly, to identify, synthesize and appraise clinical practice recommendations for family work in early intervention services for psychosis in Canada, specifically focusing on dimensions related to their implementability and identifying gaps that can contribute to their poorer uptake. Secondly, to understand the views and preferences of multiple pertinent stakeholder groups (patients, families, clinicians and program administrators) regarding family involvement in early intervention services for psychosis. Thirdly, to examine concrete forms of and attitudes towards family involvement in early intervention services for psychosis as reported by patients, families and clinicians, and how they evolve over the course of a follow-up. The summary of the key findings and contributions of these three studies is presented below.

Study 1: Synthesis and Appraisal of Clinical Practice Recommendations

The first study delved into critically synthesizing and clinical practice recommendations for family involvement in early intervention services for psychosis in Canada. Our grey literature review took a unique clinically-relevant, policy-oriented and implementability-focused approach. In doing so, it integrated two approaches that have earlier not been used in early psychosis work – the first, a patient and family engagement framework (274) and the second, AGREE-REX (275), a tool to assess the quality of guidelines in terms of rigour and implementability.

This study provides a first ever thematically classed compilation of family work recommendations in early psychosis guidelines that can guide programs, clinicians, and policymakers in early psychosis. It also identified significant gaps in the content, consistency, quality, and implementability of family work recommendations across guidelines, that may be contributing to poor and inconsistent implementation of family contact practices and family interventions in early intervention services for psychosis.

On a positive note, our review highlights clear directions for future early psychosis guideline developers to improve the quality and implementability, both of overall guidelines and their family-focused recommendations. Our recommendations will also ensure better alignment between the avowed patient- and family-oriented philosophy of early intervention services for psychosis (Martin et al., manuscript in preparation) on the one hand, and the process undertaken to create guidelines for such services and the practices they recommend for engaging families and patients in direct care, organizational design and governance and policy, on the other hand.

Study 2: Patients', Families' and Clinicians' Views and Preferences About Family Involvement

The second study explored views and priorities regarding family involvement among patients, families and clinicians using the modified nominal group technique. While previous research had investigated perceptions about family involvement, our study is unique in its incorporation of a preference-based, multiple stakeholder standpoint. Three main themes emerged: meaning and value of family involvement, factors influencing family involvement (including a subtheme around consent and confidentiality), and preferred methods of family involvement.

Analysis of participant rankings revealed consensus on several key points, including the importance of family involvement during crises and relapses, regular communication between families and treating teams, the need for common guidelines for family involvement, and the idea that lack of patient consent should not hinder the sharing of generic, illness-related information with families and receiving information from families. All stakeholders also emphasized the need to have dialogue with patients about the known value of family involvement in care.

This paper contributed to understanding how stakeholders (patients, families, and clinicians) perceive and prioritize family involvement in early intervention service for psychosis and provided concrete recommendations for family involvement in treatment in early psychosis.

Furthermore, this novel attempt involved soliciting preferences about two understudied domains i.e., consent and confidentiality (89, 226), highlighting their multifaceted, evolving nature and providing specific advice on navigating these while still making room for family involvement in care.

Study 3: Empirical Evidence on Family Involvement Practices

The third study examined concrete forms of and attitudes towards family involvement in early intervention settings. Using longitudinal data and employing generalized estimating equations and proportional odds models, our study threw light on how stakeholders (patient, families, clinicians) report on the same concrete forms of and attitudes towards family involvement in treatment. We found that generally, family involvement decreases over time, is higher for younger patients, and reports of multiple stakeholders need not always converge. There is a gap between families' own reports of their involvement and patients and clinicians' reports of families' involvement in care.

Moreover, families and clinicians preferred similar levels of family involvement in care, but patients desired a lower level. Both patients and clinicians rated family involvement as less helpful than families did. Thus, there's a notable incongruence in the desired level and perceived helpfulness of family involvement across stakeholder groups. This paper provided valuable insights into why families may feel excluded from care despite clinicians endorsing that they involve and value families. The study has implications for both research – family involvement must be studied from the perspective of multiple stakeholders and at repeated intervals over follow-up – and care – clinicians need to be aware that family involvement and attitudes towards it evolve over time, and that they cannot assume alignment in their views about family involvement vis-à-vis that of the patient and their family.

Summary of Comparative Analysis of Findings and Implications

Together, these studies showcased the intricate interplay between policy, stakeholder preferences, and empirical realities in the landscape of family involvement in early intervention services for psychosis. They point to converging recommendations for improving the involvement of families in early psychosis care, with each study also yielding unique insights.

Recognition of the importance of family involvement: All three studies highlight that the valuable role of families in the treatment of early psychosis is acknowledged by all stakeholders (patients, families, clinicians and policymakers as reflected in guidelines). Family involvement may take multiple helpful forms and may vary based on the phase of illness and follow-up, age of patients, cultural background and so on. Families are seen as needing support, particularly in the form of psychoeducation. The studies also highlight gaps in the recognition of the importance of family involvement. Families are rarely seen as needing to be involved in higher-level services and policy design. Families are also primarily seen as recipients of care and useful to consult especially during initial phases. Despite the important role families play in the treatment and lives of young people with psychosis, there may be a need for concerted advocacy and specific strategies for the healthcare systems to view families as essential partners in care.

Communication and collaboration: Communication (or need for communication) between families, patients, and clinicians emerges as a common theme across all three studies. All three studies underscore the importance of open channels of communication and collaboration between stakeholders for effective family involvement in treatment, emphasizing their role in building and maintaining therapeutic alliance and improving overall family engagement with services. The results from Studies 1 and 2 emphasize regular contact between families and the clinicians. However, Study 3 shows that contact decreases over time. This implies that frequent contact between families and treating teams may be particularly necessary during the initial phases of treatment, typically marked by acute illness.

As treatment progresses and patients improve, contact between clinicians and families may be seen as less essential and perhaps even as somewhat opposed to the patient's exercises of agency and autonomy. This was also a theme from the group discussion in Study 2. Still, both stakeholders' views and the evidence (252, 276, 277) point to the need for consistent contact between treating teams and families throughout treatment. Particularly in the later phases of treatment and when things seem to be going well, clinicians may need reminders or nudges to maintain contact with families, even if by phone/texts/online modes. If opportunities are built in for dialogue, expectations setting and responsibilities for family involvement between all three stakeholders, families may also feel more comfortable assuming the joint responsibility for their contact with teams that all stakeholders endorsed.

Need for tailored approaches: Study 2 highlighted several factors that influence family involvement and that should therefore be considered in engaging families in care. These include factors that are patient-level such as age, symptoms and phase of the illness; familial such as resources and norms; cultural such as views about autonomy and independence-interdependence; and structural-societal such as views about the primacy of individual agency and the place of consent and confidentiality. Study 3 also provided clear evidence for family involvement and attitudes towards it evolving over the course of the follow-up and based on the age of the patient. It is important to note that, as Study 1 revealed, guidelines and standards documents do not provide adequate guidance on how recommendations should be tailored to particular subsets of patients and families and contexts. Future guidelines should promptly address this limitation informed by the best available evidence and clinical wisdom at this time. At the same time, there is also a need for more research on implementation science and personalized care in early psychosis.

Interpretation of Findings

The complex dynamics of family involvement: The synthesized findings uncover the intricate dynamics that govern family involvement in early intervention services for psychosis. The acknowledgement of families as pivotal in supporting individuals with early psychosis contrasts sharply with the sense of marginalization they experience within the system (264, 265, 278). This points to a systemic challenge where the theoretical recognition of family importance does not seamlessly translate into practical, and respectful integration within healthcare structures (226). The current research exposes the multifaceted nature of barriers to family involvement, emphasizing the ambiguity surrounding key elements such as consent, confidentiality, and the logistics of involvement. By identifying these barriers, the current study lays the groundwork for potential strategies and interventions to mitigate these obstacles.

Systemic Influences on Family Involvement*:* The three studies in our examination of family involvement in early psychosis care extend from the individual and familial levels to the broader healthcare system and policy landscape. The examination of clinical practice recommendations in Study 1 underscores the impact of governing healthcare systems on family involvement. Our findings point to a need for policy measures that not only endorse family (and patient) involvement in care, but also explicitly elicit and integrate their values and preferences. Study 2 then goes on to showcase the value of eliciting stakeholders' views and of innovative methodologies (such as ranking following an in-depth discussion) that can lead to recommendations prioritized by stakeholders (while still being informed by evidence). By emphasizing the role of policy in shaping clinical practices, the present study contributes a fresh perspective to the discourse on psychosocial approaches in early intervention services for psychosis. More importantly, the present research serves as a clarion call for centring practices and policies for involving families (and patients) in their voices and preferences.

Stakeholder Collaborations as Critical: Stakeholder collaborations, or their absence, emerge as critical factors shaping family involvement practices. The preference-based exploration in Study 2 delved into the perspectives of multiple stakeholders—patients, families, and clinicians -regarding family involvement. The consensus on the fluid nature of the consent process and how consent (lack of consent) can be negotiated to allow for family involvement, and the need for common guidelines for family involvement in care highlight the interconnectedness of stakeholder views. The study demonstrates that effective family involvement requires not only recognizing the preferences of families but also understanding the diverse perspectives within the patient-clinician-family triad. The convergence and divergence of views, preferences and attitudes about family involvement in studies 2 and 3 underscore the need for a collaborative approach among stakeholders and the importance of building consensus to foster family-friendly delivery of care in early intervention services for psychosis.

Navigating Variations in Views Through Dialogue: Our work highlights that family involvement is influenced by individual preferences and structures and processes within the broader healthcare system, as well as dynamically shaped by stakeholder collaborations. By highlighting the fluidity of family involvement and the need to navigate variations in views between stakeholders, the current research advocates for dialogue that engages the patient-clinician-family triad at multiple junctures throughout treatment, including on views and preferences about the mores and methods of family involvement in care. Such dialogue has the potential to help shift early intervention services for psychosis beyond recognizing the importance of family to actively incorporating their (and other stakeholders') preferences, acknowledging and navigating barriers, and working towards a collaborative and equitable model of care. Future family interventions research can focus on finding ways to support such dialogue and evaluate its implementation and impacts across diverse contexts.

Evaluation of Existing Theories and Models

The research findings outlined in this thesis gently challenge prevailing models of family involvement in mental healthcare by highlighting the significant role of policy and healthcare structures and processes in shaping family involvement practices. The triangle model of care (170) primarily focuses on the alliance between patients, families and clinicians, and the pyramid model of care focuses on interventions for families (166, 169). Such traditional models often focus on individual or interpersonal factors, neglecting broader systemic influences (166). This thesis underscores that family involvement is influenced not only by individual actors (particularly families) and their preferences, but also by multiple actors interacting with each other, as well as by macro-level structures and processes (e.g., laws around consent, the extent to which guidelines endorse family involvement).

Furthermore, the current study introduces a nuanced discussion on the fluid nature of the consent process and its relation to family involvement. Findings revealed that consent was seen as a dynamic process influenced by various factors, including the severity of the condition, changes in the patient's illness, and the evolving needs of both the patient and the family. This dynamic understanding challenges conventional models that treat consent as a one-time event and emphasizes the need for flexible, ongoing processes that account for the evolving and multifaceted (legal, pragmatic, social, relational, etc.) nature of consent and confidentiality, as our Study 2 revealed.

Finally, our work aligns with and advances patient-oriented research and patient-centred care approaches within early psychosis. Our studies and their conclusions recognize the vital contribution of families (as well as patients and clinicians) in co-designing and implementing care strategies, promoting a collaborative and patient-centred approach to healthcare delivery. The three studies also focus on knowledge-data-practice gaps that exist in early intervention services vis-à-vis family involvement and provide strategies for bridging such gaps.

The studies focus on multi-stakeholder preferences and reports on family involvement, as well as the policy context guiding and impeding it. The work in this thesis makes clear, the need for patient- and family-centred recommendations around co-development of policy guidelines with families to reflect their needs, preferences, and priorities; fostering open communication among all involved parties; and the need to see families not as passive recipients or assistants in executing treatment plans developed by clinicians, but as active partners alongside patients in envisioning and shaping care plans, services and policies.

Overall Strengths and Limitations

The overall study was guided by the pragmatic paradigm of research, as the aim was to generate practical and implementable knowledge on family involvement in early psychosis. We approached the research in a holistic manner by employing a variety of research methods such as knowledge synthesis, group discussion followed by ranking (consensus building) and quantitative methods. In both Studies 2 and 3, we used an inclusive approach of triangulation (279) by bringing together perspectives of patients, families, and clinicians. Both studies 1 and 2 resulted in a generation of concrete recommendations that can guide practice and policy/guidelines development in early psychosis.

While this research makes novel contributions to the field of family involvement in early psychosis, we acknowledge some of its limitations. The research is Canada-centric (a high-income country with a strong public healthcare system) with two studies being conducted in stand-alone early psychosis services in Montreal (one city within Canada). This limits the generalizability of our findings to other countries with varying healthcare systems or resources, as well as diverse contexts within Canada (e.g., Indigenous communities, rural settings or hub-and-spoke models of early psychosis care). The studies predominantly focused on the perspectives of clinicians, patients, and family members, whereas the preferences of policymakers (aside from the clinical guidance documents) at the systemic level (280, 281) were excluded. The current research is primarily focused on early intervention services for psychosis, and its findings may not be generalizable to other mental health contexts.

Future Research Recommendations

Future research should broaden its scope to explore family involvement in diverse geo-cultural contexts within and beyond Canada, as well as to more carefully integrate individual, familial, clinical, cultural, social, and systemic considerations. This expansion could help uncover variations in family involvement across different healthcare systems, cultural norms, and policy frameworks. Within Canada, this is important given that Canada is increasingly a multicultural society. Furthermore, the Canadian early psychosis guidelines provide little guidance on how care and family involvement can be tailored for Indigenous populations and contexts. Our samples in Studies 2 and 3 also did not include significant numbers of Indigenous peoples. Future research, in close partnership with Indigenous communities, should focus on generating knowledge that would allow early intervention services for psychosis to provide culturally safe care to Indigenous young people, including in relation to family and community engagement.

Future work can also design and evaluate tailored strategies for family involvement and interventions, based on evolving needs, illness severity, and stakeholder preferences, including around consent and confidentiality. By conducting co-designed research on family involvement with thoughtfully selected diverse samples in varied contexts, research can also illuminate how cultural nuances shape family involvement. Exploring the potential of telehealth, mobile applications, and other technological solutions to enhance family engagement in early psychosis treatment could offer new pathways for more accessible and inclusive practices (282), including for maintaining contact throughout the course of treatment.

Conclusion

To conclude, in synthesizing the converging and diverse findings across the three studies, this research provides a comprehensive understanding of family involvement in early intervention services for psychosis in the Canadian context. The synthesis brings together clinical practice recommendations, and stakeholder perspectives, preferences and practices on family involvement. By integrating these dimensions, the research contributes a comprehensive and nuanced perspective on the complexities surrounding family involvement in early psychosis care, laying the groundwork for informed improvements in service delivery and guidelines. Ultimately, enhancing the involvement of families in early psychosis care will improve outcomes and the quality of lives of persons with psychosis and their families, as well as potentially improve the well-being of service providers and the performance of early psychosis services.

Bibliography

1. Keks N, Blashki G. The acutely psychotic patient: Assessment and initial management. Australian family physician. 2006;35(3).
2. Harris A, Brennan J, Anderson J, Taylor A, Sanbrook M, Fitzgerald D, et al. Clinical profiles, scope and general findings of the Western Sydney First Episode Psychosis Project. Australian & New Zealand Journal of Psychiatry. 2005;39(1-2):36-43.
3. Kilkku N, Munnukka T, Lehtinen K. From information to knowledge: the meaning of information-giving to patients who had experienced first-episode psychosis. Journal of psychiatric and mental health nursing. 2003;10(1):57-64.
4. Power PJR, Bell RJ, Mills R, Herrman-Doig T, Davern M, Henry L, et al. Suicide prevention in first episode psychosis: the development of a randomized controlled trial of cognitive therapy for acutely suicidal patients with early psychosis. Australian & New Zealand Journal of Psychiatry. 2003;37(4):414-20.
5. Solmi M, Radua J, Olivola M, Croce E, Soardo L, Salazar de Pablo G, et al. Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. Molecular psychiatry. 2022;27(1):281-95.
6. Morgan C, Cohen A, Esponda GM, Roberts T, John S, Pow JL, et al. Epidemiology of untreated psychoses in 3 diverse settings in the global south: the international research program on psychotic disorders in diverse settings (INTREPID II). JAMA psychiatry. 2023;80(1):40-8.
7. Malla AK, Norman RMG, Joober R. First-episode psychosis, early intervention, and outcome: what have we learned? The Canadian Journal of Psychiatry. 2005;50(14):881-91.
8. Mullen A, Murray L, Happell B. Multiple family group interventions in first episode psychosis: Enhancing knowledge and understanding. International Journal of Mental Health Nursing. 2002;11(4):225-32.
9. Breitborde NJ, Srihari VH, Woods SW. Review of the operational definition for first-episode psychosis. Early Intervention in Psychiatry. 2009;3(4):259-65.
10. Gariépy G, Danna SM, Hawke L, Henderson J, Iyer SN. The mental health of young people who are not in education, employment, or training: a systematic review and meta-analysis. Social psychiatry and psychiatric epidemiology. 2021:1-15.
11. Mackrell L, Lavender T. Peer relationships in adolescents experiencing a first episode of psychosis. Journal of Mental Health. 2004;13(5):467-79.
12. Sanbrook M, Harris A, Parada R, Young P. The effectiveness of an early intervention team in the treatment of first-episode psychosis. Australian e-Journal for the Advancement of Mental Health. 2003;2(1):16-24.
13. Malla A, Iyer SN, Rangaswamy T, Ramachandran P, Mohan G, Taksal A, et al. Comparison of clinical outcomes following 2 years of treatment of first-episode psychosis in urban early intervention services in Canada and India. The British Journal of Psychiatry. 2020;217(3):514-20.
14. Whiteford HA, Ferrari AJ, Degenhardt L, Feigin V, Vos T. The global burden of mental, neurological and substance use disorders: an analysis from the Global Burden of Disease Study 2010. PloS one. 2015;10(2):e0116820.
15. Smetanin P, Briante C, Khan M, Stiff D, Ahmad S. The life and economic impact of major mental illnesses in Canada: Economic impact of major mental illnesses in Canada. 2015.
16. Sairanen S, Matzanke D, Smeall D. The business case: collaborating to help employees maintain their mental well-being. HealthcarePapers. 2011;11:78-84.
17. Department of Health-Ageing. National Mental Health Report 2013: tracking progress of mental health reform in Australia 1993–2011. Commonwealth of Australia Canberra; 2013.
18. Trautmann S, Wittchen H-u. Do our societies react appropriately to the burden of mental disorders. EMBO reports. 2016;17(9):1245-9.

19. McGrath J, Saha S, Welham J, El Saadi O, MacCauley C, Chant D. A systematic review of the incidence of schizophrenia: the distribution of rates and the influence of sex, urbanicity, migrant status and methodology. BMC medicine. 2004;2(1):1-22.
20. Lecomte T, Addington J, Bowie C, Lepage M, Potvin S, Shah J, et al. The Canadian network for research in schizophrenia and psychoses: a nationally focused approach to psychosis and schizophrenia research. The Canadian Journal of Psychiatry. 2022;67(3):172-5.
21. Public Health Agency of Canada. Schizophrenia in Canada. 2020.
22. Émond AL-V. Surveillance of Mental Disorders in Quebec: Prevalence, Mortality and Service Utilization Profile. 2013.
23. Vos T, Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. The Lancet. 2017;390(10100):1211-59.
24. Bourque F, van der Ven E, Malla A. A meta-analysis of the risk for psychotic disorders among first-and second-generation immigrants. Psychological medicine. 2011;41(5):897-910.
25. Selten J-P, Van Der Ven E, Termorshuizen F. Migration and psychosis: a meta-analysis of incidence studies. Psychological medicine. 2020;50(2):303-13.
26. Xavier SM, Jarvis GE, Ouellet-Plamondon C, Gagné G, Abdel-Baki A, Iyer SN. Comment les services d'intervention précoce pour la psychose peuvent-ils mieux servir les migrants, les minorités ethniques et les populations autochtones? Santé mentale au Québec. 2021;46(2):331-64.
27. Anglin DM, Ereshefsky S, Klaunig MJ, Bridgwater MA, Niendam TA, Ellman LM, et al. From womb to neighborhood: a racial analysis of social determinants of psychosis in the United States. American Journal of Psychiatry. 2021;178(7):599-610.
28. Matheson SL, Shepherd AM, Pinchbeck RM, Laurens KR, Carr VJ. Childhood adversity in schizophrenia: a systematic meta-analysis. Psychological medicine. 2013;43(2):225-38.
29. Misiak Bl, Krefft M, Bielawski T, Moustafa AA, Sąsiadek MM, Frydecka D. Toward a unified theory of childhood trauma and psychosis: a comprehensive review of epidemiological, clinical, neuropsychological and biological findings. Neuroscience & Biobehavioral Reviews. 2017;75:393-406.
30. Varese F, Smeets F, Drukker M, Lieverse R, Lataster T, Viechtbauer W, et al. Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective-and cross-sectional cohort studies. Schizophrenia bulletin. 2012;38(4):661-71.
31. Tewfik GI, Okasha A. Psychosis and immigration. Postgraduate Medical Journal. 1965;41(480):603.
32. Zolkowska K, Cantor-Graae E, McNeil TF. Increased rates of psychosis among immigrants to Sweden: is migration a risk factor for psychosis? Psychological Medicine. 2001;31(4):669-78.
33. Allardyce J, Gilmour H, Atkinson J, Rapson T, Bishop J, McCreadie RG. Social fragmentation, deprivation and urbanicity: relation to first-admission rates for psychoses. The British Journal of Psychiatry. 2005;187(5):401-6.
34. Croudace TJ, Kayne R, Jones PB, Harrison GL. Non-linear relationship between an index of social deprivation, psychiatric admission prevalence and the incidence of psychosis. Psychological medicine. 2000;30(1):177-85.
35. Anderson KK, Cheng J, Susser E, McKenzie KJ, Kurdyak P. Incidence of psychotic disorders among first-generation immigrants and refugees in Ontario. Cmaj. 2015;187(9):E279-E86.
36. Cheng SC, Backonja U, Buck B, Monroe-DeVita M, Walsh E. Facilitating pathways to care: A qualitative study of the self-reported needs and coping skills of caregivers of young adults diagnosed with early psychosis. Journal of Psychiatric and Mental Health Nursing. 2020;27(4):368-79.
37. Longden E, Read J. Social adversity in the etiology of psychosis: A review of the evidence. American Journal of Psychotherapy. 2016;70(1):5-33.

38. Santesteban-Echarri O, Sandel D, Liu L, Bearden CE, Cadenhead KS, Cannon TD, et al. Family history of psychosis in youth at clinical high risk: A replication study. Psychiatry Research. 2022;311:114480.

39. Collip D, Myin-Germeys I, Van Os J. Does the concept of “sensitization” provide a plausible mechanism for the putative link between the environment and schizophrenia? Schizophrenia bulletin. 2008;34(2):220-5.

40. Fusar-Poli P, McGorry PD, Kane JM. Improving outcomes of first-episode psychosis: an overview. World psychiatry. 2017;16(3):251-65.

41. Beiser M, Erickson D, Fleming JA, Iacono WG. Establishing the onset of psychotic illness. American Journal of Psychiatry. 1993;150(9):I349-1354.

42. Olsen KA, Rosenbaum B. Prospective investigations of the prodromal state of schizophrenia: review of studies. Acta Psychiatrica Scandinavica. 2006;113(4):247-72.

43. Yung AR, McGorry PD. The prodromal phase of first-episode psychosis: past and current conceptualizations. Schizophrenia bulletin. 1996;22(2):353-70.

44. Shah JL, Crawford A, Mustafa SS, Iyer SN, Joober R, Malla AK. Is the clinical high-risk state a valid concept? Retrospective examination in a first-episode psychosis sample. Psychiatric Services. 2017;68(10):1046-52.

45. Addington J, Heinssen R. Prediction and prevention of psychosis in youth at clinical high risk. Annual review of clinical psychology. 2012;8:269-89.

46. Cannon TD, Cadenhead K, Cornblatt B, Woods SW, Addington J, Walker E, et al. Prediction of psychosis in youth at high clinical risk: a multisite longitudinal study in North America. Archives of general psychiatry. 2008;65(1):28-37.

47. Norman RMG, Malla AK. Duration of untreated psychosis: a critical examination of the concept and its importance. Psychological medicine. 2001;31(3):381-400.

48. Perkins DO, Gu H, Boteva K, Lieberman JA. Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: a critical review and meta-analysis. American journal of psychiatry. 2005;162(10):1785-804.

49. Díaz-Caneja CM, Pina-Camacho L, Rodríguez-Quiroga A, Fraguas D, Parellada M, Arango C. Predictors of outcome in early-onset psychosis: a systematic review. npj Schizophrenia. 2015;1(1):1-10.

50. Santesteban-Echarri O, Paino M, Rice S, González-Blanch C, McGorry P, Gleeson J, et al. Predictors of functional recovery in first-episode psychosis: a systematic review and meta-analysis of longitudinal studies. Clinical Psychology Review. 2017;58:59-75.

51. Chang WC, Hui CLM, Tang JYM, Wong GHY, Chan SKW, Lee EHM, et al. Impacts of duration of untreated psychosis on cognition and negative symptoms in first-episode schizophrenia: a 3-year prospective follow-up study. Psychological Medicine. 2013;43(9):1883-93.

52. Ito S, Nemoto T, Tsujino N, Ohmuro N, Matsumoto K, Matsuoka H, et al. Differential impacts of duration of untreated psychosis (DUP) on cognitive function in first-episode schizophrenia according to mode of onset. European Psychiatry. 2015;30(8):995-1001.

53. Wang MY, Ho NF, Sum MY, Collinson SL, Sim K. Impact of duration of untreated psychosis and premorbid intelligence on cognitive functioning in patients with first-episode schizophrenia. Schizophrenia Research. 2016;175(1-3):97-102.

54. Sarpal DK, Robinson DG, Fales C, Lencz T, Argyelan M, Karlsgodt KH, et al. Relationship between duration of untreated psychosis and intrinsic corticostriatal connectivity in patients with early phase schizophrenia. Neuropsychopharmacology. 2017;42(11):2214-21.

55. Guo X, Li J, Wei Q, Fan X, Kennedy DN, Shen Y, et al. Duration of untreated psychosis is associated with temporal and occipitotemporal grey matter volume decrease in treatment naive schizophrenia. PLoS One. 2013;8(12):e83679.

56. Malla AK, Bodnar M, Joober R, Lepage M. Duration of untreated psychosis is associated with orbital–frontal grey matter volume reductions in first episode psychosis. Schizophrenia Research. 2011;125(1):13-20.

57. Anderson KK, Rodrigues M, Mann K, Voineskos A, Mulsant BH, George TP, et al. Minimal evidence that untreated psychosis damages brain structures: a systematic review. Schizophrenia Research. 2015;162(1-3):222-33.
58. Howes OD, Whitehurst T, Shatalina E, Townsend L, Onwordi EC, Mak TLA, et al. The clinical significance of duration of untreated psychosis: an umbrella review and random-effects meta-analysis. World Psychiatry. 2021;20(1):75-95.
59. Norman RM, Malla AK, Manchanda R. Is untreated psychosis socially toxic? Early Intervention in Psychiatry. 2007;1(3):267-70.
60. Iyer SN, Anderson KK, Malla A, Shah J, Norman R. The case for cautious interpretation and replication: lead-time bias as a potential explanation for the link between duration of untreated psychosis and outcome. American Journal of Psychiatry. 2020;177(12):1180-1.
61. Birchwood M, McGorry P, Jackson H. Early intervention in schizophrenia. The British Journal of Psychiatry. 1997;170(1):2-5.
62. Harrison G, Hopper K, Craig T, Laska E, Siegel C, Wanderling J, et al. Recovery from psychotic illness: a 15-and 25-year international follow-up study. The British journal of psychiatry. 2001;178(6):506-17.
63. Iyer S, Jordan G, MacDonald K, Joober R, Malla A. Early intervention for psychosis: a Canadian perspective. J Nerv Ment Dis. 2015;203(5):356-64.
64. Birchwood M, Macmillan F. Early intervention in schizophrenia. Australian & New Zealand Journal of Psychiatry. 1993;27(3):374-8.
65. Malla A, Malla A, Norman R, McLean T, Scholten D, Townsend L. A Canadian programme for early intervention in non-affective psychotic disorders. Australian & New Zealand Journal of Psychiatry. 2003;37(4):407-13.
66. McGorry PD. Schizophrenia: risk and possibility of prevention. Handbook of studies on preventive psychiatry. 1995:491-514.
67. Bertelsen M, Jeppesen P, Petersen L, Thorup A, Øhlenschlæger J, le Quach P, et al. Five-year follow-up of a randomized multicenter trial of intensive early intervention vs standard treatment for patients with a first episode of psychotic illness: the OPUS trial. Archives of general psychiatry. 2008;65(7):762-71.
68. Craig TKJ, Garety P, Power P, Rahaman N, Colbert S, Fornells-Ambrojo M, et al. The Lambeth Early Onset (LEO) Team: randomized controlled trial of the effectiveness of specialized care for early psychosis. Bmj. 2004;329(7474):1067.
69. Garety PA, Craig TKJ, Dunn G, Fornells-Ambrojo M, Colbert S, Rahaman N, et al. Specialised care for early psychosis: symptoms, social functioning and patient satisfaction: randomized controlled trial. The British Journal of Psychiatry. 2006;188(1):37-45.
70. Harvey P-O, Lepage M, Malla A. Benefits of enriched intervention compared with standard care for patients with recent-onset psychosis: a metaanalytic approach. The Canadian Journal of Psychiatry. 2007;52(7):464-72.
71. Correll CU, Galling B, Pawar A, Krivko A, Bonetto C, Ruggeri M, et al. Comparison of early intervention services vs treatment as usual for early-phase psychosis: a systematic review, meta-analysis, and meta-regression. JAMA psychiatry. 2018;75(6):555-65.
72. International Early Psychosis Association Writing Group. International clinical practice guidelines for early psychosis. The British Journal of Psychiatry. 2005;187(S48):s120-s4.
73. Early Psychosis Guidelines Writing Group, Asian Network of Early Psychosis Writing program, EPPIC National Support. Australian Clinical Guidelines for Early Psychosis, 2nd edition update. Melbourne: Orygen, The National Centre of Excellence in Youth Mental Health; 2016.
74. Addington D, Anderson E, Kelly M, Lesage A, Summerville C. Canadian practice guidelines for comprehensive community treatment for schizophrenia and schizophrenia spectrum disorders. The Canadian Journal of Psychiatry. 2017;62(9): 662-72.
75. Early Psychosis Intervention Ontario Netwok. 2024.

76. Association québécoise des programmes pour premiers épisodes psychotiques. Programmes pour premiers épisodes psychotiques. 2024.
77. Alberta Health Services. Early Psychosis Intervention Program. 2024.
78. University of Alberta. Edmonton Early Psychosis Intervention Program 2024 [Available from: https://www.ualberta.ca/psychiatry/divisions/division-of-community-psychiatry/edmonton-early-psychosis-intervention-program.html#:~:text=EEPIC%20provides%20a%20comprehensive%2C%20initial,counsellors%2C%20social%20workers%20and%20psychiatrists.
79. Early Psychosis Intervention Program. BC Early Psychosis Intervention Programs 2024 [Available from: https://www.earlypsychosis.ca/bc-epi-programs/.
80. Nova Scotia Health Authority. Nova Scotia Early Psychosis Program (NSEPP) 2024 [Available from: https://mha.nshealth.ca/en/services/nova-scotia-early-psychosis-program-nsepp.
81. Horizon Health Network (Horizon). Early Psychosis Program 2024 [Available from: https://horizonnb.ca/services/addictions-mental-health/child-and-youth-services/early-psychosis-program/.
82. Bertulies-Esposito B, Nolin M, Iyer SN, Malla A, Tibbo P, Otter N, et al. Ou en sommes-nous? An Overview of Successes and Challenges after 30 Years of Early Intervention Services for Psychosis in Quebec: Ou en sommes-nous? Un apercu des reussites et des problemes apres 30 ans de services d’intervention precoce pour la psychose au Quebec. The Canadian Journal of Psychiatry. 2020;65(8):536-47.
83. De Maio M, Graham P, Vaughan D, Haber L, Madonick S. Review of international early psychosis programmes and a model to overcome unique challenges to the treatment of early psychosis in the United States: Model to overcome unique challenges. Early Intervention in Psychiatry. 2015;9(1):1-11.
84. Canadian Mental Health Association. About us 2024 [Available from: https://cmha.ca/who-we-are/the-cmha-federation/.
85. Joseph R, Birchwood M. The national policy reforms for mental health services and the story of early intervention services in the United Kingdom. Journal of Psychiatry and Neuroscience. 2005;30(5):362-5.
86. Foster K, Maybery D, Reupert A, Gladstone B, Grant A, Ruud T, et al. Family-focused practice in mental healthcare: An integrative review. Child & Youth Services. 2016;37(2):129-55.
87. Kohn-Wood LP, Wilson MN. The context of caretaking in rural areas: family factors influencing the level of functioning of seriously mentally ill patients living at home. American journal of community psychology. 2005;36(1-2):1-13.
88. Wynaden D, Ladzinski U, Lapsley J, Landsborough I, Butt J, Hewitt V. The caregiving experience: How much do health professionals understand? Collegian. 2006;13(3):6-10.
89. Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres–a nested qualitative study. BMC Health Services Research. 2022;22(1):1-16.
90. Pusey-Murray A, Miller P. ‘I need help’: caregivers’ experiences of caring for their relatives with mental illness in Jamaica. Mental Health in Family Medicine. 2013.
91. Nascimento LAd, Leão A. Estigma social e estigma internalizado: a voz das pessoas com transtorno mental e os enfrentamentos necessários. História, Ciências, Saúde-Manguinhos. 2019;26:103-21.
92. Hartley D, Agger M, Miller M. Effects of managed mental healthcare on service use in rural areas: Maine Rural Health Research Center, Edmund S. Muskie School of Public …; 1998 1998.
93. Ricketts TC. Rural health in the United States: Oxford University Press; 1999 1999.
94. McCabe S, Macnee CL. Weaving a new safety net of mental healthcare in rural America: A model of integrated practice. Issues in mental health nursing. 2002;23(3):263-78.

95. Roberts LW, Battaglia J, Epstein RS. Frontier ethics: Mental healthcare needs and ethical dilemmas in rural communities. Psychiatric services. 1999;50(4):497-503.
96. Liu N, Zhang J. Experiences of caregivers of family member with schizophrenia in China: A qualitative study. Perspectives in Psychiatric Care. 2020;56(1):201-12.
97. Ennis E, Bunting BP. Family burden, family health and personal mental health. BMC Public Health. 2013;13:1-9.
98. Schene AH. Objective and subjective dimensions of family burden: towards an integrative framework for research. Social Psychiatry and Psychiatric Epidemiology. 1990;25:289-97.
99. Tsang HW, Tam PK, Chan F, Chang W. Sources of burdens on families of individuals with mental illness. International journal of rehabilitation research. 2003;26(2):123-30.
100. Talley RC, Crews JE. Framing the public health of caregiving. American Journal of Public Health. 2007;97(2):224-8.
101. Flinn B. Millennials: The emerging generation of family caregivers US: American Association of Retired Persons 2018 [240].
102. Möller-Leimkühler AM, Wiesheu A. Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics. European archives of psychiatry and clinical neuroscience. 2012;262:157-66.
103. Shiraishi N, Reilly J. Positive and negative impacts of schizophrenia on family caregivers: a systematic review and qualitative meta-summary. Social psychiatry and psychiatric epidemiology. 2019;54:277-90.
104. Weimand BM, Hall-Lord ML, Sällström C, Hedelin B. Life-sharing experiences of relatives of persons with severe mental illness–a phenomenographic study. Scandinavian journal of caring sciences. 2013;27(1):99-107.
105. Graneheim UH, Åström S. Until death do us part: adult relatives' experiences of everyday life close to persons with mental ill-health. Issues in mental health nursing. 2016;37(8):602-8.
106. Olwit C, Musisi S, Leshabari S, Sanyu I. Chronic sorrow: lived experiences of caregivers of patients diagnosed with schizophrenia in Butabika mental hospital, Kampala, Uganda. Archives of psychiatric nursing. 2015;29(1):43-8.
107. Ali L, Ahlström BH, Krevers B, Skärsäter I. Daily life for young adults who care for a person with mental illness: A qualitative study. Journal of psychiatric and mental health nursing. 2012;19(7):610-7.
108. Huang C, Lam L, Plummer V, Cross WM. Feeling responsible: Family caregivers' attitudes and experiences of shared decision-making regarding people diagnosed with schizophrenia: A qualitative study. Patient Education and Counseling. 2021;104(7):1553-9.
109. Weller BE, Faulkner M, Doyle O, Daniel SS, Goldston DB. Impact of patients' psychiatric hospitalization on caregivers: a systematic review. Psychiatric services. 2015;66(5):527-35.
110. Du Plessis JM, Poggenpoel M, Myburgh C, Temane A. Family members' lived experiences of non-compliance to psychiatric medication given to female adults living with depression. CURATIONIS Journal of the Democratic Nursing Organisation of South Africa. 2021;44(1):2105.
111. Wymbs BT, Pelham WE, Jr., Gnagy EM, Molina BS. Mother and Adolescent Reports of Interparental Discord among Parents of Adolescents with and without Attention-Deficit Hyperactivity Disorder. J Emot Behav Disord. 2008;16(1):29-41.
112. Weimand BM, Sällström C, Hall-Lord M-L, Hedelin B. Nurses' dilemmas concerning support of relatives in mental healthcare. Nursing Ethics. 2013;20(3):285-99.
113. Neuberg SL, Smith DM, Hoffman JC, Russell FJ. When we observe stigmatized and" normal" individuals interacting: Stigma by association. Personality and social psychology bulletin. 1994;20(2):196-209.
114. Larson JE, Corrigan P. The stigma of families with mental illness. Academic psychiatry. 2008;32:87-91.

115. van der Sanden RLM, Bos AER, Stutterheim SE, Pryor JB, Kok G. Experiences of stigma by association among family members of people with mental illness. Rehabilitation Psychology. 2013;58(1):73.
116. Statistics Canada. General Social Survey - Caregiving and Care Receiving (GSS). 2018.
117. Fast J, Duncan KA, Keating NC, Kim C. Valuing the Contributions of Family Caregivers to the Care Economy. Journal of Family and Economic Issues. 2023:1-14.
118. Employer Panel for Caregivers. When work and caregiving collide: How employers can support their employees who are caregivers. Ottawa ON; 2015.
119. Sinha M. Portrait of caregivers, 2012. 2013.
120. Canadian Institute for Health Information. Health Indicators 2010. Statistics Canada 2010.
121. MacCourt P, Committee FCA, Canada MHCo. National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses. Calgary, AB: Mental Health Commission of Canada; 2013.
122. Angermeyer MC, Schulze B, Dietrich S. Courtesy stigma. Social Psychiatry and Psychiatric Epidemiology. 2003;38(10):593-602.
123. Gerson R, Davidson L, Booty A, McGlashan T, Malespina D, Pincus HA, et al. Families' Experience With Seeking Treatment for Recent-Onset Psychosis. Psychiatric Services. 2009;60(6):812-6.
124. Addington J, Collins A, McCleery A, Addington D. The role of family work in early psychosis. Schizophrenia Research. 2005;79(1):77-83.
125. Lobban F, Glentworth D, Haddock G, Wainwright L, Clancy A, Bentley R. The views of relatives of young people with psychosis on how to design a Relatives Education And Coping Toolkit (REACT). Journal of Mental Health. 2011;20(6):567-79.
126. Ward L, Gwinner K. “It Broke Our Hearts”: Understanding Parents’ Lived Experiences of Their Child’s Admission to an Acute Mental Health Care Facility. Journal of Psychosocial Nursing and Mental Health Services. 2014;52(7):24-9.
127. Wainwright LD, Glentworth D, Haddock G, Bentley R, Lobban F. What do relatives experience when supporting someone in early psychosis? Psychology and Psychotherapy: Theory, Research and Practice. 2015;88(1):105-19.
128. Lavis A, Lester H, Everard L, Freemantle N, Amos T, Fowler D, et al. Layers of listening: Qualitative analysis of the impact of early intervention services for first-episode psychosis on carers' experiences. The British Journal of Psychiatry. 2015;207(2):135-42.
129. Petrakis M, Oxley J, Bloom H. Carer psychoeducation in first-episode psychosis: Evaluation outcomes from a structured group programme. International Journal of Social Psychiatry. 2013;59(4):391-7.
130. Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, Young N, Woodhams P, Shiers D, et al. Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. The British Journal of Psychiatry. 2015;206(4):268-74.
131. Falloon IR, Held T, Coverdale JH, Roncone R, Laidlaw TM. Family interventions for schizophrenia: A review of long-term benefits of international studies. Psychiatric Rehabilitation Skills. 1999;3(2):268-90.
132. Miklowitz DJ, Simoneau TL, George EL, Richards JA, Kalbag A, Sachs-Ericsson N, et al. Family-focused treatment of bipolar disorder: 1-year effects of a psychoeducational program in conjunction with pharmacotherapy. Biological psychiatry. 2000;48(6):582-92.
133. Pilling S, Bebbington P, Kuipers E, Garety P, Geddes J, Orbach G, et al. Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. Psychol Med. 2002;32(5):763-82.
134. Randolph ET, Eth S, Glynn SM, Paz GG, Leong GB, Shaner AL, et al. Behavioural family management in schizophrenia: outcome of a clinic-based intervention. The British Journal of Psychiatry. 1994;164(4):501-6.

135. Shimazu K, Shimodera S, Mino Y, Nishida A, Kamimura N, Sawada K, et al. Family psychoeducation for major depression: randomized controlled trial. The British Journal of Psychiatry. 2011;198(5):385-90.
136. Honig A, Hofman A, Rozendaal N, Dingemans P. Psycho-education in bipolar disorder: effect on expressed emotion. Psychiatry Research. 1997;72(1):17-22.
137. Pharoah F, Mari JJ, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane database of systematic reviews. 2010(12).
138. Xiong W, Phillips MR, Hu X, Wang R, Dai Q, Kleinman J, et al. Family-based intervention for schizophrenic patients in China: a randomized controlled trial. The British Journal of Psychiatry. 1994;165(2):239-47.
139. Fleury M-J, Grenier G, Caron J, Lesage A. Patients' report of help provided by relatives and services to meet their needs. Community Mental Health Journal. 2008;44:271-81.
140. Claxton M, Onwumere J, Fornells-Ambrojo M. Do family interventions improve outcomes in early psychosis? A systematic review and meta-analysis. Frontiers in Psychology. 2017;8:371.
141. Boydell KM, Stasiulis E, Volpe T, Gladstone B. A descriptive review of qualitative studies in first episode psychosis. Early Interv Psychiatry. 2010;4(1):7-24.
142. Windell DL, Norman R, Lal S, Malla A. Subjective experiences of illness recovery in individuals treated for first-episode psychosis. Social Psychiatry and Psychiatric Epidemiology. 2015;50:1069-77.
143. Ran M-S, Xiao Y, Fazel S, Lee Y, Luo W, Hu S-H, et al. Mortality and suicide in schizophrenia: 21-year follow-up in rural China. BJPsych Open. 2020;6(6):e121.
144. Reininghaus U, Dutta R, Dazzan P, Doody GA, Fearon P, Lappin J, et al. Mortality in schizophrenia and other psychoses: a 10-year follow-up of the SOP first-episode cohort. Schizophr Bull. 2015;41(3):664-73.
145. Herz MI, Lamberti JS, Mintz J, Scott R, O'Dell SP, McCartan L, et al. A program for relapse prevention in schizophrenia: a controlled study. Archives of general psychiatry. 2000;57(3):277-83.
146. Norman RM, Malla AK, Manchanda R, Harricharan R, Takhar J, Northcott S. Social support and three-year symptom and admission outcomes for first episode psychosis. Schizophr Res. 2005;80(2-3):227-34.
147. Tempier R, Balbuena L, Garety P, Craig TJ. Does assertive community outreach improve social support? Results from the Lambeth Study of early-episode psychosis. Psychiatr Serv. 2012;63(3):216-22.
148. Barrowclough C, Tarrier N, Lewis S, Sellwood W, Mainwaring J, Quinn J, et al. Randomised controlled effectiveness trial of a needs-based psychosocial intervention service for carers of people with schizophrenia. Br J Psychiatry. 1999;174:505-11.
149. McFarlane WR, Link B, Dushay R, Marchal J, Crilly J. Psychoeducational multiple family groups: Four-year relapse outcome in schizophrenia. Family process. 1995;34(2):127-44.
150. Bergner E, Leiner AS, Carter T, Franz L, Thompson NJ, Compton MT. The period of untreated psychosis before treatment initiation:: A qualitative study of family members' perspectives. Comprehensive psychiatry. 2008;49(6):530-6.
151. Fridgen GJ, Aston J, Gschwandtner U, Pflueger M, Zimmermann R, Studerus E, et al. Help-seeking and pathways to care in the early stages of psychosis. Social psychiatry and psychiatric epidemiology. 2013;48:1033-43.
152. Saha G. Advocacy in mental health. Indian J Psychiatry. 2021;63(6):523.
153. Spaniol L, Nelson A. Family recovery. Community mental health journal. 2015;51:761-7.
154. Muhlbauer SA. Navigating the storm of mental illness: phases in the family's journey. Qualitative Health Research. 2002;12(8):1076-92.
155. World Health Organization. The world health report 2001: Mental health: new understanding, New Hope.; 2001.
156. Aass LK, Moen ØL, Skundberg-Kletthagen H, Lundqvist LO, Schröder A. Family support and quality of community mental healthcare: Perspectives from families living with mental illness. Journal of Clinical Nursing. 2022;31(7-8):935-48.

157. Glick ID, Stekoll AH, Hays S. The role of the family and improvement in treatment maintenance, adherence, and outcome for schizophrenia. J Clin Psychopharmacol. 2011;31(1):82-5.

158. Bighelli I, Rodolico A, García-Mieres H, Pitschel-Walz G, Hansen W-P, Schneider-Thoma J, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2021;8(11):969-80.

159. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010(12):CD000088.

160. Pitschel-Walz G, Leucht S, Bäuml J, Kissling W, Engel RR. The effect of family interventions on relapse and rehospitalization in schizophrenia—a meta-analysis. Schizophrenia bulletin. 2001;27(1):73-92.

161. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2022.

162. Iyer SN, Malla A, Taksal A, Maraj A, Mohan G, Ramachandran P, et al. Context and contact: a comparison of patient and family engagement with early intervention services for psychosis in India and Canada. Psychological Medicine. 2022;52(8):1538-47.

163. Durbin J, Selick A, Hierlihy D, Moss S, Cheng C. A first step in system improvement: a survey of Early Psychosis Intervention Programmes in Ontario. Early Interv Psychiatry. 2016;10(6):485-93.

164. Onwumere J, Shiers D, Chew-Graham C. Understanding the needs of carers of people with psychosis in primary care. British Journal of General Practice; 2016. p. 400-1.

165. Landeweer E, Molewijk B, Hem MH, Pedersen R. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. BMC Health Services Research. 2017;17(1):1-10.

166. Mottaghipour Y, Bickerton A. The pyramid of family care: A framework for family involvement with adult mental health services. Australian e-journal for the Advancement of Mental Health. 2005;4(3):210-7.

167. Mental Health Commission of Canada. Promising practices guide: Engaging caregivers in mental health and addiction services in Canada Ottawa, Canada2019 [Available from: https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/2020-04/Promising_Practices_Guide_eng.pdf.

168. Grácio J, Gonçalves-Pereira M, Leff J. What do we know about family interventions for psychosis at the process level? A systematic review. Family process. 2016;55(1):79-90.

169. Worthington A, Rooney P, Hannan R. The triangle of care — Carers included: A guide to best practice in mental healthcare in England. 2nd ed2013.

170. Hannan R. The Triangle of Care: carers included. Journal of Public Mental Health. 2013;12(3):171-2.

171. McFarlane WR, Dixon L, Lukens E, Lucksted A. Family psychoeducation and schizophrenia: A review of the literature. Journal of marital and family therapy. 2003;29(2):223-45.

172. Alvarez-Jimenez M, Alcazar-Corcoles MA, Gonzalez-Blanch C, Bendall S, McGorry PD, Gleeson JF. Online, social media and mobile technologies for psychosis treatment: a systematic review on novel user-led interventions. Schizophrenia Research. 2014;156(1):96-106.

173. Sin J, Jordan CD, Barley EA, Henderson C, Norman I. Psychoeducation for siblings of people with severe mental illness. Cochrane Database of Systematic Reviews. 2015(5).

174. Sin J, Norman I. Psychoeducational interventions for family members of people with schizophrenia: a mixed-method systematic review. The Journal of clinical psychiatry. 2013;74(12):16055.

175. Xia J, Merinder LB, Belgamwar MR. Psychoeducation for schizophrenia. Cochrane database of systematic reviews. 2011(6).

176. Verma S, Poon LY, Subramaniam M, Abdin E, Chong SA. The Singapore early psychosis intervention programme (EPIP): A programme evaluation. Asian Journal of Psychiatry. 2012;5(1):63-7.

177. NICE. Psychosis and schizophrenia in adults: Prevention and management, Clinical guideline. Retrieved from United Kingdom2014.

178. Druss BG, Zhao L, von Esenwein SA, Bona JR, Fricks L, Jenkins-Tucker S, et al. The Health and Recovery Peer (HARP) Program: a peer-led intervention to improve medical self-management for persons with serious mental illness. Schizophrenia Research. 2010;118(1-3):264-70.

179. D'Souza R, Piskulic D, Sundram S. A brief dyadic group based psychoeducation program improves relapse rates in recently remitted bipolar disorder: a pilot randomized controlled trial. Journal of Affective Disorders. 2010;120(1-3):272-6.

180. Pickett SA, Diehl S, Steigman PJ, Prater JD, Fox A, Cook JA. Early outcomes and lessons learned from a study of the Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES) program in Tennessee. Psychiatric Rehabilitation Journal. 2010;34(2):96.

181. Jewell TC, Downing D, McFarlane WR. Partnering with families: Multiple family group psychoeducation for schizophrenia. Journal of clinical psychology. 2009;65(8):868-78.

182. Miklowitz DJ, Chung B. Family-Focused Therapy for Bipolar Disorder: Reflections on 30 Years of Research. Family Process. 2016;55(3):483-99.

183. Rummel-Kluge C, Kissling W. Psychoeducation for patients with schizophrenia and their families. Expert review of neurotherapeutics. 2008;8(7):1067-77.

184. Brady P, Kangas M, McGill K. “Family matters”: a systematic review of the evidence for family psychoeducation for major depressive disorder. Journal of marital and family therapy. 2017;43(2):245-63.

185. Poole R, Smith D, Simpson S. Patients’ perspectives of the feasibility, acceptability and impact of a group-based psychoeducation programme for bipolar disorder: a qualitative analysis. BMC psychiatry. 2015;15(1):1-16.

186. Petrakis M, Bloom H, Oxley J. Family Perceptions of Benefits and Barriers to First Episode Psychosis Carer Group Participation. Social Work in Mental Health. 2014;12(2):99-116.

187. Hackethal V, Spiegel S, Lewis-Fernández R, Kealey E, Salerno A, Finnerty M. Towards a cultural adaptation of family psychoeducation: Findings from three Latino focus groups. Community Mental Health Journal. 2013;49:587-98.

188. Ingvarsdotter K, Persson K, Hjärthag F, Östman M. How professionals view multifamily psychoeducation: A qualitative study. Psychiatric quarterly. 2016;87:479-91.

189. Coulthard K, Patel D, Brizzolara C, Morriss R, Watson S. A feasibility study of expert patient and community mental health team led bipolar psychoeducation groups: implementing an evidence based practice. BMC psychiatry. 2013;13(1):1-12.

190. Higgins A, Downes C, Murphy R, Barry J, Monahan M, Doyle L, et al. Factors influencing attendees’ engagement with group psychoeducation: a multi-stakeholder perspective. Administration and Policy in Mental Health and Mental Health Services Research. 2022;49(4):539-51.

191. Oluwoye O, Stiles B, Monroe-DeVita M, Chwastiak L, McClellan JM, Dyck D, et al. Racial-ethnic disparities in first-episode psychosis treatment outcomes from the RAISE-ETP study. Psychiatric Services. 2018;69(11):1138-45.

192. Leclerc C, Lecomte T. TCC pour premiers épisodes de psychose: pourquoi la thérapie de groupe obtient les meilleurs résultats? Journal de thérapie comportementale et cognitive. 2012;22(3):104-10.

193. Cormier H, Guimond G, Joncas G, Leblanc G, Morin R, Vaillancourt S. Profamille, programme d’intervention de groupe auprès des familles de personnes atteintes de schizophrénie. 1991.

194. Martin H, Xavier S, Taksal A, Levasseur M, Iyer SN. Family involvement in mental healthcare. In: Leclerc TLaC, editor. Manuel de réadaptation psychiatrique. 3rd ed. Quebec, Canada: Presses de l’Université du Québe; 2023.

195. Iyer SN, Loohuis H, Pawliuk N, Joober R, Malla AK. Concerns reported by family members of individuals with first-episode psychosis. Early Intervention in Psychiatry. 2011;5(2):163-7.

196. Falloon IRH, Boyd JL, McGill CW. Family care of schizophrenia: A problem-solving approach to the treatment of mental illness. New York: Guilford Press; 1984.

197. McFarlane WR. Multifamily groups in the treatment of severe psychiatric disorders: Guilford Press; 2004.
198. Stuart BK, Schlosser DA. Multifamily group treatment for schizophrenia. Int J Group Psychother. 2009;59(3):435-40.
199. Varghese M, Kirpekar V, Loganathan S. Family Interventions: Basic Principles and Techniques. Indian J Psychiatry. 2020;62(Suppl 2):S192-S200.
200. Von Bertalanffy L. The history and status of general systems theory. Academy of management journal. 1972;15(4):407-26.
201. Shi J, Wang L, Yao Y, Zhan C, Su N, Zhao X. Systemic therapy for youth at clinical high risk for psychosis: a pilot study. Frontiers in psychiatry. 2017;8:211.
202. Burbach FR. Family therapy and schizophrenia: a brief theoretical overview and a framework for clinical practice. BJPsych Advances. 2018;24(4):225-34.
203. Levasseur MA, Ferrari M, McIlwaine S, Iyer SN. Peer-driven family support services in the context of first-episode psychosis: Participant perceptions from a Canadian early intervention programme. Early Intervention in Psychiatry. 2019;13(2):335-41.
204. Solomon M, Pistrang N, Barker C. The benefits of mutual support groups for parents of children with disabilities. American journal of community psychology. 2001;29:113-32.
205. Crossley N. Making sense of social movements: McGraw-Hill Education (UK); 2002.
206. Crossley* N. Not being mentally ill: Social movements, system survivors and the oppositional habitus. Anthropology & Medicine. 2004;11(2):161-80.
207. Mead S, MacNeil C. Peer support: A systemic approach. Family Therapy Magazine. 2005;4(5):28-31.
208. Mead S, Hilton D, Curtis L. Peer support: a theoretical perspective. Psychiatric rehabilitation journal. 2001;25(2):134.
209. Cohen MB, Mullender A. The personal in the political: Exploring the group work continuum from individual to social change goals. Social work with groups. 2005;28(3-4):187-204.
210. Cheah J. Chronic disease management: a Singapore perspective. Bmj. 2001;323(7319):990-3.
211. Ahmed AO, Doane NJ, Mabe PA, Buckley PF, Birgenheir D, Goodrum NM. Peers and peer-led interventions for people with schizophrenia. Psychiatric Clinics of North America. 2012;35(3):699-715.
212. Dennis C-L. Peer support within a healthcare context: a concept analysis. International journal of nursing studies. 2003;40(3):321-32.
213. Bellamy C, Schmutte T, Davidson L. An update on the growing evidence base for peer support. Mental Health and Social Inclusion. 2017;21(3):161-7.
214. Walker G, Bryant W. Peer support in adult mental health services: a metasynthesis of qualitative findings. Psychiatric Rehabilitation Journal. 2013;36(1):28.
215. Bucci S, Berry K, Barrowclough C, Haddock G. Family interventions in psychosis: a review of the evidence and barriers to implementation. Australian Psychologist. 2016;51(1):62-8.
216. Dixon L, McFarlane WR, Lefley H, Lucksted A, Cohen M, Falloon I, et al. Evidence-based practices for services to families of people with psychiatric disabilities. Psychiatr Serv. 2001;52(7):903-10.
217. Hestmark L, Heiervang KS, Pedersen R, Hansson KM, Ruud T, Romøren M. Family involvement practices for persons with psychotic disorders in community mental health centres–a cross-sectional fidelity-based study. BMC psychiatry. 2021;21(1):1-11.
218. Fjell A, Bloch Thorsen GR, Friis S, Johannessen JO, Larsen TK, Lie K, et al. Innovations: Psychoeducation: Multifamily group treatment in a program for patients with first-episode psychosis: experiences from the TIPS project. Psychiatric Services. 2007;58(2):171-3.
219. Slade M, Leese M, Cahill S, Thornicroft G, Kuipers E. Patient-rated mental health needs and quality of life improvement. The British Journal of Psychiatry. 2005;187(3):256-61.
220. Oluwoye O, Dyck D, Mcpherson SM, Lewis-Fernández R, Compton MT, Mcdonell MG, et al. Developing and implementing a culturally informed FAmily Motivational Engagement Strategy

(FAMES) to increase family engagement in first episode psychosis programs: mixed methods pilot study protocol. BMJ Open. 2020;10(8):e036907.
221. Glynn S, Gingerich S, Meyer-Kalos P, Mueser K, Chan-Golston A, Sugar C, et al. T255. WHO PARTICIPATED IN FAMILY WORK IN THE US RAISE-ETP FIRST EPISODE SAMPLE? Schizophrenia Bulletin. 2018;44(suppl_1):S216-S7.
222. Fiorillo A, Bassi M, de Girolamo G, Catapano F, Romeo F. The impact of a psychoeducational intervention on family members' views about schizophrenia: results from the OASIS Italian multi-centre study. International journal of social psychiatry. 2011;57(6):596-603.
223. Conus P, Lambert M, Cotton S, Bonsack C, McGorry PD, Schimmelmann BG. Rate and predictors of service disengagement in an epidemiological first-episode psychosis cohort. Schizophrenia Research. 2010;118(1-3):256-63.
224. Stowkowy J, Addington D, Liu L, Hollowell B, Addington J. Predictors of disengagement from treatment in an early psychosis program. Schizophrenia Research. 2012;136(1-3):7-12.
225. Polillo A, Voineskos AN, Foussias G, Kidd SA, Bromley S, Soklaridis S, et al. Disengagement from early psychosis intervention services: an observational study informed by a survey of patient and family perspectives. Schizophrenia. 2022;8(1):94.
226. Eassom E, Giacco D, Dirik A, Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open. 2014;4(10):e006108.
227. Keepers GA, Fochtmann LJ, Anzia JM, Benjamin S, Lyness JM, Mojtabai R, et al. The American Psychiatric Association practice guideline for the treatment of patients with schizophrenia. American Journal of Psychiatry. 2020;177(9):868-72.
228. Lucksted A, McFarlane W, Downing D, Dixon L. Recent developments in family psychoeducation as an evidence-based practice. Journal of marital and family therapy. 2012;38(1):101-21.
229. McFarlane WR. Family interventions for schizophrenia and the psychoses: A review. Family Process. 2016;55(3):460-82.
230. Mueser KT, Deavers F, Penn DL, Cassisi JE. Psychosocial treatments for schizophrenia. Annual review of clinical psychology. 2013;9:465-97.
231. Corrigan P. How stigma interferes with mental healthcare. American psychologist. 2004;59(7):614.
232. Phelan JC, Bromet EJ, Link BG. Psychiatric illness and family stigma. Schizophrenia bulletin. 1998;24(1):115-26.
233. Papoulias C, Robotham D, Drake G, Rose D, Wykes T. Staff and service users' views on a 'Consent for Contact'research register within psychosis services: a qualitative study. BMC psychiatry. 2014;14(1):1-8.
234. Riley G, Freeman E, Laidlaw J, Pugh D. 'A frightening experience': detainees' and carers' experiences of being detained under Section 136 of the Mental Health Act. Medicine, Science and the Law. 2011;51(3):164-9.
235. Slade M, Holloway F, Kiuipers E. Skills development and family interventions in an early psychosis service. Journal of Mental Health. 2003;12(4):405-15.
236. Kennedy ESE, Horton S. "Everything that I thought that they would be, they weren't:" Family systems as support and impediment to recovery. Social Science & Medicine. 2011;73(8):1222-9.
237. Rose LE, Mallinson RK, Walton-Moss B. Barriers to family care in psychiatric settings. Journal of Nursing Scholarship. 2004;36(1):39-47.
238. Cree L, Brooks HL, Berzins K, Fraser C, Lovell K, Bee P. Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. BMC psychiatry. 2015;15(1):1-11.
239. Peters S, Pontin E, Lobban F, Morriss R. Involving relatives in relapse prevention for bipolar disorder: a multi-perspective qualitative study of value and barriers. BMC psychiatry. 2011;11(1):1-10.

240. Petrakis M, Hamilton B, Penno S, Selvendra A, Laxton S, Doidge G, et al. Fidelity to clinical guidelines using a care pathway in the treatment of first episode psychosis. J Eval Clin Pract. 2011;17(4):722-8.
241. Caqueo-Urízar A, Rus-Calafell M, Craig TKJ, Irarrazaval M, Urzúa A, Boyer L, et al. Schizophrenia: Impact on Family Dynamics. Current Psychiatry Reports. 2017;19(1).
242. Baker-Ericzén MJ, Jenkins MM, Haine-Schlagel R. Therapist, parent, and youth perspectives of treatment barriers to family-focused community outpatient mental health services. Journal of Child and Family Studies. 2013;22:854-68.
243. Barrera M. Mexican-American mental health service utilization: A critical examination of some proposed variables. Community Mental Health Journal. 1978;14:35-45.
244. McCann TV, Lubman DI, Clark E. First-time primary caregivers' experience accessing first-episode psychosis services: Caregivers accessing FEP services. Early Intervention in Psychiatry. 2011;5(2):156-62.
245. Fadden G. Implementation of family interventions in routine clinical practice following staff training programs: a major cause for concern. Journal of Mental Health. 1997;6(6):599-612.
246. Gall SH, Atkinson J, Elliott L, Johansen R. Supporting carers of people diagnosed with schizophrenia: evaluating change in nursing practice following training. Journal of Advanced Nursing. 2003;41(3):295-305.
247. Kavanagh DJ, Piatkowska O, Clark D, O'Halloran P, Manicavasagar V, Rosen A, et al. Application of cognitive-behavioural family intervention for schizophrenia in multidisciplinary teams: What can the matter be? Australian Psychologist. 1993;28(3):181-8.
248. Kim H-W, Salyers MP. Attitudes and perceived barriers to working with families of persons with severe mental illness: mental health professionals’ perspectives. Community Mental Health Journal. 2008;44:337-45.
249. Outram S, Harris G, Kelly B, Cohen M, Bylund CL, Landa Y, et al. Contextual barriers to discussing a schizophrenia diagnosis with patients and families: need for leadership and teamwork training in psychiatry. Academic Psychiatry. 2015;39:174-80.
250. Cohen AN, Glynn SM, Hamilton AB, Young AS. Implementation of a family intervention for individuals with schizophrenia. Journal of General Internal Medicine. 2010;25:32-7.
251. Park M. Understanding complexity of Asian American family care practices. Archives of psychiatric nursing. 2010;24(3):189-201.
252. Murray-Swank A, Glynn S, Cohen AN, Sherman M, Medoff DP, Fang LJ, et al. Family contact, experience of family relationships, and views about family involvement in treatment among VA consumers with serious mental illness. J Rehabil Res Dev. 2007;44(6):801-11.
253. Hungerford C, Richardson F. Operationalising Recovery-oriented services: The challenges for carers. Advances in Mental Health. 2013;12(1):11-21.
254. Chatzidamianos G, Lobban F, Jones S. A qualitative analysis of relatives’, health professionals’ and service users’ views on the involvement in care of relatives in Bipolar Disorder. BMC psychiatry. 2015;15:1-12.
255. Nilsen L, Frich JC, Friis S, Røssberg JI. Patients’ and Family Members’ Experiences of a Psychoeducational Family Intervention after a First Episode Psychosis: A Qualitative Study. Issues in Mental Health Nursing. 2014;35(1):58-68.
256. Blomqvist M, Ziegert K. ‘Family in the waiting room’: A Swedish study of nurses' conceptions of family participation in acute psychiatric inpatient settings. International Journal of Mental Health Nursing. 2011;20(3):185-94.
257. Ruffolo MC, Capobianco J. Moving an evidence-based intervention into routine mental healthcare: a multifaceted case example. Social Work in Health Care. 2012;51(1):77-87.
258. Bailey R, Burbach F, Lea S. The ability of staff trained in family interventions to implement the approach in routine clinical practice. Journal of Mental Health. 2003;12(2):131-41.

259. Beecher B. Mental health practitioners' views of the families of individuals with schizophrenia and barriers to collaboration: a mixed methods study. Journal of Family Social Work. 2009;12(3):264-82.
260. Turcotte M. Family caregiving: What are the consequences? Canada: Statistics Canada= Statistique Canada, Minister of Industry; 2013.
261. Employment and Social Development Canada. When work and caregiving collide : how employers can support their employees who are caregivers Canada2015 [Available from: publications.gc.ca/pub?id=9.700220&sl=0
262. Canadian Caregiver Coalition. A Canadian Caregiver Strategy 2013 [
263. Mental Health Commission of Canada. The National Standard of Canada for Psychological Health and Safety in the Workplace. 2013.
264. Dillinger RL, Kersun JM. Caring for caregivers: Understanding and meeting their needs in coping with first episode psychosis. Early Intervention in Psychiatry. 2020;14(5):528-34.
265. Mui EYW, Chan SKW, Chan PY, Hui CLM, Chang WC, Lee EHM, et al. Systematic review (meta-aggregation) of qualitative studies on the experiences of family members caring for individuals with early psychosis. Int Rev Psychiatry. 2019;31(5-6):491-509.
266. Creswell JW, Poth CN. Qualitative inquiry and research design: Choosing among five approaches: Sage publications; 2016.
267. Tashakkori A, Teddlie C. Mixed methodology: Combining qualitative and quantitative approaches: sage; 1998.
268. Ma CF CW, Bressington DT. 2018 Aug;12(4):535-60. Family intervention for caregivers of people with recent-onset psychosis: A systematic review and meta-analysis. Early intervention in psychiatry. 2018;12(4):535-60.
269. Lucksted A, Stevenson J, Nossel I, Drapalski A, Piscitelli S, Dixon LB. Family member engagement with early psychosis specialty care. Early Interv Psychiatry. 2018;12(5):922-7.
270. Reininghaus U, Dutta R, Dazzan P, Doody GA, Fearon P, Lappin J, et al. Mortality in schizophrenia and other psychoses: a 10-year follow-up of the ÆSOP first-episode cohort. Schizophrenia bulletin. 2015;41(3):664-73.
271. Falloon IR. Family interventions for mental disorders: efficacy and effectiveness. World Psychiatry. 2003;2(1):20-8.
272. Rodriguez-Meirinhos A, Antolin-Suarez L, Oliva A. Support needs of families of adolescents with mental illness: a systematic mixed studies review. Archives of Psychiatric Nursing. 2018;32(1):152-63.
273. Swartz MS, Swanson JW, Wagner HR, Hannon MJ, Burns BJ, Shumway M. Assessment of four stakeholder groups' preferences concerning outpatient commitment for persons with schizophrenia. American Journal of Psychiatry. 2003;160(6):1139-46.
274. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health affairs. 2013;32(2):223-31.
275. Brouwers MC, Spithoff K, Kerkvliet K, Alonso-Coello P, Burgers J, Cluzeau F, et al. Development and validation of a tool to assess the quality of clinical practice guideline recommendations. JAMA Network Open. 2020;3(5):e205535-e.
276. Oluwoye O, Kriegel L, Alcover KC, Compton MT, Cabassa LJ, Mcdonell MG. The impact of early family contact on quality of life among non-Hispanic Blacks and Whites in the RAISE-ETP trial. Schizophrenia Research. 2020;216:523-5.
277. Jones N, Basaraba C, Piscitelli S, Jewell T, Nossel I, Bello I, et al. Clients' preferences for family involvement and subsequent family contact patterns within OnTrackNY early psychosis services. Psychiatric Services. 2021;72(4):399-407.
278. McCann TV, Lubman DI, Clark E. First-time primary caregivers' experience of caring for young adults with first-episode psychosis. Schizophrenia bulletin. 2011;37(2):381-8.

279. Graham RW. Illustrating triangulation in mixed-methods nursing research. Nurse researcher. 2005;12(4).

280. Tricco AC, Zarin W, Rios P, Nincic V, Khan PA, Ghassemi M, et al. Engaging policymakers, health system managers, and policy analysts in the knowledge synthesis process: a scoping review. Implementation Science. 2018;13(1):1-19.

281. Al Sabahi S, Wilson MG, Lavis JN, El-Jardali F, Moat K. Examining and contextualizing approaches to establish policy support organizations–a mixed method study. International Journal of Health Policy and Management. 2022;11(9):1788.

282. Khanna A, Jones GB. Envisioning post-pandemic digital neurological, psychiatric and mental healthcare. Frontiers in digital health. 2021;3:803315.

Appendices

Manuscript I

Supplementary table Y: New Brunswick specific recommendations mapped with theme(s) and framework (n=3)			
Themes	Specific Recommendations	Framework mapping	
		Level of engagement	Continuum of Engagement
Family education/ psychoeducation	Psychoeducation for the client and family is essential	Direct care	Consultation
Other family supports (e.g., self-care, links to community services)	Early engagement, support and ongoing involvement with family members and key supporters is critical	Direct care	Involvement
Provision of Family intervention/approach specialist in treatment team	Clinician(s) and psychiatrists will have a good understanding of best practice according to research on early psychosis (includes CBT/family intervention).	Not applicable as it is directed to clinicians as opposed to family knowledge base	

Supplementary table Y: Canada 2017a specific recommendations mapped with theme(s) and framework (n=3)			
Themes	Specific Recommendations	Framework mapping	
		Level of engagement	Continuum of engagement
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Consent to treatment	Include family members or other carers as part of the initial assessment whenever possible, with the consent of the competent patient. [De novo recommendation (Good Practice Point)]	Direct care	Consultation
Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.)	Assessment of the First Episode of Psychosis: An assessment for the first episode of psychosis includes recommendation 1 (assessment and care planning) as well as a family history of psychiatric disorders. [De novo recommendation (Good Practice Point)]	Direct care	Involvement
Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.)	Assessment and Care Planning An initial comprehensive multidisciplinary assessment (including an evaluation by a psychiatrist) comprised the following:..... Current occupational or educational functioning, social network size and satisfaction, sexual functioning, housing, and financial status. Where possible, include information from family or partners and health records. [APA practice guidelines for the psychiatric evaluation of adults (level of evidence: C)]	Direct care	Involvement

Supplementary table Y: Nova Scotia specific recommendations mapped with theme(s) and framework (n=4)

Themes	Specific Recommendations	Framework mapping	
		Level of engagement	Continuum of Engagement
Description of service/ program given to families	Individuals and families/support systems will be provided with comprehensive, current information related to psychosis, treatment, recovery, and associated resources.	Direct care	Consultation
Families involved in patient's treatment plan development/ shared decision-making with patient and clinician AND consent to treatment AND Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.)	Families /support systems will be actively involved in the engagement, assessment, treatment and recovery process with consent of the individual and consistent with optimal care.	Direct care	Partnership and shared leadership
Other family supports (e.g., self-care, links to community services)	Collaborative partnerships are developed to facilitate a comprehensive range of local resources to support individuals, families and support systems.	Direct care	Partnership and shared leadership
Families involved in community outreach / referrals	Referrals are accepted from multiple sources including individuals, families, schools, and community agencies as well as healthcare professionals, so as to maximize early detection.	Organizational design and governance	Involvement

Supplementary table Y: Canada 2017b specific recommendations mapped with theme(s) and framework (n=1)

Themes	Specific Recommendations	Framework mapping	
		Level of engagement	Continuum of engagement
Family education/ psychoeducation	Individuals in the first episode of psychosis should receive treatment within the context of an evidence-based coordinated specialty service. This should be multidisciplinary and encompass the following:.......Family involvement and family interventions [SIGN (Grade A)]	Direct care	Consultation

Supplementary table Y: British Columbia specific recommendations mapped with theme(s) and framework (n=40)

Themes	Specific Recommendations	Framework mapping	
		Level of engagement	Continuum of engagement
Description of service/ program given to families AND Families involved in patient's treatment plan development/ shared decision making with patient and clinician	Encourage the client and family to discuss the description of services provided by the EPI program and to be active partners in the assessment and treatment process.	Direct care	Partnership and shared leadership
Description of service/ program given to families	Provide clients and families with sufficient information to make informed decisions about participation.	Direct care	Consultation
Description of service/ program given to families AND Family involvement in program/ service improvement	Inform clients and families of best practices and encourage them to advocate for these if they perceive any aspect of service falls short.	Direct care	Involvement
Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.) AND Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	Perform the intake assessment in the preferred setting of the client and family to facilitate engagement (where practical and safe to do so).	Direct care	Involvement
Families involved in patient's treatment plan development/ shared decision making with patient and clinician	Encourage clients and families to be partners in planning and carrying out interventions.	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician	Develop care plans collaboratively with client and family (when possible) and provide them with a copy of initial and when plans are substantively updated.	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician	Involve the client and family (if possible) in the risk assessment and include their views in the documentation of the risk assessment. If necessary, provide communication to other relevant authorities.	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Develop care plan for the family member AND Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Assess and incorporate into the care plan, client and family needs with respect to social relationships, vocational/educational pursuits, recreation, basic living skills, wellness, financial security, health and medical care, parenting, housing (safe environments) and community and/or legal resources.	Direct care	Partnership and shared leadership
Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.)	Evaluate outcomes (functional and symptomatic) from clinician, client, and family perspectives.	Direct care	Partnership and shared leadership
Family peer support	Facilitate peer interaction and peer support for both clients and family.	Direct care	Involvement
Family-focused psychosocial interventions (e.g., family therapy)	Make specialized psychosis and substance use group interventions available for clients and families.	Direct care	Involvement
Family education/ psychoeducation AND Families involved in relapse prevention	Ensure clients and families are engaged in individualized and ongoing psychoeducation over a period of at least six months. Psychoeducation should also be reviewed following any relapses.	Direct care	Consultation
Family education/ psychoeducation	Make available a suite of tools and protocols to provide comprehensive and individualized psychoeducation to clients and families.	Direct care	Consultation
Recommendation outlines prescribed type/frequency for treatment team to have communication/contact with family	Assign each client and client family a primary contact at the time of admission to the EPI program. A secondary contact is also identified to provide back-up when the primary contact is unavailable (in urban areas this would be another member of the EPI team, while in rural areas this secondary contact may be another community care provider or service).	Direct care	Involvement
Recommendation outlines prescribed type/frequency for treatment team to have communication/contact with family	Ensure that outside the EPI program's hours of operation, clients and families have access to (and are informed of) crisis coverage and after-hours services (e.g., after-hours crisis programs, special arrangements with local services, etc.).	Direct care	Consultation
Recommendation outlines prescribed type/frequency for treatment team to have communication/contact with family	Ensure that contact between the client and family and the primary EPI clinician occurs at the following minimum frequencies during the first year: Family: Acute/relapse - 1/week, Early recovery -1/month, Later recovery -1/month	Direct care	Consultation
Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	Make EPI programs available to clients and families for a period of at least three years	Direct care	Consultation
Other family supports (e.g., self-care, links to community services)	Provide interventions designed to improve self-care for both clients and families.	Direct care	Partnership and shared leadership
Families involved in transition/ discharge planning	Hold joint transition sessions until the client and family are engaged with the new treatment providers.	Direct care	Partnership and shared leadership

Families involved in relapse prevention	Ensure that each client has a relapse prevention plan in place, provide a written copy to the client and family, and include the plan in the clients chart. Relapse prevention plans are reviewed at least every six months for the first two years (and annually for subsequent years).	Direct care	Consultation
Family-focused psychosocial interventions (e.g., family therapy)	Provide evidence-based psychological therapies (e.g., cognitive behavioural therapy, interpersonal therapy, family therapy) to treat accompanying distress such as depression, anxiety and relationship problems.	Direct care	Consultation
Family-focused psychosocial interventions (e.g., family therapy)	Make psychosocial interventions available in both individual and group formats.	Direct care	Consultation
Family-focused psychosocial interventions (e.g., family therapy)	Make other specialized interventions available for families as needed (e.g., financial assistance, respite service).	Direct care	Consultation
Family involvement in program/ service improvement	Partner with youth and families to plan and implement educational activities. (community education).	Organizational design and governance	Involvement
Family involvement in program/ service improvement	Seek input from youth and families regularly on program promotion, education, and services.	Organizational design and governance	Partnership and shared leadership
Family involvement in program/ service improvement AND Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Provide clients and families with appropriate and confidential opportunities to provide feedback on the quality of care and service delivery (e.g., satisfaction surveys, discharge interviews, etc.).	Organizational design and governance	Consultation
Family involvement in program/ service improvement	Encourage client and family participation in EPI program services (e.g., by providing peer support, participating on an advisory committee, participating in community education, etc.)	Organizational design and governance	Involvement
Families involved in community outreach / referrals	Incorporate contact with young people who have early psychosis or their families in community education.	Organizational design and governance	Involvement
Families involved in community outreach / referrals	Accept and process referrals from any source (self, professional, family, friend, etc.).	Organizational design and governance	Involvement
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Assess client and family satisfaction with services during their involvement in the program.	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Undertake a review whenever a critical adverse event occurs (e.g., suicide, seriously aggressive behaviour, or major complaints from staff, client or family members).	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Client and family surveys about whether any aspect of the program is viewed as stigmatizing	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Client and family questionnaire or interviews asking about satisfaction with the intake process	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Tracking the number of clients and families engaged – i.e., the annual proportion of accepted clients who disengaged contrary to the recommendation of the program	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Survey of client and family opinion on the extent to which care is collaborative and fosters self-management	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Client and family sign care plans indicating approval	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Proportion of families receiving psychoeducation for at least ten hours over six months	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Number and types of psychosocial interventions available within a program	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Documented primary and secondary contact for each client and family	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Frequency of clinician contact with families per year	Organizational design and governance	Consultation

Supplementary table Y: Quebec specific recommendations mapped with theme(s) and framework (n=6)

Themes	Specific Recommendations	Framework mapping	
		Level of engagement	Continuum of Engagement
Families involved in patient's treatment plan development/ shared decision making with patient and clinician	Each recovery-oriented intervention plan is updated every six months in collaboration with the young person and his/her family, if the young person agrees.	Direct care	Partnership and shared leadership
Family education/ psychoeducation	The PPEP team offers family interventions to every person with a PEP admitted to PPEP who is in contact with a family member or friend.	Direct care	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	The PPEP team conducts a needs assessment of the loved ones of each person with a PEP admitted to the PPEP and who is in contact with a family member or friend.	Direct care	Consultation
Provision of family specialist in treatment team	The PPEP interdisciplinary team is composed of a variety of human resources acting as focal points. The PPEP team includes at least one psychiatrist and one nurse. Some practitioners have developed a specialization in working with young psychotics (in socio-professional and educational reintegration, **family approaches**, drug addiction, cognitive behavioural approaches).	Not applicable as it is directed to clinicians as opposed to family knowledge base	
Provision of family specialist in treatment team	When a PPEP team consists of five to seven ETC workers, the essential functions that must be fulfilled in the team are as follows: - a team leader; - a nurse; - a specialist in socio-professional and educational reintegration; - a **specialist in family approaches;** - a specialist in substance abuse; - a specialist in cognitive-behavioral approaches.	Not applicable as it is directed to clinicians as opposed to family knowledge base	
Type of service delivery setting (e.g. family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	Offer therapeutic follow-up with an optimal duration: The duration of the follow-up varies from three to five years, and its established according to the clinical judgement of the PPEP team, in partnership with the young person and his/her entourage. (Entourage includes parents, siblings, foster families, spouses, children, friends, or any other person interested in the recovery process of a loved one. It also includes parental authority holder or guardian, mainly with regard to legal aspects (e.g., consent)	Direct care	Partnership and shared leadership

Supplementary table Y: Ontario specific recommendations mapped with theme(s) and framework (Recommendations N=39)

Themes	Specific Recommendations	Framework mapping	
		Level of engagement	**Continuum of Engagement**
Family education/ psychoeducation AND Families involved in community outreach / referrals	To promote early identification and referral of people with first episode psychosis, EPI programs support providers and organizations in their communities by: ..... ·encouraging schools and community mental health agencies to provide education for youth and families.	Direct care	Partnership and shared leadership
Families involved in community outreach / referrals	The EPI program uses various strategies to educate the public and raise awareness of the early signs and symptoms of psychosis, the importance of early identification and referral, and the services available to help, including: .....·encouraging families and their organizations to play an active role in public awareness efforts	Organizational design and governance	Partnership and shared leadership
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Programs have established client and family-friendly policies and procedures for addressing and resolving complaints that are transparent, accessible, confidential, and timely.	Direct care	Consultation
Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	Barrier-Free Services 11.1 Programs must adhere to the requirements of human rights and accessibility legislation when providing services.	Direct Care	Involvement
Other family supports (e.g., self-care, links to community services)	Programs offer and provide services in the client's preferred language either directly or using interpreter services at no cost to the client or family. Family and friends should not be used to provide interpretation services (except by request of the client or where interpreter services are not available).	Direct care	Involvement
Description of service/ program given to families	Programs provide client and family information that is easy to understand, and post signs in the languages commonly used in the service area.	Direct care	Consultation
Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	The physical environment and setting must reflect the needs of the client in that it is youth-oriented, family friendly, and stigma-free.	Direct care	Involvement
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Consent to treatment AND Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	Comprehensive assessments are client centred. In keeping with a client and family centred approach, the program strongly encourages client and family involvement in assessment and treatment. Families are involved in the assessment with the client's consent.	Direct care	Partnership and shared leadership
Description of service/ program given to families AND Recommendation outlines prescribed frequency for treatment team to have communication/contact with family AND Description of families roles and responsibilities given to families	The program follows established procedures for communicating with the client and family, which include providing a clear written description of the services the program provides as well as the client's and family's role and responsibilities.	Direct care	Consultation
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	During the assessment, the practitioner(s) allow enough time to begin to develop a therapeutic alliance with the individual and family, and identify the person's and the family's goals and aspirations.	Direct care	Involvement

Involve families in patient assessment/ outcomes for patients (e.g., intake assessment, family history, etc.)	A comprehensive assessment includes, as a minimum: …….·an assessment of information provided by people important to the client (e.g., family, friends), ·a psychosocial assessment including: social/family functioning, support and resources; living situation; income	Direct care	Consultation
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND consent to treatment	Assessment findings are shared with the client, and with the family with the client's consent.	Direct care	Partnership and shared leadership
Recommendation outlines prescribed type/frequency for treatment team to have communication/contact with family AND consent to treatment	Treatment: Effective treatment depends on open communication with all those supporting the client's recovery, with the client's consent. These can include:…..· the client's family	Direct Care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND consent to treatment	Whenever possible, the client's family is actively involved in the client's treatment (with the client's consent).	Direct care	Partnership and shared leadership
Recommendation outlines prescribed type/frequency for treatment team to have communication/contact with family	The program has established mechanisms and protocols to ensure regular, timely, effective communication with clients, families and all those supporting the client's recovery.	Direct care	Consultation
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Transition/ Discharge planning AND families involved in relapse prevention	The client, family and team negotiate and document a comprehensive, individualized, client-centred wellness/recovery plan that includes specific plans for: ·medical treatment ·education ·psychosocial support for the client that addresses all aspects of daily living ·family support ·crisis prevention ·relapse prevention ·graduation/discharge – including any services or supports the client may required after graduation from EPI	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	The initial wellness/recovery plan is developed within four weeks of the first appointment, and is regularly reviewed and updated to reflect the client's and family's changing needs and goals until the client graduates from the program.	Direct care	Partnership and shared leadership
Families involved in community outreach / referrals	Programs use proactive outreach strategies (e.g., in-home visits, wherever possible, outreach to families, services provided as part of recreation activities in the community) designed to keep clients engaged in treatment, reduce missed appointments, and minimize the number of clients lost during treatment.	Direct Care	Consultation
Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	To minimize disruption and anxiety for the client or family, treatment is provided in community settings.	Direct care	Involvement
Consent to treatment	Informed consent is required for all treatment, including treatment with anti-psychotic medication. Programs have protocols and procedures to ensure that, before beginning treatment with anti-psychotic medications, clients are fully informed about the benefits and risk, and capable of giving informed consent. If clients are not capable of giving informed consent, the team will defer to substitute decisions makers (e.g., parents, guardians) as set out in the Health Care Consent Act.	Direct care	Involvement
Other family supports (e.g., self-care, links to community services)	The team helps the client and family deal with the impact of psychosis and treatment on other functions (e.g., providing nutrition counselling to counter metabolic disruption and weight gain) either directly or through referral to other services.	Direct care	Partnership and shared leadership
Family education/ psychoeducation	Programs provide ongoing education tailored to the client's and family's needs.	Direct care	Consultation

Family education/ psychoeducation AND Other family supports (e.g., self-care, links to community services)	Clients and families are supported to learn as much as possible about: ·the illness and symptoms ·the role of treatment, including medications and side effects ·rights and responsibilities ·the impact of substance use on psychosis (including marijuana and alcohol use) ·how to manage the illness in a way that allows the client to function as well as possible with the fewest symptoms ·stigma associated with mental illness and how to cope with it ·risk assessment ·how to sustain recovery and prevent relapses ·strategies to reintegrate into the community, and return to work and/or school ·services and supports in the community	Direct care	Consultation
Family-focused psychosocial interventions (e.g., family therapy)	Programs actively promote a culture of health and wellbeing, and help clients address a broad range of issues, such as weight gain, smoking and other behaviours that affect health. The focus is on improving the client's and family's quality of life.	Direct Care	Consultation
Families involved in relapse prevention	To reduce the need for hospitalization, the lead practitioner, client and family identify the client's early warning signs for relapse as well as strategies the client and family can use to prevent or reduce the severity of a relapse.	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician AND Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	The team, client and family monitor the client's progress in achieving educational, vocational and other personal goals.	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision making with patient and clinician	Programs keep the family informed about the young person's progress and involve the family as often as possible in psychiatric consultations and key treatment meetings (with the client's consent).	Direct care	Partnership and shared leadership
Families involved in patient's treatment plan development/ shared decision-making with patient and clinician AND consent to treatment AND Type of service delivery setting (e.g., family-friendly physical environment) or modality (e.g., treatment in community settings or for 3 years for continuity of care for families)	Programs use assertive outreach to provide support for the family and actively engage the family in the family member's ongoing care (with the client's consent). (Definition: "Assertive outreach is a way of working with an identified client group of severely mentally ill adults who do not effectively engage with mental health services. The approach is characterized by work with clients in their own environment, wherever that may be. … In assertive outreach, the worker goes to see the client in his or her environment - be that home, a cafe, a park or in the street – wherever it is most needed and most effective. Housing departments, police stations, social security offices and inpatient units can also be suitable locations for meetings between client and assertive outreach team workers." (The Sainsbury Centre for Mental Health, 2001))	Direct care	Partnership and shared leadership
Family education/ psychoeducation AND families involve in relapse prevention	To encourage the family's full engagement, programs provide education about: ·the illness and symptoms ·the role of treatment, including medications and side effects ·acute symptom management, including safety risks ·rights and responsibilities ·the impact of substance use on psychosis (including alcohol and marijuana) ·how to support their family member during treatment and recovery ·how to help the family member manage the illness ·stigma associated with mental illness and how to cope with it ·how to sustain recovery and prevent relapses ·services and supports in the community ·acute symptom management, including safety risks.	Direct care	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment) AND Develop care plan for the family member	The team assesses and identifies the family's needs and works with the family to develop a support plan.	Direct care	Partnership and shared leadership
Recommendation outlines prescribed type/frequency for treatment team to have communication/contact with family	The team has at least monthly contact with the family.	Direct care	Consultation
Family peer support	The team identifies or develops appropriate opportunities for families to connect with support groups, network with other families, and train to be peer facilitators	Direct care	Partnership and shared leadership

Other family supports (e.g., self-care, links to community services)	Programs provide ongoing support for families and link them with crisis support and intervention services in the community.	Direct care	Consultation
Family education/ psychoeducation AND family peer support	Education and support services for families may be provided by professionals and/or by other families who have experienced similar challenges.	Direct care	Involvement
Other family supports (e.g., self-care, links to community services) AND culturally sensitive care for families	Programs provide education for all staff and team members in human rights, the duty to accommodate clients and families with disabilities (e.g., Braille, large print, American Sign Language, etc.) And how to deliver culturally appropriate services.	Direct care	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Programs have an evaluation plan that includes: ….. -a consistent process to assess client and family satisfaction with the program/services.	Organizational design and governance	Consultation
Assessment/ outcomes for families (e.g., Family satisfaction, needs assessment)	Programs collect program data as requested by the Ministry of Health and Long-Term Care and/or the Local Health Integration Network that can be used to assess the impact of the program on access to service, hospitalization rates, client and family satisfaction, and longer-term health outcomes (e.g., return to school, gainful employment).	Organizational design and governance	Consultation
Families involved in community outreach / referrals	A community's Early Identification/Rapid Response system for psychosis should include all organizations with the potential to assist in identifying adolescents and young adults (ages 14 to 35) with early signs of psychosis, such as: …….Schizophrenia Society/Mood Disorders Association and other family organizations	Direct Care	Consultation
Addressing confidentiality issues (e.g., discuss confidentiality with patient and family)	Actively Promoting Family Involvement: When clients do not consent to having their family involved, programs assertively promote the family's role by explaining that the road to recovery is smoother with family support. If clients still refuse, the team informs the client it will continue to have contact with the family. Although team members will not be able to talk about the young person's care, they can still listen to the family's concerns and provide psychosocial support and education about psychotic disorders.	Direct Care	Partnership and shared leadership

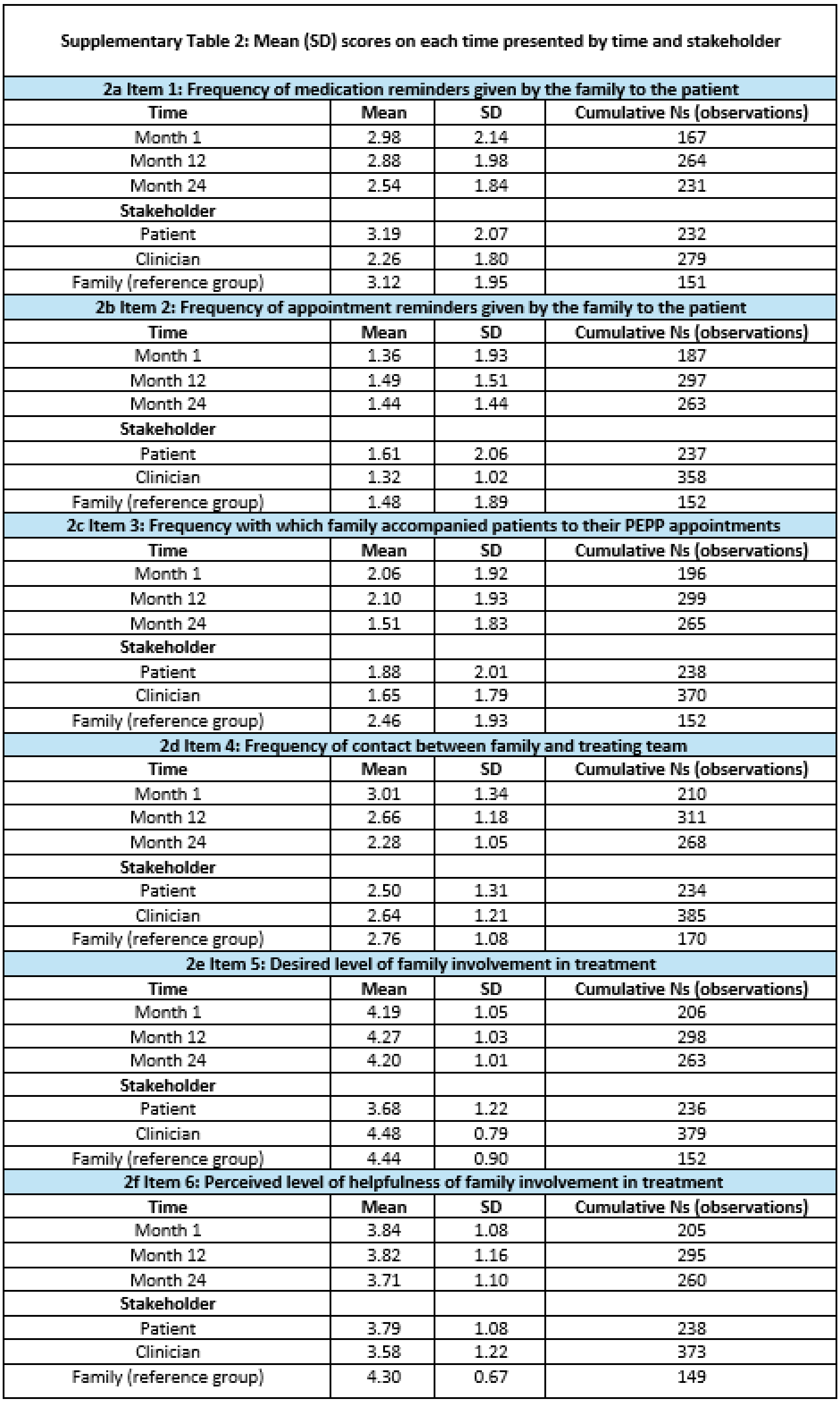
Manuscript II

Supplementary table: List of 40 statements used for importance ranking
1.In what ways should families/ carers of persons with psychosis be involved?
Families can have the young person with psychosis live with them.
Families can support during crises, relapses, or hospitalizations.
Families can accompany the young person during appointments at the clinic.
Families can support the young person with their work or school.
Families can update the treating team about progress and concerns such as changes in young family member's behavior, so that treatment can be adjusted.
Families can educate themselves about the illness.
Families can develop emotional acceptance and adjust their expectations from their young family member.
Families can help the young person to stay in treatment and be in contact with the treating team.
Families can be aware of and be involved in developing treatment plans.
Families can offer emotional support.
2. What influences the involvement of families/carers of persons with psychosis?
Involvement is influenced by each family's culture around autonomy and support.
Involvement is influenced by the resources of families such as finances, accessibility of the clinic, time available based on job and other commitments, etc.
Involvement is influenced by the age or development of patients (e.g., adolescents versus young adults versus adults).
There should always be some involvement of families/carers in treatment.
There should always be some involvement of families/carers in treatment, except when the families/carers are unhelpful or harmful.
The young person's consent is necessary for families/carers to be involved in treatment.
The need for and frequency of family contact depends on the phase of recovery, e.g., more contact when there is a crisis or relapse and less contact when the person is doing well.
The frequency and types of involvement of families should be discussed jointly by patients, families and treating teams.
The frequency and types of involvement of families should be set based on patients' preferences.
When patients are doing well, it is okay for busy treating teams to not contact families.
3. How often should families/carers be involved?
Families should be present at every point in treatment.
Families and the treating team should have contact with each other at least once a week for the first month.
Families and the treating team should have contact with each other at least once a month throughout treatment (which is usually for 2 years at *).
Over the course of two years, there should be a minimum number of times that treatment teams should contact families. Beyond this minimum, treatment teams can also increase contact depending on patients' needs.
Over the course of two years, there should not be a minimum number of times that treatment teams should contact families. Instead, they should contact families as and when needed.
Families and treating teams should be jointly responsible for maintaining contact with each other.
Maintaining contact with the family should be the primary responsibility of the treatment team (with families having the option of initiating contact).
Programs like * should systematically record presence or absence of contact with families in each patient's chart.
There should be guidelines about involving families for treatment teams to follow.
Because each person's situation is different, there cannot be any common guidelines about involving families in treatment.
4. How should consent and confidentiality be dealt with in involving families/carers?
If a patient is not a threat to himself or others, there should be no insistence on involving families/carers if the patient does not desire such involvement.
If the patient does not consent to their treatment provider sharing information with families/carers, the treating team can still receive information or updates from families and can share general information about the illness and treatment if families contact them.
If the patient does not consent to their treatment provider sharing information with families/carers, the treating team should not have any contact with families/carers.
Even if the patient has consented for families to be involved, treatment providers should always check with patients before disclosing any specific information.
When the **patient has consented f**or families to be involved, treatment providers should use their judgment in deciding what information should and should not be disclosed to families.
Laws and regulations around consent and confidentiality make it difficult to involve families.
When a patient **does not consent to** involving families/carers, treating teams should try to convince them that family support can be helpful and discuss their concerns about family involvement.
It is possible to involve families/carers and also respect patient consent and confidentiality.
Even when patients consent for families to be involved, patients themselves should make key treatment decisions.
When patients consent for families to be involved, key treatment decisions should involve both the patient and the family.
Legend: *Name of the early psychosis intervention program redacted for confidentiality purposes

Manuscript III

Supplementary Table 1: Items as presented to each stakeholder group

Stakeholder	**Item 1: Medication reminders**
Patient version	My family reminded me to take my medication
Family version	I reminded my family member to take his/her medication
Clinician version	The patient's family reminded the patient to take his/her medication
	Item 2: Appointment reminders
Patient version	My family reminded me about _____ of my appointments at (name of clinic)
Family version	I reminded my family member about ____ of his/her appointments at (name of clinic)
Clinician version	The patient's family reminded him/her about ______ of his/her appointments at (name of clinic)
	Item 3: Appointment accompaniment
Patient version	My family accompanied me to _____ of my appointments at (the clinic)
Family version	I accompanied my family member to ____ of his/her appointments at (the clinic)
Clinician version	The patient's family accompanied him/her to ______ of his/her appointments at (the clinic)
	Item 4: Family-treating team contact
Patient version	My family was in contact with my treatment team at (the clinic)
Family version	I was in contact with my family member's treatment team at (the clinic)
Clinician version	The patient's family was in contact with me (i.e., clinician)
	Item 5: Preferred level of family involvement in treatment than now
Patient version	With respect to my treatment, I wish my family was involved _________ than/as now
Family version	With respect to my family member's treatment, I wish I was involved ________ than/as now
Clinician version	With respect to the patient's treatment, I wish the patient's family was involved __________ than/as now
	Item 6: Perceived level of helpfulness of family involvement in treatment
Patient version	In my opinion, my family's involvement in my treatment has been
Family version	In my opinion, my involvement in my family member's treatment has been
Clinician version	In my opinion, the family's involvement in treatment has been



Supplementary Table 2: Mean (SD) scores on each time presented by time and stakeholder

2a Item 1: Frequency of medication reminders given by the family to the patient

Time	Mean	SD	Cumulative Ns (observations)
Month 1	2.98	2.14	167
Month 12	2.88	1.98	264
Month 24	2.54	1.84	231
Stakeholder			
Patient	3.19	2.07	232
Clinician	2.26	1.80	279
Family (reference group)	3.12	1.95	151

2b Item 2: Frequency of appointment reminders given by the family to the patient

Time	Mean	SD	Cumulative Ns (observations)
Month 1	1.36	1.93	187
Month 12	1.49	1.51	297
Month 24	1.44	1.44	263
Stakeholder			
Patient	1.61	2.06	237
Clinician	1.32	1.02	358
Family (reference group)	1.48	1.89	152

2c Item 3: Frequency with which family accompanied patients to their PEPP appointments

Time	Mean	SD	Cumulative Ns (observations)
Month 1	2.06	1.92	196
Month 12	2.10	1.93	299
Month 24	1.51	1.83	265
Stakeholder			
Patient	1.88	2.01	238
Clinician	1.65	1.79	370
Family (reference group)	2.46	1.93	152

2d Item 4: Frequency of contact between family and treating team

Time	Mean	SD	Cumulative Ns (observations)
Month 1	3.01	1.34	210
Month 12	2.66	1.18	311
Month 24	2.28	1.05	268
Stakeholder			
Patient	2.50	1.31	234
Clinician	2.64	1.21	385
Family (reference group)	2.76	1.08	170

2e Item 5: Desired level of family involvement in treatment

Time	Mean	SD	Cumulative Ns (observations)
Month 1	4.19	1.05	206
Month 12	4.27	1.03	298
Month 24	4.20	1.01	263
Stakeholder			
Patient	3.68	1.22	236
Clinician	4.48	0.79	379
Family (reference group)	4.44	0.90	152

2f Item 6: Perceived level of helpfulness of family involvement in treatment

Time	Mean	SD	Cumulative Ns (observations)
Month 1	3.84	1.08	205
Month 12	3.82	1.16	295
Month 24	3.71	1.10	260
Stakeholder			
Patient	3.79	1.08	238
Clinician	3.58	1.22	373
Family (reference group)	4.30	0.67	149