Positive Change Following a First Episode of Psychosis: A Mixed Methods Study

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Table of Contents

CHAPTER 1 - Introduction

Abstract

Introduction: A first episode of psychosis (FEP) is often a severe and highly traumatic mental illness. However, FEP may also present an opportunity for positive change. While positive changes have been reported following various physical illnesses (e.g., HIV) or traumatic events (e.g., war), little research has investigated positive changes following FEP. To address this knowledge gap, this dissertation addressed two research questions: 1) What are the positive changes persons experience following FEP, and 2) What factors or processes facilitate such changes? **Methods:** These research questions were addressed through synthesizing the extant scientific knowledge in two systematic reviews (i.e., a scoping and systematic mixed studies review), and through conducting one empirical mixed methods study that was separated into two chapters. The scoping review was carried out in six steps: identifying the research question and relevant studies, selecting studies, charting the data, coding and summarizing results, and consulting with stakeholders. All data were charted and subject to thematic analysis. The systematic mixed studies review employed a convergent qualitative synthesis design, and was conducted in five steps: formulating a review question, defining eligibility criteria, identifying sources of information, identifying and selecting studies, and appraising the quality of studies. Data were analyzed using thematic synthesis. The empirical mixed methods study employed a mixed methods convergent design, whereby participants completed a quantitative (n = 94) and qualitative component (n = 12). In the quantitative component, participants completed validated questionnaires assessing positive change (i.e., the Posttraumatic Growth Inventory) and predictors of positive change (i.e., the Subjective Experiences of Psychosis Scale, Brief COPE, Recovery Assessment Scale, Child and Youth/Adult Resilience Measure, and Multidimensional Scale for Perceived Social Support). In the qualitative component, participants partook in semi-structured interviews assessing why participants felt they came to receive services at an early intervention service; how they feel they changed following their FEP; and what they perceive facilitated such change. Quantitative data were analyzed using descriptive statistics and multiple regression, while qualitative data were analyzed using thematic analysis. **Results:** Findings across studies revealed that following FEP, participants (including persons with lived experience of FEP themselves as well as their families and friends) experienced positive change at the individual level (e.g., developing a stronger sense of self, improved mental health, etc.), interpersonal level (e.g., improving relationships with others) and spiritual/religious level (e.g., experiencing greater spirituality). These changes were facilitated by factors and processes at the personal level (e.g., coping, experiencing personal recovery, engaging in spirituality, etc.), relational or social level (e.g., social support, etc.), contextual level (e.g., through receiving mental health services, etc.), as well as by processes unrelated to FEP (e.g., normative developmental experiences). **Conclusions:** A FEP may lead to perceptions of positive change among persons themselves, their families and friends. These findings validate the experiences of persons who have experienced positive change as a result of their experience of FEP, and can inform the delivery of positive, hopeful, strengths-based services to persons experiencing FEP.

Resumé

Introduction : Un premier épisode psychotique (PEP) est souvent une maladie mentale grave et pénible. Cependant, un PEP peut également constituer une opportunité de changement positif. Bien que des changements positifs aient été rapportés à la suite de diverses maladies physiques (par exemple, le VIH) ou d'événements traumatiques (par exemple, la guerre), très peu d'études ont porté sur les changements positifs pouvant suivre un PEP. Pour combler cette lacune, cette thèse aborde deux questions de recherche: 1) Quels sont les changements positifs qu'éprouvent les personnes après un PEP et 2) Quels facteurs ou processus peuvent faciliter de tels changements? **Méthodes :** Ces questions de recherche ont été abordées en synthétisant les connaissances scientifiques existantes, basées sur deux revues de la littérature (un examen de la portée et une revue systématique) et en menant une étude empirique à méthodes mixtes, divisée en deux chapitres. L'examen de la portée de la littérature a été effectué en six étapes: l'identification de la question de recherche et des études pertinentes, la sélection d'études, la présentation des données, le codage et la synthèse des résultats, et une consultation avec des parties prenantes. Toutes les données ont été décrites et soumises à une analyse thématique. La revue systématique d'études mixtes, employant une synthèse qualitative convergente, a été réalisée en cinq étapes: la formulation d'une question de revue, la définition des critères d'éligibilité, l'identification des sources d'information, l'identification et la sélection des études et l'évaluation de la qualité des études. Les données ont été analysées en utilisant une synthèse thématique. L'étude empirique des méthodes mixtes a utilisé un design convergent de méthodes mixtes, incluant une composante quantitative (n=94) et une composante qualitative (n=12). Dans la composante quantitative, les participants ont rempli des questionnaires validés évaluant les changements positifs (l'échelle *Posttraumatic Growth Inventory*) et les prédicteurs de changement positif (les échelles *Subjective Experiences of Psychosis Scale,* le *Brief COPE,* le *Recovery Assessment Scale,* le *Child and Youth/Adult Resilience Measure,* et le *Multidimensional Scale for Perceived Social Support*). Dans la composante qualitative, les individus ont participé à des entrevues semi-structurés évaluant les raisons pour lesquelles ces participants estimaient avoir reçu des services d'intervention précoce; comment ils pensent avoir changé après leur PEP; et les facteurs qu'ils perçoivent comment ayant facilité de tels changements. Les données quantitatives ont été analysées à l'aide de statistiques descriptives et de régression multiple, tandis que les données qualitatives ont été analysées à l'aide d'une analyse thématique. **Résultats**: Les résultats des études ont révélé que les participants (y compris les personnes ayant une expérience vécue de PEP eux-mêmes, ainsi que leurs familles et amis) ont vécu des changements positifs au niveau individuel (par exemple, le développement d'un sentiment d'identité plus robuste, l'amélioration de la santé mentale, etc.), du niveau interpersonnel (par exemple, l'amélioration des relations avec autrui) et au niveau spirituel/religieux (par exemple, une spiritualité renforcée). Ces changements étaient facilités par des facteurs et des processus personnels (par exemple, l'adaptation, le rétablissement, la spiritualité, etc.), par des facteurs relationnels ou sociaux (par exemple, le soutien social, etc.), par des facteurs contextuels (par exemple, avoir reçu des services de santé mentale; avoir des cadres culturels sur lesquels s'appuyer, etc.), ainsi que par des processus non liés au PEP (ex., expériences de développement normatives). **Conclusion** : Un PEP peut mener à des perceptions de changement positif parmi les personnes elles-mêmes, leurs familles et leurs amis. Ces découvertes valident les expériences des personnes qui ont connu des changements positifs grâce à leur expérience de PEP et peuvent alimenter la prestation de services porteurs d'espoir, et axés sur les forces pour les personnes vivant un PEP.

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I dedicate this thesis to my late grandfather, Pierino Lombardi, who wanted nothing more than to see me write and submit this work, and to finally become “il Dottore”. I also dedicate this work to my late grandmother who nurtured my interest and curiosity in science from a young age.

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Contribution to Original Knowledge

To date, only five studies have sought to investigate positive changes following a first episode of psychosis. Four of these are qualitative studies, and one is a quantitative study. In carrying out this dissertation, I published the only scoping review of the state of knowledge on this topic. I published the only available systematic review of empirical studies reporting positive change following a first episode psychosis. This review is also the only extant review of positive change following a mental illness. The two empirical chapters are also the only two mixed methods studies on this topic which have been published.

Contributions to Manuscripts

Title: Post-traumatic growth following a first episode of psychosis: a scoping review

Authors: Gerald Jordan, Megan Pope, Angella Lambrou, Ashok Malla, Srividya Iyer

Contributions: Gerald Jordan conceived of and carried out this study; and he wrote the manuscript. Megan Pope helped screen articles, chart data, and helped write the manuscript. Angella Lambrou developed the search strategy and retrieved relevant articles. Ashok Malla and Srividya Iyer helped conceive this study, supervised Gerald Jordan throughout its implementation, and helped write the manuscript.

Manuscript status: Published in Early Intervention in Psychiatry

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Title: Positive changes experienced after a first episode of psychosis a systematic review

Authors: Gerald Jordan, Kathleen MacDonald, Megan A. Pope, Emily Schorr, Ashok K Malla, Srividya, N. Iyer.

Contributions: Gerald Jordan conceived of and carried out this study; and he wrote the manuscript. Kathleen MacDonald helped screen articles, helped analyze data, and helped write the manuscript. Megan Pope helped screen articles, and helped write the manuscript. Emily Schorr helped screen articles. Ashok Malla and Srividya Iyer helped conceive this study, supervised Gerald Jordan throughout its implementation, and helped write the manuscript.

Manuscript status: Published in Psychiatric Services

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Title: Positive changes following a first episode of psychosis: a mixed methods study using a convergent design

Authors: Gerald Jordan, Ashok Malla, Srividya Iyer

Contributions: Gerald Jordan conceived of this study; and he wrote the manuscript. Ashok Malla and Srividya Iyer helped conceive this study, supervised Gerald Jordan throughout its implementation, and helped write the manuscript.

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Other Manuscripts and Published Abstracts

Peer-Reviewed Publications

Papers in Press/Accepted

1. Pope, M., **Jordan, G**., Venkataraman S., Malla, A., Iyer., SN. (2018). "Everyone has a role": a qualitative study of multi-stakeholder perspectives on responsibility for supporting individuals with mental health problems. *Qualitative Health Research*. *Accepted with revisions.*

2. McIlwaine, S. V., Jordan, G., Pruessner, M., Malla, A., Faridi, K., Iyer, S.N., Joober, R. & Shah, J. (2018). Does an integrated outreach intervention targeting all stages of psychosis improve the identification of those at clinical high risk? *Accepted in Early Intervention in Psychiatry.*

Published Papers

1. **Jordan G,** Kinkaid M, Iyer SN, Joober R, Goldberg K, Malla A, Shah J. (2018). Baby or bathwater? Referrals of "non-cases" in a targeted early intervention program for psychosis. *Social Psychiatry and Psychiatric Epidemiology.* DOI: 10.1007/s00127-018-1502-5

2. **Jordan G,** MacDonald K, Pope M, Schorr E, Malla A, Iyer SN. (2018). Positive changes experienced following a first episode of psychosis: a systematic review. *Psychiatric Services*. DOI: 10.1176/appi.ps.201600586

3. **Jordan G,** Veru F, Lepage M, Joober R, Malla A, Iyer SN. (2017). Pathways to functional outcomes following a first episode of psychosis: the roles of premorbid adjustment, verbal memory and symptom remission. *The Australian and New Zealand Journal of Psychiatry*. DOI: 10.1177/0004867417747401

4. Malla A, De Bonneville M, Shah J, **Jordan G**, Pruessner M, Faridi K, Rabinovitch M, Iyer SN, Joober R. (2017). Outcome in patients converting to psychosis following a treated clinical high risk state. *Early Intervention in Psychiatry*; DOI:10.1111/eip.12431

5. Venkataraman S, **Jordan G**, Pope MA, Iyer SN. (2017). An examination of cultural competence in service providers in an early intervention program for psychosis in Montreal, Quebec: perspectives of service users and treatment providers. *Early Intervention in Psychiatry*; DOI:10.1111/eip.12422

6. **Jordan G**, Malla A, Iyer SN. (2016). Posttraumatic growth following a first episode of psychosis: A mixed methods research protocol using a convergent design. *BMC Psychiatry*; DOI:10.1186/s12888-016-0977-4

7. **Jordan G**, Pope M, Lambrou A, Malla A, Iyer SN. (2016). Post-traumatic growth following a first episode of psychosis: a scoping review. *Early Intervention in Psychiatry*; DOI:10.1111/eip.12349

8. Veru F, **Jordan G**, Joober R, Malla A, Iyer SN. (2016). Adolescent vs. adult onset of a first episode psychosis: Impact on remission of positive and negative symptoms. *Schizophrenia Research;* DOI:10.1016/j.schres.2016.03.035

9. Iyer SN, **Jordan G**, MacDonald K, Joober R, Malla A. (2015). Early intervention for psychosis: a Canadian perspective. *The Journal of Nervous and Mental Disease*; DOI:10.1097/NMD.0000000000000288

10. Iyer SN, Boksa P, Lal S, Shah J, Marandola G, **Jordan G**, Doyle M, Joober R, Malla AK. (2015). Transforming youth mental health: A Canadian perspective. *Irish Journal of Psychological Medicine*; DOI:10.1017/ipm.2014.89

11. Malla A, **Jordan G**, Joober R, Schmitz N, Norman R, Brown T, Goldberg K, Loohuis H, Vracotas N, Rochford J. (2014). A controlled evaluation of a targeted early case detection intervention for reducing delay in treatment of first episode psychosis. *Social Psychiatry and Psychiatric Epidemiology*; DOI:10.1007/s00127-014-0893-1

12. **Jordan G**, Lutgens D, Joober R, Lepage M, Iyer SN, Malla A. (2014). The relative contribution of cognition and symptomatic remission to functional outcome following treatment of a first episode of psychosis. *The Journal of Clinical Psychiatry*; DOI:10.4088/JCP.13m08606

13. **Jordan G**, Pope M, Wallis P, Iyer SN. (2014). The relationship between openness to experience and willingness to engage in online political participation is influenced by news consumption. *Social Science Computer Review*; DOI:10.1177/0894439314534590

14. Malla A, Chue P, **Jordan G**, Stip E, Koczerginski D, Milliken H, Joseph A, Williams R, Adams B, Manchanda R, Oyewumi K, Roy MA. (2013). An exploratory open-label randomized trial comparing risperidone long acting injectable (RLAI) with oral antipsychotic medication in the treatment of early psychosis. *Clinical Schizophrenia & Related Psychoses*; DOI:10.3371/CSRP.MACH.061213

15. **Jordan G.** (2011). Gender differences in the developmental trajectories, risk factors and outcomes of antisocial behaviors. *Gender and Behaviour, 9*, 3528-3542.

16. Coria-Avila GA, Jones SL, Solomon CE, Gavrila AM, **Jordan G**, Pfaus JG. (2006). Conditioned partner preference in female rats for strain of male. *Physiology & Behavior*; DOI:10.1016/j.physbeh.2006.05.001

Presentations

Peer-Reviewed Conference Papers

1. **Jordan, G.**, Malla, A., Iyer, SN. (2018). “It's brought me like a lot closer to who I am”: aspects and facilitators of change following a first episode of psychosis. Paper presented at the 11th Annual International Early Intervention in Mental Health Conference, Boston, MA.

2. Ferrari, M., McIlwaine, S., **Jordan, G.**, Lal, S., Shah, J., & Iyer, S. (2018). From floating brains to insane painters: A review of mental illness messages in commercial video games. Accepted for an oral presentation at the DiGras conference, Turrino, Italy.

3. Ferrari, M., McIlwaine, S., **Jordan, G.**, Shah J., Lal, S., Iyer, SN. (2018). From floating brains to insane painters: A review of mental illness messages in commercial video games. Paper presented at the Digital Games Research Association Conference, Turin, Italy.

4. **Jordan G***, Cowan C, Malla A, Iyer SN. (2017). A qualitative investigation of positive, transformational change following a first episode of psychosis. Paper presented at the Qualitative Health Research Conference, Quebec City, CA. *Session Chair.

5. Pope M, **Jordan G**, Venkataraman S, Loohuis H, Malla A, Iyer SN. (2016). Who should be responsible for supporting individuals with mental health problems? A qualitative descriptive study exploring the perceptions of multiple stakeholders. Poster presented at the International Early Intervention in Mental Health, Milan, Italy

6. **Jordan G**, Cowan C, Malla A, Iyer SN. (2017). “Receiving the gifts of psychosis”: positive, transformational change in youth who have experienced a first episode of psychosis. Paper presented at the World Congress on Positive Psychology, Montreal, Canada.

7. Ferrari M, McIlwaine S, **Jordan G**, Shah J, Iyer SN. (2017). Gaming against stigma: A qualitative study of mental illness messages in video games. Paper to be presented at the International Conference on Youth Mental Health, Dublin, Ireland

8. **Jordan G**, Cowan C, Malla A, Iyer SN. (2017). "It gives me so much each time": a mixed methods study exploring how youth have benefitted from psychosis. Paper to be presented at the International Conference on Youth Mental Health, Dublin, Ireland

9. **Jordan G**, Cowan T, Malla A, Iyer SN. (2017). Psychosis as a gift: a mixed methods study exploring the benefits young people experience following a first episode of psychosis. Paper presented at The Many Faces of Delusions, Psychosis, and Schizophrenia conference, Montreal, Canada.

10. **Jordan G**, Cowan T, Malla A, Iyer SN. (2017). "I needed it to get better": a qualitative investigation into the positive, transformational role of first episode psychosis. Paper presented at the Annual Douglas Student Research Day, Montreal, Canada
    (2nd Prize, Oral Presentation)

11. Cowan T, Malla A, **Jordan G**, Iyer SN. (2016). The dynamic relation between social support and post traumatic growth. Paper presented at the Prevention and Early Intervention Program for Psychoses Annual Research Day, Montreal, Canada. *This work was conducted through Doctoral work conducted by Jordan G. **(2rd Prize, Oral Presentation)**

12. **Jordan G**, Cowan T, Malla A, Iyer SN. (2016). How can early intervention services facilitate posttraumatic growth in service users? Findings from a mixed methods project. Paper presented at the Prevention and Early Intervention Program for Psychoses Research Day, Montreal, Canada

13. Venkataraman S, **Jordan G**, Pope M, Iyer SN. (2016). An examination of cultural competence in service providers in an early intervention program for psychosis in Montreal, Quebec: perspectives of service users and treatment providers. Paper presented at the Prevention and Early Intervention Program for Psychoses Annual Research Day, Montreal, Canada **(3rd Prize, Oral Presentation)**

14. **Jordan G**, Cowan T, Malla A, Iyer SN. (2016). How do early intervention services for first episode psychosis facilitate the benefits of having a first episode psychosis? Paper presented at the Canadian Association for Health Services and Policy Research, Toronto, Canada

15. **Jordan G**, MacDonald K, Malla A, Iyer SN. (2016). Challenges and solutions around meaningfully integrating findings from a mixed studies review into a larger mixed methods project: a PhD student experience. Paper presented at the Colloque Méthodes Mixtes en sciences de la santé et sciences sociales (Conference on Mixed Methods in Health and Social Science), Montreal, Canada

16. **Jordan G**, Cowan T, Malla A, Iyer SN. (2016). Positive change following a first episode of psychosis: a mixed methods study. Paper presented at the Canadian Critical Disability Studies Conference, Calgary, Canada

17. Cowan T, Malla A, **Jordan G**, Iyer SN. (2016). The dynamic relation between social support and post traumatic growth. Paper presented at the INSPIRe Virtual Research Symposium. *This work was conducted through Doctoral work conducted by Jordan G.

18. **Jordan G**, Pope M, Lambrou A, Malla A, Iyer SN. (2015). Positive change following a first episode psychosis: a mixed studies review using a convergent design. Pathways to Resilience

III: Beyond Nature vs. Nurture. Paper presented at the Pathways to Resilience Conference, Halifax, Canada

19. **Jordan G**, Pope M, Lambrou A, Malla, A, Iyer SN. (2014). Positive change and growth following a first episode psychosis: initial results from a systematic review of qualitative evidence. Paper presented at the Prevention and Early Intervention Program for Psychoses Research Day, Montreal, Canada

20. **Jordan G**, Iyer SN. (2014). Propensity to engage in political activism among people who report anxiety or depression: results from a pilot study. Paper presented at the 10th Interdisciplinary Graduate Student Research Symposium, Montreal, Canada

21. **Jordan G**, Iyer SN, Malla A. (2014). Applying disability theory to psychiatric research in first episode psychosis. Paper presented at the Society for Disability Studies Conference, Minneapolis, MN

22. **Jordan G**, Iyer SN. (2014). Implications for treating ultra high-risk states for developing psychosis. Paper presented at the conference on Complicating Normalcy: Disability Technology and Society in the Twenty-First Century, Rochester, NY

23. **Jordan G**, Veru F, Iyer SN, Malla A. (2014). Impact of systemic factors on a long duration of untreated psychosis. Paper presented at the 15e Anniversaire de la Clinique JAP conference (14th Anniversary of the JAP clinic), Montreal, Canada

24. **Jordan G**, Lutgens D, Joober R, Lepage M, Iyer SN, Malla A. (2014). The relative contribution of cognition and symptomatic remission to functional outcome following treatment of a first episode psychosis (FEP). Paper presented at the Douglas Mental Health University Institute Student Research Day, Montreal, Canada

25. Iyer SN, Marandola G, **Jordan G**, Pawliuk N, Lepage M, Malla, A. (2013). Neurocognitive deficits and functional outcome in early psychosis. Paper presented at the Early Intervention in Psychosis: Current Knowledge and Future Directions Conference, Montreal, Canada

26. Faridi K, Rho A, **Jordan G**, Malla A. (2013). Exploring the complex interplay between cannabis use, medication adherence, and symptom intensity in first-episode psychosis. Paper presented at the Early Intervention in Psychosis: Current Knowledge and Future Directions Conference, Montreal, Canada

27. Malla A, **Jordan G**, Loohuis H, Goldberg K, Vracotas N, Brown T, Joober R, Schmitz N, Norman, R. (2013). Beyond reducing DUP: unintended but positive effects of targeted early case detections of psychotic disorders in primary care. Paper presented at the International Youth Mental Health Conference, Birmingham, UK

28. **Jordan G**, Iyer SN, Malla A. (2012). Functional outcome: is cognition or symptomatic remission more important? Paper presented at the Prevention and Early Intervention Program for Psychoses Research Day, Montreal, Canada

Peer-Reviewed Symposium Presentations

1. Iyer SN, **Jordan G**, Lutgen D, Lepage M, Joober R, Malla A. (2012). The relative contribution of symptomatic remission and cognition to functional outcome in first episode psychosis. Presentation in symposium chaired by Malla A. Persistent symptoms, cognition & functional outcome in early phase of psychosis, International Conference on Schizophrenia, Chennai, India

2. Pope M, Venkataraman S, **Jordan G,** Loohuis H, Malla A, Iyer SN. (2017). Who should be responsible for supporting individuals with mental health problems? A qualitative descriptive study exploring the views of multiple stakeholders in Montreal, Canada and Chennai, India. Early psychosis in India and Canada: Investigating outcomes and family factors using mixed methods, the 38th Annual Meeting of the Society for the Study of Psychiatry and Culture, Philadelphia, PA.

Peer-Reviewed Conference Posters

1. **Jordan G**, Cowan C, Malla A, Iyer SN. (2016). "Receiving the gifts of psychosis": positive changes experienced following a first episode of psychosis. Poster presented at the International Early Intervention in Mental Health, Milan, Italy

2. Pope M, **Jordan G**, Venkataraman S, Loohuis H, Malla A, Iyer SN. (2016). Who should be responsible for supporting individuals with mental health problems? A qualitative descriptive study exploring the perceptions of multiple stakeholders. Poster presented at the International Early Intervention in Mental Health, Milan, Italy

3. Etienne G, **Jordan G**, MacDonald K, Pope M, Loohuis M, Mohan G, Rangaswamy T, Malla A, Iyer, SN**.** (2016). Canadian and Indian families of patients with a first episode of psychosis: perspectives on psychosis and medication. Poster presented at the International Conference on Schizophrenia, Chennai, India. **(1st Prize, Poster Presentation)**

4. Venkataraman S, **Jordan G**, Pope M, Iyer, SN. (2016). An examination of cultural competence in service providers in an early intervention program for psychosis in Montreal, Quebec: perspectives of service users and treatment providers. Poster presented at the International Conference on Schizophrenia, Chennai, India.

5. Pope M, **Jordan G**, Venkataraman S, Loohuis H, Malla, A, Iyer SN. (2016). Who should be responsible for supporting individuals with mental health problems? A qualitative descriptive study exploring the perceptions of multiple stakeholders. Poster accepted for presentation at the Douglas Institute Research Centre Annual Research Day, Montreal, Canada

6. Venkataraman S, Pope M, **Jordan G**, Malla A, Iyer SN. (2015). An examination of cultural competence in youth mental healthcare providers: Perspectives of service users, treatment

providers and family members. Paper presented at The Third International Conference on Youth Mental Health, Montreal, Canada.

7. **Jordan G**, Pope M, Schor E, Malla A, Iyer SN. (2015). Positive change following a first episode of psychosis: a mixed studies review. Poster presented at the International Youth Mental Health Conference, Montreal, Canada

8. Grossman M, Iyer SN, Bowie CR, **Jordan G**, Joober R. (2015). Smoking status and its relationship to clinical and demographic characteristics in first episode psychosis. Poster presented at the International Congress on Schizophrenia Research, Colorado Springs, CO

9. Iyer SN, **Jordan G**, Marandola G, Pira S, Pruessner M, Lepage M, Malla A. (2014). Subjectively perceived cognitive deficits in psychosis among first-episode and ultra-high risk groups. Poster presented at the International Early Psychosis Association Conference, Tokyo, Japan

10. Loohuis H, Pope M, **Jordan G**, Malla A, Iyer SN. (2014). Clinical utility and preliminary outcomes of two measures assessing daily functioning and aspirations of young people with first episode psychosis. Poster presented at the Institutes of Psychiatric Services Conference, San Francisco, CA

11. Malla A, Chue P, **Jordan G**, Stip E, Koczerginski D, Milliken H, Joseph A, Williams R, Adams B, Manchanda R, Oyewumi K, Roy MA. (2013). An exploratory open-label randomized trial comparing risperidone long acting injectable (RLAI) with oral antipsychotic medication in the treatment of early psychosis. Poster presented at the International Early Intervention in Psychosis Association Conference, San Francisco, CA

12. Rho A, Pawliuk N, Cassidy C, **Jordan G**, Joober R, Malla A. (2012). Addressing physical health issues in early psychosis. Poster presented at the International Early Intervention in Psychosis Association Conference, San Francisco, CA

13. Rho A, Pawliuk N, Cassidy C, **Jordan G**, Joober R, Malla A. (2012). Genetic variant of FTO associated with weight gain in a sample of patients with first-episode psychosis treated with antipsychotics. Poster presented at the International Early Intervention in Psychosis Association Conference, San Francisco

14. Lutgens D, **Jordan G**, Malla A. (2013). The duration of untreated illness and cognitive function in first episode psychosis. Poster presented at the Early Intervention in Psychosis: Current Knowledge and Future Directions Conference, Montreal, Canada

15. Marandola G, Pruessner M, Pira S, **Jordan G**, Malla A. (2013) An investigation of olfactory identification deficits in ultra-high risk individuals. Poster presented at the Early Intervention in Psychosis: Current Knowledge and Future Directions Conference, Montreal, Canada

16. Lutgens D, **Jordan G**, Malla A. (2013). Predictors of cognitive functioning in first episode psychosis. Poster presented at the International Congress on Schizophrenia Research, Orlando, FL

17. **Jordan G**, Loohuis H, Goldberg K, Vracotas N, Brown T, Joober R, Schmitz N, Norman R, Malla A.(2013). Effects of a targeted case detection intervention for first episode psychosis on pathways to care. Poster presented at the Early Intervention in Psychosis: Current Knowledge and Future Directions Conference, Montreal, Canada

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Chapter One: Introduction

The purpose of this literature review is to provide a summary about what is known about first episode psychosis (FEP); a description of important models that conceptualize how adversity can foster positive change; and an overview on the predictors of posttraumatic growth, which is the most widely-studied type of positive change following adversity.

1. Overview of First-Episode Psychosis and Early Intervention

Many ways of conceptualizing psychosis have emerged throughout time. These conceptualizations reflect the prevailing attitudes and norms about mental illness within their respective time periods (Foucault 1965). While acknowledging the existence of these multiple traditions and ways of viewing psychosis, this section is situated within, and draws knowledge from current psychiatric and psychological ways of conceptualizing a first episode of psychosis.

1.2 Symptomatology and Phenomenology of a First Episode of Psychosis

Mental disorders are an enormous contributor to the global burden of disease. Among mental illnesses, psychotic disorders are associated with some of the greatest costs and burden on individuals and societies (WHO, 2008). In Canada alone, direct and indirect healthcare costs incurred by schizophrenia have been estimated to be 2.02 billion per year. The high levels of unemployment and mortality among persons with schizophrenia have been estimated to cost the Canadian economy 4.83 billion per year (Goeree, Farahati et al. 2005).

FEP is the time when symptoms that are characteristic of psychotic disorders first emerge, which include positive symptoms (i.e., hallucinations, delusions, and bizarre behavior) and negative symptoms (i.e., affective flattening, alogia, avoilition-apathy, and anhedonia-asociality) (American Psychiatric Association 2013, McCarthy-Jones, Marriott et al. 2013). A FEP usually occurs when people are young, and often interrupts important social, educational and occupational trajectories (Malla and Payne 2005). Symptoms of FEP are often terrifying, distressing and lead to profound suffering (Kilkku, Munnukka et al. 2003, Hirschfeld, Smith et al. 2005). A recent systematic review and meta-analysis revealed that FEP is often a highly traumatic experience, with up to 42% of people reporting posttraumatic stress symptoms and 30% meeting diagnostic criteria for posttraumatic stress disorder as a result of their FEP (Rodrigues and Anderson 2017).

FEP is generally accompanied by and/or can lead to many cognitive, psychological and emotional difficulties. For instance, difficulties in thinking and other areas of cognition are associated with psychosis (Barker 2001), which may include problems with verbal memory or executive functioning (Aas, Dazzan et al. 2014). These and other cognitive problems have been found to negatively impact long term outcomes (Green 1996, Green, Kern et al. 2000). Many persons with FEP have anomalous self-experiences, whereby their sense of self is altered, disappears (Vodušek, Parnas et al. 2014), or loses coherence (McCarthy-Jones, Marriott et al. 2013). Persons who have experienced FEP may also have high levels of depression which can put them at risk for suicide (Coentre, Talina et al. 2017, McGinty, Sayeed Haque et al. 2018). Many persons with FEP also experience high levels of anxiety (Cosoff and Hafner 1998), especially social anxiety or social phobia (Birchwood, Trower et al. 2007, Michail and Birchwood 2009).

In addition, many with FEP often report strained social relations (MacDonald, Sauer et al. 2005). A FEP can disrupt friendships and family relations and may lead to difficulties in forming or maintaining romantic relationships. In many cases, families must devote a significant amount of time to caring for their loved one affected by a FEP, which may strain family relations. Caregivers may also experience reduced occupational performance and lost financial earnings;

and caregiving may lead to substance abuse problems as well as depression (Awad and Voruganti 2008).

Both experiencing an FEP and receiving a diagnosis of a psychotic disorder are associated with high levels of prejudice, discrimination and stigma (Gerlinger, Hauser et al. 2013, Baba, Nemoto et al. 2017). Many encounter difficulties with accessing care for FEP and experience challenges when dealing with various aspects of treatment for FEP. For instance, many persons seeking help for FEP experience long, drawn-out and traumatic pathways to care prior to being offered treatment at early intervention services for FEP (Anderson, Fuhrer et al. 2010, Anderson, Fuhrer et al. 2013). During this process, many are hospitalized. While being hospitalized may oftentimes be necessary and helpful for persons experiencing FEP, being hospitalized can also be a distressing experience (Fenton, Larkin et al. 2014, Lu, Mueser et al. 2017). Antipsychotic medication is often prescribed to persons experiencing FEP. Taking medication can improve functioning (Santesteban-Echarri, Paino et al. 2017) and prevent a relapse (Coldham, Addington et al. 2002); yet, taking medication often leads to side effects that are difficult to manage (Lu, Mueser et al. 2017, Wade, Tai et al. 2017).

1.3 Etiology of Psychotic disorders

The etiology of psychotic disorders is highly complex as it arises from multiple factors (Radua, Ramella-Cravaro et al. 2018). However, most theorists acknowledge that psychosis stems from an interaction between biological factors (e.g., such as genetics) and stress (Zubin and Spring 1977, Collip, Myin-Germeys et al. 2008, van Winkel, Stefanis et al. 2008, van Os, Linscott et al. 2009, DeVylder, Koyanagi et al. 2016, Pruessner, Cullen et al. 2017). Genetic predispositions may interact with stressors to dysregulate or sensitize (Collip, Myin-Germeys et al. 2008) certain biological systems, such as the hypothalamic-pituitary-axis. This dysregulation may in turn impact neurotransmitter (e.g., dopaminergic) systems and brain functioning (Pruessner, Cullen et al. 2017) thereby giving rise to a sense of aberrant salience (Kapur 2003, Howes and Nour 2016) or anomalous experiences such as hallucinations or delusions.

The genetic contribution towards the development of a psychosis is widely recognized. Evidence from twin studies has shown that persons may be 40-50% more likely to experience a psychosis if their biological twin has experienced psychosis (Tsuang, Stone et al. 2001, Tandon, Keshavan et al. 2008); and that first-degree relatives of persons with psychotic disorders are at greater risk of developing psychosis than the general population (Tandon, Keshavan et al. 2008). Recent research has shown that many genes may be involved in the etiology of psychosis (Ronald and Pain 2018).

Some environmental stressors involved in the etiology of psychosis occur early in life, while other stressors may occur later on (Olin and Mednick 1996). Examples of early stressors include obstetric complications such as placental abruption; being born with a low birth weight and the use of an emergency caesarian section (Cannon, Jones et al. 2002). Maternal diabetes (Cannon, Jones et al. 2002), infections and hypertension can elevate the risk for FEP (Suvisaari, Taxell-Lassas et al. 2013); as can paternal age during conception (El-Saadi, Pedersen et al. 2004).

Later stressors involved in the etiology of FEP include childhood physical and sexual abuse as well as emotional neglect (Matheson, Shepherd et al. 2013) (Varese, Smeets et al. 2012, Misiak, Krefft et al. 2017); difficulties forming strong and secure attachments with adults during childhood (Read and Gumley 2010); living in an urban environment (Krabbendam and van Os 2005, Vassos, Pedersen et al. 2012); social (Croudace, Kayne et al. 2000, Allardyce, Gilmour et al. 2005) and material deprivation (Anderson, Cheng et al. 2015); cannabis use during early adolescence (Semple, McIntosh et al. 2005); and migration (Bourque, van der Ven et al. 2011, Veling 2013, Tarricone, Boydell et al. 2016). A recent umbrella review identified urbanicity and experiencing a clinical high-risk state as the strongest predictors of psychosis (Radua, Ramella-Cravaro et al. 2018). Another recent review highlighted the central etiological role of socially adverse events such as racism, discrimination, social injustice, rape, war, torture, and witnessing domestic violence or murder, trauma, loss, stress, and disempowerment in psychosis (Longden and Read 2016).

1.4 Incidence and Prevalence

Compared to other mental disorders with clearer diagnostic boundaries (Perala, Suvisaari et al. 2007), FEP can be associated with a range of different diagnoses (e.g., schizophrenia, major depression, etc.). The lifetime prevalence of all psychotic disorders has been reported to range from 3.06 – 4.05% (Jacobi, Wittchen et al. 2004, Perala, Suvisaari et al. 2007). Overall incidence estimates of FEP vary between 16.7 and 31.6 per 100 000 across all diagnostic categories (Jongsma, Gayer-Anderson et al. 2018) (Amminger, Harris et al. 2006, Reay, Mitford et al. 2010, Kirkbride, Errazuriz et al. 2012). Incidence rates have also been found to be higher among migrants (Anderson, Cheng et al. 2015), ethnic minorities (Kirkbride, Errazuriz et al. 2012, Jongsma, Gayer-Anderson et al. 2018), and persons who experience high levels of social or material deprivation (Anderson, Fuhrer et al. 2012).

1.5 The Psychosis Prodrome and At-Risk State

While some persons develop a psychotic disorder quite suddenly, many persons first experience a prodromal state prior to a first episode of psychosis (Yung and McGorry 1996). The prodromal phase is the period between a person’s change in psychiatric premorbid functioning and the first presentation of psychotic symptoms. Prodromal symptoms are often non-specific to psychosis (Addington, van Mastrigt et al. 2003), and may include depression and anxiety (Malla and Norman 1994), as well as irritability, reduced cognitive ability, and a deterioration in functioning (Yung and McGorry 1996). A key defining feature of the prodrome is that it involves psychiatric or behavioral changes that are contiguous with the onset of psychosis.

In addition, some individuals may also experience a clinically high-risk state prior to FEP (Yung, Phillips et al. 1998, McGorry, Yung et al. 2003, Yung, Phillips et al. 2003). This state is often characterized by declines in cognitive, social or occupational functioning in the context of a family history of psychotic disorders; subthreshold psychotic experiences; short-lived, time limited psychotic experiences (e.g., hearing an occasional voice); or short bouts of psychosis lasting only a few days (Fusar-Poli, Borgwardt et al. 2013).

1.6 Duration of Untreated Psychosis

Persons experiencing psychosis often experience delays before seeking and receiving appropriate treatment. Such treatment delays have been well-researched and are often referred to as the duration of untreated psychosis, which is the time from when psychotic symptoms first appear until the initiation of adequate treatment using antipsychotic medication (Norman and Malla 2001). There is a wealth of evidence linking a longer duration of untreated psychosis with higher levels of depression, anxiety and positive, negative and disorganization symptoms; as well as a poorer quality of life and functioning (Marshall, Lewis et al. 2005, Perkins, Gu et al. 2005, Diaz-Caneja, Pina-Camacho et al. 2015, Santesteban-Echarri, Paino et al. 2017). Longer durations of psychosis can also lead to social and functional repercussions by disrupting critical developmental trajectories in young persons lives (Marshall, Lewis et al. 2005). The duration of untreated psychosis is comprised of help-seeking delays (i.e., the time between the onset of a psychosis and the first mental health contact) and referral delays (i.e., the time between the first mental health contact until the referral to an early intervention service for psychosis) (Bechard-Evans, Schmitz et al. 2007). For these reasons, reducing the duration of untreated psychosis and offering high-quality treatment early on to persons affected by FEP early on have become global priorities.

1.7 Early Intervention Services for First Episode Psychosis

Early intervention services for psychosis are widely recognized as the gold standard of care for FEP. Early intervention services were created in the 2000s as a reaction to the pessimistic forms of treatment typically offered to persons experiencing psychosis up until that point; and from emerging evidence that treating psychosis early in its course can improve long-term outcomes (McGorry, Killackey et al. 2008).

Early intervention services usually offer treatment within the *critical period* of a person's illness. This period spans the first two to five years following the beginning of a person's illness. The critical period is considered to be the most malleable phase for improving long term outcomes for service users (Birchwood, Todd et al. 1998). Studies have shown that while two years of treatment at early intervention services may improve patient outcomes, receiving five years of treatment may potentially be more beneficial (McGorry, Killackey et al. 2008, Norman, Manchanda et al. 2011, Malla, Joober et al. 2017).

Treatment offered at early intervention services often includes comprehensive assessments and care; pharmacotherapy using available antipsychotic medications; psychotherapy targeting depression, anxiety, and posttraumatic stress disorder; as well as psychosocial, psychoeducational, and family-based interventions (Addington, McKenzie et al. 2013, Iyer, Jordan et al. 2015).

The World Health Organization and International Early Psychosis Association consensus statement on early intervention services outlines five targets for early intervention services (Bertolote and McGorry 2005). These include “improving access and engagement; raising community awareness; promoting recovery; family engagement and support; and practitioner training”. These guidelines also state that early intervention services should challenge stigma; raise awareness about psychosis; assist practitioners in better supporting persons affected by FEP; and foster optimism and expectations for recovery (Bertolote and McGorry 2005).

In addition to meeting these targets, an important aim of early intervention services is to reduce durations of untreated psychosis among persons living in communities where early intervention services are based (McGorry, Killackey et al. 2007). A common strategy to reduce durations of untreated psychosis involves carrying out targeted early case identification campaigns designed to inform either the public or healthcare professionals about the presentation of FEP (Lloyd-Evans, Crosby et al. 2011). A second such strategy may involve making such services more easily accessible for persons seeking help, such as by having an open referral source policy, or promptly offering care to persons seeking help (MacDonald, Malla et al. 2018).

Despite the optimism of the early intervention movement and the orientation of early intervention services towards providing recovery-oriented and strengths-based care, most research in psychosis has operated from a focus on its negative aspects and has included examinations of risk factors; negative pathways to care; symptoms, relapses and hospitalizations; cognitive and functional declines; disease burden and poor quality of life; and caregiver burden. With some exceptions (e.g., research on subjective perceptions of recovery), very little research has sought to address positive outcomes following a FEP, and there appears to be a paucity of research examining the positive changes that persons may experience following an FEP.

2. The Continuity between Mental Illness and Mental Health

The proposition that experiencing a mental illness may lead to positive changes may seem counterintuitive. After all, psychotic disorders (especially schizophrenia) are associated with a large, costly, multifaceted burden to persons themselves, their families, and society (Rossler, Salize et al. 2005). Mental illness has been seen as an indicator of poor mental health (Keyes 2005) or a lack of resilience (Levine, Laufer et al. 2009).

Distinctions between mental illness and mental health however may not be so clear cut. For instance, positive change has been reported following the *trauma* or *distress* induced by a wide range of negative experiences, such as cancer (Jim and Jacobsen 2008), HIV(Sherr, Nagra et al. 2011), burns (Martin, Byrnes et al. 2017), interpersonal violence (Elderton, Berry et al. 2015), multiple sclerosis (Barskova and Oesterreich 2009, Hefferon, Grealy et al. 2009), and brain injury (Grace, Kinsella et al. 2015). A new iteration of positive psychology recognizes that both positive and negative emotional states are important and can contribute to positive development (Wong 2011). Similarly, it is recognized that both positive and negative emotions can occur following an adverse experience (Fredrickson, Tugade et al. 2003, O'Donnell, Creamer et al. 2004).

Some have argued and shown that mental health and mental illness represent two correlated and independent dimensions of a singular experience, with evidence of poor mental health presenting in persons without diagnosed mental illnesses (Keyes 2005). Consistent with this, epidemiological studies have shown that psychotic experiences are more common in the general population than psychotic disorder diagnoses (van Os, Linscott et al. 2009), and thus occur in “healthy” people. Some psychotic experiences have been reported to serve benign, purposeful or supportive functions (Jenner, Rutten et al. 2008). In addition, persons who have experienced psychosis can also possess resources that foster resilience (Lal, Ungar et al. 2017). Finally, individuals are able to experience a subjective sense of recovery while still experiencing symptoms of mental illnesses (Davidson 2009). Hence, the presence of mental illness does not automatically preclude wellbeing, flourishing or growth.

3. The Affirmation Model of Disability and its Links to Neurodiversity, Mad Pride, and the Recovery Movement

A useful starting point for discussing positive change following FEP is a description of the affirmation model of disability, which stems from a disability studies framework. In short, the affirmation model of disability rejects the notion that disability and impairment are personal tragedies. This model instead purports that disability and impairment can be beneficial (Swain 2000). One group for which the affirmation model has been deemed relevant is the neurodiversity community. This community consists of persons with high-functioning autism as well as persons diagnosed with other conditions traditionally viewed as deficits, such as persons with attention deficit hyperactivity disorder or Tourette's syndrome. A key tenet of the neurodiversity movement is that such "conditions" are not "deficits"; rather, they are "differences" that should be respected and celebrated—not cured (Jaarsma and Welin 2012).

Some members of the Mad Pride movement, which is a "movement of psychiatric consumers/survivors/ex-patients/mental health service users who self-identify as proud of their Mad identity" (LeFrancois 2013); p. 337), also identify with the affirmation model. It has been claimed that there is a positive side to schizophrenia (Chadwick 1997), which is consistent with the affirmation model. However, others argue that distress arising from psychiatric disorders is problematic and should not be cherished or celebrated (Graby 2015).

In a related vein, the Recovery Movement arose from the work of consumer activists who rejected the medical model of mental illnesses and the dehumanizing forms of treatment they were subject to as patients; as well as from research demonstrating that recovery is a common long-term outcome among persons with serious mental illness. Core tenets of the Recovery Movement are that persons with mental illness can recover or may live full lives while still experiencing symptoms (Davidson 2016). As described later in this chapter, many first-person accounts and qualitative reports of recovery following serious mental illnesses describe how positive change is a characteristic that is inherent in the recovery process.

4. Emerging Adulthood and Developmental Perspectives on Positive Change

Most mental illnesses (including FEP) have their onset when individuals are young (Kessler, Amminger et al. 2007) and living through early adolescence or a developmental phase known as emerging adulthood. This phase has been described as a distinct developmental period in industrialized societies spanning the ages between 18 and 25 (sometimes 30) years. Emerging adulthood has been characterized by great fluctuation and experimentation with identity formation, work, romantic relationships, and views about the world (Arnett 2000). Thus, positive changes following FEP may interact or co-occur with the processes of maturation occurring during emerging adulthood.

Pioneering writers such as Jung (Jung 1993) and Maslow (Maslow 1943, Maslow 1954) described how humans are on a natural developmental course towards full personhood. Of note, Jung described how humans are on an involuntary, natural path of self-discovery, growth and creativity. Jung described this progression as the process of individuation and argued that the individuation process could be initiated by a crisis. Subsequent work by Perry (Perry 1974) described how the process of individuation could be brought about through psychosis. Recent theorists have argued that the processes of human development and positive change following advertises have many similarities (Aldwin, Levenson et al. 2009). For instance, studies have shown that developmentally normative events experienced by emerging adults (e.g., transitioning to university) can also lead to positive changes (Gottlieb 2007, Iimura and Taku 2018).

Models of Positive Change following Adversity

5.1 Important Early Theoretical Foundations of the Study of Positive Change Following Adversity.

Accounts of how positive change or growth can follow adversity have been chronicled throughout history (Linley 2003). Most major world religions, including Buddhism, Christianity, Hinduism, Islam and Judaism, describe the potential for positive change following suffering (Tedeschi and Calhoun 1995). Most modern approaches to understanding positive change following adversity are rooted in the existential philosophies of Yalom (Yalom 1980), who argued that in the face of existential anxiety, people can grow; and in Frankl's (Frankl 1959) autobiographical account of searching and finding meaning and purpose while being held captive in a Nazi concentration camp. Caplan (Caplan 1964) described how an inability to cope with stress can prompt disorganization, followed by greater self-understanding. Aldwin and colleagues described how if persons have many resources available to deal with a negative experience, they will successfully cope with the experience, which may lead to new opportunities (Aldwin 1988, Aldwin 1994, Aldwin, Sutton et al. 1996). Similarly, Schaefer and Moos (Schaefer and Moos 1992, Schaefer and Moos 1998) described how persons can experience enhanced personal, coping and social resources following life crises; and that coping strategies as well as personal, environmental and crisis-related factors could facilitate such changes. Drawing inspiration from myths and legends (Campbell 1949), Frank's work described three trajectories and narrative styles which follow the experience of illness, including the restitution narrative, the chaos narrative, and the quest narrative. The quest narrative, where, “losses continue to be mourned, but the emphasis is on gains” (p.128) fits well within concepts of positive change (Frank 1997). Narrative approaches to conceptualizing positive change have also been developed (Pals and McAdams 2004).

5.2 Posttraumatic Growth.

The most well-established and empirically tested model of positive change is that of Posttraumatic Growth (PTG) (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006). PTG refers to veridical, profound and positive shifts in functioning that follow the highly emotional *struggle* with traumatic or highly stressful experiences.

PTG typically follows negative experiences that significantly challenge the schemas, concepts and paradigms that people use to understand the world and themselves. Five domains of PTG have been proposed by Tedeschi and Calhoun (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006). These domains include having a greater appreciation for life; closer, more intimate relationships with others; increased personal strength; new possibilities and paths in life; and greater spiritual or existential growth. Other domains of PTG have also been reported and seem linked to the types of trauma or negative experiences following which people have reported growth. For instance, persons may develop a new awareness of the body following physical illness (Hefferon, Grealy et al. 2009); or perceive a change in power and movement from a “victim to survivor” following interpersonal violence (Thompson 2000).

Tedeschi and Calhoun have outlined a process through which PTG occurs. Following a highly negative experience, individuals engage in intense, automatic cognitive processing about the experience. Such processing features intrusive rumination over the experience and the suffering it has induced. As persons begin to accept that the experience occurred, they may begin to cope with the impact of the negative experience. Persons may become less distressed about the experience, and disengage from now unattainable goals. Eventually, persons engage in more deliberate forms of rumination over the experience, which may involve re-appraising one's situation; finding meaning in what has happened; reconstructing their understanding of their post-experience world; and evaluating how PTG has occurred. The emergence of PTG may be reinforced by wisdom and the development of a new life narrative (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006).

PTG may be an adaptive experience that can enhance a person's ability to deal with future negative experiences. However, Tedeschi and Calhoun (Tedeschi and Calhoun 2006) also note that persons who have experienced PTG may nonetheless still feel significant amounts of distress related to the experience.

5.3 Challenges to the PTG model.

While the PTG model has received tremendous empirical support (Bostock, Sheikh et al. 2009, Meyerson, Grant et al. 2011, Harding, Sanipour et al. 2014, Elderton, Berry et al. 2015), some authors have levelled criticism against this model. For instance, Zoellner and Maercker have proposed a two-component model of PTG that highlights PTG's illusory side and its transformative side (Zoellner and Maercker 2006, Zoellner, Rabe et al. 2008). The illusory side may reflect a coping mechanism related to self-enhancing cognitions that persons may experience in the face of immediate stressful events. This component is related to using avoidant coping strategies such as denial; and has been theorized to predict declines in functioning following an adverse experience. Conversely, the transformative side of PTG results from the actual struggle with trauma, and is associated with gains in functioning. Both the illusory and transformative components of PTG can coexist while persons struggle to make sense of what has occurred to them.

Like Zoellner and Maercker’s two-component mode (Zoellner and Maercker 2006), Hobfoll and colleagues argued that PTG is comprised of both constructive and illusory components (Hobfoll, Hall et al. 2007). Both components may lead to functional or psychological declines if the meaning derived from adverse events is not translated into behavioural action. Interestingly, Hobfoll and colleagues argued that acting on the illusory component of PTG is the key ingredient for experiencing the constructive component of PTG. According to them, persons who act on the illusory component of PTG may experience improvements in psychological functioning and resilience; whereas persons who do not act on the cognitions associated with the illusory component experience functional declines.

6. Additional models of positive change

In addition to these aforementioned models, several additional models have been developed to account for how persons grow following adversity. These models have conceptualized the ontology of positive change in ways that are different from PTG, and therefore add breadth to our understanding about the types of positive change people experience following adversity. However, fewer studies have been conducted focused on these models, which is in contrast to the empirical attention that PTG has enjoyed.

6.1 Stress-related Growth and the Meaning-Making Model.

Stress-related growth was originally described as positive change resulting from *stressful* experiences. Aspects of stress-related growth include discovering improved ways of coping with stress; broadening one’s life perspectives; and developing improved personal and social resources (Park, Cohen et al. 1996). Later, the concept of stress-related growth was clarified as being veridical (as opposed to illusory); less dramatic than other forms of positive change; and relatively common and permanent (Park 2009).

Stress-related growth was eventually described as a common form of meaning that persons ascribe to the aftermath of a negative life event or experience. In the meaning-making model of stress-related growth (Park 2010, Park 2013), negative experiences are seen as contributing to distress and discrepancies between one's global meaning (e.g., how persons understand the universe, God, etc.) and situational meaning (e.g., how persons appraise stressors, etc.). This leads persons to search for ways of reducing these discrepancies through finding meaning in what had happened, such as by engaging in positive reappraisals of the experience (Park 2010). Multiple forms of meaning may result from the meaning-making process, and include having changed beliefs; developing causal attributions about why the experience happened; integrating the negative experience into one's self concept; and developing perceptions of having grown or benefited from the negative experience (Park 2010, Park 2013).

6.2 Cognitive adaptation theory.

According to cognitive adaptation theory (Taylor 1983, Taylor and Armor 1996, Taylor, Kemeny et al. 2000), negative experiences may lead persons to enhance their own perceptions of themselves; experience unrealistic optimism about what has happened; and believe they are in control of events even when the opposite is "true". Taylor argues that such positive illusions are important for maintaining and promoting positive psychological adjustment; whereas viewing a negative situation as it "really" is can lead to depression and anxiety. It may be important to note that Taylor developed her theory while working with cancer and HIV patients in the 1980s, when the hope that one could thrive or even survive with this illness was low.

6.3 Benefit finding.

Similar to Cognitive Adaptation Theory, benefit finding refers to the "the process of deriving positive growth from adversity" (Helgeson, Reymolds et al. 2006). Benefit finding results in *perceptions* that positive change has occurred following adversity (Tennen and Affleck 2002, Park 2009). Benefit finding may reflect actual change or the illusion that change has occurred (Davis and Nolen-Hoeksema 2009). Benefit finding may be transient; and is a common response to adversity (Park 2009).

6.4 Organismic valuing theory.

The premise of Organismic Valuing Theory is that humans are intrinsically motivated along an organismic valuing process, or a path of continuous improvement, growth and actualization (Joseph and Linley 2005, Joseph and Linley 2006). Adversity plays a role in the organismic valuing process by challenging individuals' assumptive world, forcing them to let go of old ways of thinking about themselves, others, and the world around them. Following an adverse event, persons can either assimilate the trauma or accommodate and revise their assumptive world. Individuals experience positive change when the adverse event is accommodated in a positive way.

Positive change following psychosis

Descriptions of the positive consequences of mental illness are not new. For instance, Socrates explained how the madness of lovers and poets, initiation and prophecy were gifts (Jowett 1892). The following review is not exhaustive, but features the key historical foundations of, and empirical work investigating, positive change following psychosis.

Perhaps the first modern theorist to describe the value of psychosis was Carl Jung. Specifically, Jung argued that psychosis was nature's attempt to heal an affected individual

(Perry 1974, Perry 1999); and that the irrational thinking of the unconscious and psychosis were meaningful (Jung 1967). Jung himself experienced a psychotic episode which profoundly shaped his theories and career (Kyburz, Peck et al. 2009).

Jung's model of human development (Jung 1993) (i.e., the process of individuation) informed how John Perry saw the value of psychosis. Perry argued that a psychosis could help persons heal old wounds and initiate the process of individuation; and if handled properly, psychosis could lead to self- renewal, growth, authenticity, a new life direction, and improved relationships (Perry 1974, Perry 1999). Perry argued against interfering with psychosis in any way in order to give the unconscious the time and space that it needed to foster self-renewal and positive change. He was especially critical of prescribing antipsychotic medications to treat psychosis. However, Perry argued that other persons (e.g., therapists) could help facilitate the process of self-renewal by listening to persons experiencing psychosis with love and compassion and without judgement; and by helping persons experiencing psychosis understand the deeper meaning of their psychosis.

Similar to these psychodynamic conceptualizations of how psychosis could initiate healing and self-renewal, transpersonal psychologists have described phenomena akin to psychotic experiences (e.g., voice hearing, seeing visions) as expressions of a spiritual experience or emergency. A spiritual emergency entails a process of "spiritual awakening" that follows a crisis, trauma, or religious or spiritual practice (e.g., meditation) (Grof and Grof 1989). Such awakenings can lead to improved health; freedom; and connections with others and the universe (Grof and Grof 1991).

While psychoanalytic and transpersonal traditions describing positive change following psychosis (or psychotic-like experiences) may be interesting on a philosophical level, and highlight the history of the field, the validity of these traditions has often been met with skepticism. Although these traditions suggest that positive changes may follow psychosis, it can be argued that such a conclusion was arrived at through largely unfalsifiable, unscientific methods of inquiry.

Arguably more amenable to scientific inquiry was the approach of Epstein to understanding how psychosis or psychotic-like phenomena can bring about positive change (Epstein 1979). He developed a cognitive model of how schizophrenia could lead to an improved organization of a person's conceptual systems. He described how schizophrenia arose from the disintegration of a person's "conceptual integrative system" (p. 313). Disintegration begins when one encounters information that cannot be integrated within one's conceptual system, such as threats from the outside world. When confronted with such threats, persons activate coping strategies such as withdrawal and denial. Eventually, persons are forced to reconfigure their assumptions about themselves and the world. In some cases, this reorganization will lead to a newly organized, resilient conceptual system that will be "better able to accomplish the functions of an implicit theory of reality" (p. 313). While Epstein's work is interesting, it did not launch an empirical field of inquiry into how positive changes can follow psychosis.

Most modern, empirical work describing positive change within the context of serious mental illnesses like psychosis has contextualized such change as being part of—or the end result of—a personal, or "consumer"-defined recovery process. Rather than reflecting a return to "normal" (Deegan 1996), personal recovery has been broadly defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitation caused by illness. Recovery involves the development of new meaning and purpose in one's life *as one grows* beyond the catastrophic effects of mental illness" (p.527) (Anthony 1993). This definition highlights the role of positive change in recovery; and demonstrates congruence with concepts investigated by positive psychologists (Slade 2010).

Several literature reviews and qualitative studies have described elements of positive change as occurring within the context of personal recovery. For instance, one review presented stage models of recovery which describe "growth" as a final stage of the recovery process (Andresen, Oades et al. 2003). However, stage models often do not take into account the non-linear and shifting nature of the recovery process (Jacobson and Greenley 2001). Given this, positive change may occur at different phases during the recovery process.

In addition to the recovery model described by Andresen et al (2003), several qualitative studies have described recovery as an expression of one's ability to thrive (Onken, Craig et al. 2007) or transform (Mancini 2007) beyond pre-illness ways of being; as a process of learning and refining one's self-definition (Young and Ensing 1999); and as a function of coping (Roe and Chopra 2003) or meaning-making whereby persons construe their "illness as evolution" (Pettie and Triolo 1999).

Positive change may also reflect specific forms or processes of recovery in serious mental illnesses like psychosis, which have been varyingly conceptualized thus far. Three such conceptualizations are integrative versus sealing-over recovery styles (McGlashan, Levy et al. 1975), philosophical or spiritual styles (Jacobson 2001), and a political/activist style (Jacobson 2001). Persons with an integrative recovery style may be curious about, and accepting of their experience of psychosis; and may also attempt to find personal significance and meaning in their psychosis. They may also experience growth following their psychosis (McGlashan, Levy et al. 1975). Persons with philosophical or spiritual explanatory models of their mental illness may recover in a way that leads them to feel reborn, enlightened, wiser and more compassionate (Jacobson 2001). Persons with a political explanatory model of mental illness experience recovery as defined by engaging in political activism (Jacobson 2001), which may yield benefits to activists themselves (Klar and Kasser 2009) as well as society.

Given the importance of recovery to experiences of growth and positive change from serious mental illnesses, recovery, in addition to PTG, is a useful lens through which to understand positive change following FEP.

7. Facilitators and Predictors of Posttraumatic Growth

Most of the empirical work examining predictors of PTG has been conducted with respect to adverse experiences other than psychosis-spectrum disorders. The predictors of positive change that have been examined include demographic factors; adversity or event-related factors; treatment-related factors; and post-trauma factors.

7.1 Demographic factors.

Several demographic factors may be important in the experience of PTG. For instance, females may experience greater PTG following adversity relative to males (Helgeson, Reynolds et al. 2006, Vishnevsky, Cann et al. 2010, Hirooka, Fukahori et al. 2018). Reasons for these differences may reflect differences in how females tend to experience trauma and cope with its aftermath (Vishnevsky, Cann et al. 2010). Younger people may also experience greater PTG than older people (Linley and Joseph 2004, Ramos and Leal 2013, Husson, Zebrack et al. 2017). This may be because younger people possess greater openness to experience [which may be related to positive change (Karanci, Isikli et al. 2012)] relative to older people (Donnellan and Lucas 2008). Finally, there is some evidence suggesting that socioeconomic status (Jim and Jacobsen 2008, Wilson, Marin et al. 2016), ethnicity (Jim and Jacobsen 2008, Kent, Alfano et al. 2013) and education (Grace, Kinsella et al. 2015) are related to PTG (Linley and Joseph 2004). However, the direction of these effects is very heterogeneous and there is no conceptual clarity as to why these factors may predict PTG.

7.2 Adversity/Event-related factors.

Several characteristics and processes associated with adverse experiences or events have been associated with PTG. One characteristic is the degree to which an adverse experience is perceived as traumatic, stressful or impactful. Tedeschi and Calhoun have argued that the distress arising from a negative experience may have a curvilinear relationship with PTG (Tedeschi and Calhoun 2006). Experiences that produce low distress may have a lower likelihood of shattering a person's assumptions about the world, in turn reducing the chances of PTG. Conversely, highly distressing experiences may overwhelm a person's ability to cope, which may also preclude PTG from occurring. Hence, PTG is more likely to occur in persons who experience a moderate amount of distress. Empirical studies have largely supported this claim, especially when the form of distress measured relates to posttraumatic stress symptoms (Kleim and Ehlers 2009, Shakespeare-Finch and Lurie-Beck 2014).

The severity of an illness may correspond to the severity of distress caused by an illness. However, studies investigating the severity of an illness or the general negative impact of an experience on PTG have yielded more mixed results (Devine, Reed-Knight et al. 2010, Harding, Sanipour et al. 2014). Within the context of multiple-episode psychosis, one study investigating PTG in persons who have experienced multiple psychotic episodes revealed that positive and negative symptoms were negatively correlated with PTG (Mazor, Gelkopf et al. 2016).

An additional adversity-related factor related to PTG may be the amount of time that a person has had to process an adverse experience (Tedeschi and Calhoun 1995, Tedeschi and

Calhoun 2004, Tedeschi and Calhoun 2006). Given that many models of positive change describe such change as unfolding through a gradual process (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Joseph and Linley 2005, Tedeschi and Calhoun 2006), individuals may need a sufficient amount of time to experience PTG. Findings from several studies support this hypothesis (Danhauer, Case et al. 2013, Grace, Kinsella et al. 2015, Morgan and Desmarais 2017). However, other studies have not found an association between PTG and the amount of time that has elapsed following an adverse event (Basak and Atak 2015, Wayment, Al-Kire et al. 2018).

Finally, some adverse experiences may be likelier to lead to PTG than others. One meta-analysis showed that the relationship between PTSD and PTG was greatest in civilians living in conflict zones and in survivors of natural disasters (Shakespeare-Finch and Lurie-Beck 2014). A review of PTG among burn victims showed that victims with more visible burns were more likely to experience PTG (Martin, Byrnes et al. 2017). However, rather than being attributable to the experience itself, these findings may be a reflection of the perceived impact of the experience (Linley and Joseph 2004).

7.3 Post-Adversity Factors.

Coping. Coping has most often been defined as the attempt “to prevent or diminish threat, harm, and loss, or to reduce associated distress”(p.685) (Carver and Connor-Smith 2010). However, other definitions of coping exist and reflect the vast number of coping models which have been developed since the beginning of the 20th century. Early conceptualizations of coping described coping strategies as defense mechanisms to ward off anxiety (Somerfield and McCrae 2000). Modern approaches to coping began with Lazarus and Folkman’s work that conceptualized coping as a cognitive process (Folkman and Lazarus 1980, Lazarus and Folkman

1984). These modern approaches recognize that coping is a multifaceted, multidimensional, contextually bound process embedded within complex structures, such as hierarchies (Skinner, Edge et al. 2003). Whether coping strategies are adaptive or not depends largely on the context coping occurs in; and the same coping styles may be effective in some situations but not others (Folkman and Moskowitz 2004). Some coping dimensions that have received empirical attention include problem- and emotion-focused coping; engagement and disengagement coping; primary and secondary coping; as well proactive coping (Compas, Connor-Smith et al. 2001, Carver and Connor-Smith 2010). Some have argued that investigating these and other coping dimensions should be abandoned in favor of investigating action-based categories of coping such as mastery (Skinner, Edge et al. 2003).

Researchers have long been interested in how coping relates to positive change. Some have argued that PTG is in some part or fully a reflection of a person's attempt to cope with stress (Taylor 1983, Taylor and Armor 1996, Taylor, Kemeny et al. 2000, Zoellner and Maercker 2006, Zoellner, Rabe et al. 2008). Others have argued that how persons cope with an adverse experience greatly determines if PTG will occur following a negative experience (Tedeschi and Calhoun 2006, Park 2010).

Most research investigating how coping predicts or relates to PTG has examined dimensions (e.g., problem- vs emotion- focused) or categories (e.g., substance use, religious coping, acceptance, etc.) of coping. Of these, positive reframing and religious or spiritual coping seem to be the strongest predictors of PTG (Prati and Pietrantoni 2009). Positive reframing has been shown to predict PTG in both cross-sectional and, to a lesser extent, longitudinal studies (Barskova and Oesterreich 2009, Prati and Pietrantoni 2009). Other coping categories that predict PTG include problem-focused coping; emotion-focused coping; as well as acceptance and approach coping (Linley and Joseph 2004, Barskova and Oesterreich 2009, Prati and Pietrantoni 2009, Elderton, Berry et al. 2015, Shand, Cowlishaw et al. 2015). Conversely, coping categories such as avoidance coping are generally unrelated to PTG (Barskova and Oesterreich 2009).

In the domain of mental illnesses, research has shown that persons can employ effective coping strategies to manage their illness (Mueser, Rosenberg et al. 2002); (Yanos and Rosario 2014), both prior to and after an FEP (Kommescher, Gross et al. 2017). However, there is other evidence that suggests that some persons with psychosis-spectrum disorders have limited capacity to effectively cope with stress (Taylor and Stanton 2007, Wigman, Devlin et al. 2014, McNeill and Galovski 2015). Thus far, three studies have found a relationship between coping and PTG in persons with multiple-episode psychotic disorders. Two studies showed that self-efficacy coping mediated the relationship between psychotic symptoms and PTG (Mazor, Gelkopf et al. 2016); and between posttraumatic stress symptoms and PTG (Mazor, Gelkopf et al. 2018). A third study reported a positive relationship between “effective” coping approaches (which the authors defined as social support as well self-confident and optimistic coping strategies) and PTG (Simsek and Buldukoglu 2018). The degree to which coping predicts PTG following FEP is unknown, but may be consistent with how coping predicts PTG in other contexts.

Social support. There is no agreement on how to best define social support (Uchino 2006). Social support commonly refers to as referring to resources available within a person’s social network that could help cope with stress and negative experiences (Cohen 2000). Some recognized forms of social support include emotional support (e.g., being empathetic, warm and caring with a person); instrumental support (e.g., providing concrete support, such as financial aid etc.); informational support (e.g., providing suggestions, guidance and perspective about a problem, etc.); and appraisal support (e.g., providing help with making decisions, etc.) (House 1981, House, Kahn et al. 1985). Structural elements of an individual's social world are also important for social support (e.g., having a family, belonging to a group) (Cohen 2000).

The role of social support in promoting physical and mental health is well established (Cobb 1976, Berkman, Glass et al. 2000, Uchino 2006). In general, the perception that one has social support (i.e., perceived social support) is a better predictor of health outcomes than the actual social support persons receive (Uchino 2009). Yet, social support can also have a negative impact on a person's health and wellbeing (Thoits 2011); for instance, if social support leads to conflict or oppression. Social support can help persons deal with stress arising from difficult events and everyday circumstances (Cohen and Wills 1985). Serious stressors and challenges may change the nature of support persons receive from others; and persons experiencing serious crises often turn to secondary sources of social support, such as mental health professionals (Thoits 2011).

Tedeschi and Calhoun have theorized that social support is instrumental in facilitating PTG (Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006). In addition to social support being generally mportant for helping persons cope with distress, social support can offer opportunities for self-disclosure and for the development of narratives around survival and growth (Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006). These claims have received strong empirical support, as PTG has consistently been predicted by perceived social support from friends, families and professionals (Linley and Joseph 2004, Prati and Pietrantoni 2009, Elderton, Berry et al. 2015, Shand, Cowlishaw et al. 2015).

Social support has been shown to predict a range of outcomes in persons who have experienced FEP, such as lower levels of positive symptoms and fewer hospitalizations (Norman, Malla et al. 2005); improved social and occupational functioning (Erickson, Beiser et al. 1998); and medication adherence (Rabinovitch, Cassidy et al. 2013). Yet, no study has investigated if social support predicts PTG within the context of psychosis.

Resilience. Conceptualizations of resilience have evolved substantially since resilience was first described (Ungar 2011). Originally seen as a trait that persons possess to help them bounce back from stress, recent ecological approaches to resilience acknowledge the multiple personal, social, cultural, temporal, and historical factors which foster one's ability to cope with stress; and the capacity of persons to navigate and use such resources (Bottrell 2009, Ungar, Ghazinour et al. 2013). One important definition of resilience that reflects its ecological nature has been developed by Ungar (2008):

"In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided and experienced in culturally meaningful ways"(Ungar, 2008) (p. 225).

There is a lack of consensus on how resilience and PTG or other constructs of positive change are different. For instance, resilience and PTG have been described as common salutogenic processes leading to positive adaptation (Westphal and Bonanno 2007). PTG and resilience have also been described as synonymous or identical processes (Hobfoll, Hall et al. 2007). Tedeschi and Calhoun (Tedeschi and Calhoun 2004) have argued that resilience is an adaptive response to negative events that leads to recovery, and is therefore unrelated to PTG.

This argument has received some empirical support (Vieselmeyer, Holguin et al. 2017) (Levine, Laufer et al. 2009).

Although some attempts to distinguish PTG from resilience have been made, and several studies have investigated the impact of resilience on PTG, such work has important limitations. PTG researchers have either conceptualized or measured resilience as a trait (Garrido-Hernansaiz, Murphy et al. 2017, Li, Liu et al. 2018, Yuan, Xu et al. 2018) (Vieselmeyer, Holguin et al. 2017); defined resilience as the absence of psychopathology in empirical studies (Kaye-Tzadok and Davidson-Arad 2016); or defined resilience vis à vis PTG as a marker of healthy functioning (Westphal and Bonanno 2007). This work is perplexing since persons with mental illness such as schizophrenia have been demonstrated to possess resilience (Garmezy 1970, Perlman, Patterson et al. 2017, Sumskis, Moxham et al. 2017). To date, no study has investigated if ecological forms of resilience predict PTG, which is a major limitation in the field.

Recovery. As described above, within the PTG literature, recovery has seldom been considered a predictor of PTG following adversities other than mental illnesses. Recovery is typically conceptualized as a return to normality within the field of PTG (O'Leary and Ickovics 1995, Carver 1998, Tedeschi and Calhoun 2006, Zoellner and Maercker 2006, Westphal and Bonanno 2007); and has even been described as a state that “does not easily allow for transformative outcomes” (p.1), at least within the context of bereavement (Tedeschi and Calhoun 2008). However, personal definitions of recovery from mental illness are highly commensurate with definitions of positive change. As described in the early parts of this chapter, positive changes are sometimes framed as part of the process of recovery from mental illness. Further, recovery may even be an important facilitator of positive change following FEP. Hence, while recovery has not been conceptualized as a predictor of PTG by PTG researchers, there are strong theoretical and empirical justifications for examining recovery within the context of PTG following serious mental illnesses like psychosis.

7.4 Treatment-related factors. Some conceptual models of positive change have described how receiving treatment or care following adversities other than mental illnesses may facilitate PTG (Mahoney 1985, Hager 1992). There is emerging evidence showing that PTG is a possible outcome following a range of psychological interventions (Roepke 2015) such as cognitive behavioral therapy (Wagner, Torbit et al. 2016). In addition, there is mixed evidence showing that interventions aimed at treating the underlying causes of illnesses such as cancer may also facilitate PTG (Lelorain, Bonnaud-Antignac et al. 2010). Finally, perceptions of care may also influence PTG (Simsek and Buldukoglu 2018). However, there is a paucity of literature demonstrating the impact of treatment (e.g., medications, psychotherapy, etc.) on positive change following mental illnesses, including psychosis. Overall, it can also be theorized that the contributions of treatment to positive change and PTG following illnesses can operate through other well-supported mechanisms underpinning PTG such as effective coping, social supports, etc.

Summary

A psychosis is a serious mental illness with often devastating consequences (WHO, 2008). Early intervention services are a key provider of care for FEP (McGorry, Killackey et al. 2008). Despite the optimism inherent in early intervention services, most research on FEP has focused on the negative consequences of FEP. While this research has generated important knowledge, the apparent paucity of knowledge on the positive changes following FEP may preclude the development of strengths-based, resilience enhancing care in early intervention services.

A substantial body of knowledge on positive change (namely, posttraumatic growth) following adversity exists. A plethora of studies have established that positive change can follow physical adversities and the trauma which follows; and that specific demographic, adversity-related, post-adversity, and treatment-related factors facilitate or predict positive change. (Bostock, Sheikh et al. 2009, Sawyer, Ayers et al. 2010, Meyerson, Grant et al. 2011, Rajandram, Jenewein et al. 2011, Harding, Sanipour et al. 2014, Martin, Byrnes et al. 2017). However, it is unclear if any studies have investigated positive change following a first episode of psychosis.

Given this paucity of knowledge, this dissertation aims to answer two research questions using a combination of methods: 1) what are the positive changes persons experience following a first episode of psychosis, and 2) what are the facilitators of positive change following a first episode of psychosis?

The following chapter (Chapter Two) is a scoping review which examines the state of knowledge on PTG following FEP. In Chapter Three, a systematic review synthesizing all available scientific, peer-reviewed knowledge on positive change following FEP is presented. Chapter Four presents the paradigms guiding this work. Chapter Five describes how reflexivity was applied when conducting my Doctoral research. Chapter Six presents the research protocol developed to address the two research questions using an empirical, mixed methods approach. Chapters Seven and Eight address the first and second research questions, respectively, through an empirical, mixed methods study. The conclusion to this thesis is presented in Chapter Nine.

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Chapter Two

Title: Post-traumatic growth following a first episode of psychosis: A scoping review

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Abstract

Background: A first episode psychosis (FEP) is a traumatic experience that results in great suffering. However, in addition to suffering, persons affected by FEP may also experience post traumatic growth (PTG), or the perception that good has followed psychosis. While much is known concerning the negative outcomes following FEP, little is known concerning the state of scientific knowledge on PTG following FEP **Aims**: To determine the state of knowledge concerning PTG following FEP to help set the stage for a full systematic review. **Methods**: A scoping review was conducted following six steps: identifying the research question and relevant studies; selecting studies; charting the data; coding and summarizing results; and consulting with relevant stakeholders regarding the findings. **Results**: PTG following FEP was described mostly following recovery, and embedded within qualitative articles. Themes related to PTG included developing positive character traits; making positive lifestyle changes; developing stronger connections with others; integrating the FEP with the self; experiencing greater religiosity; and appreciating life more. **Conclusions**: In addition to the negative aftermath of FEP, PTG may also occur. Evidence of PTG following FEP will be explored in a systematic review focused on the recovery and qualitative literature. **Declaration of Interest**: None.

Keywords: First episode psychosis; post traumatic growth; scoping review; qualitative research; recovery

Introduction

A first episode psychosis (FEP) is often a traumatizing, disruptive experience that leaves young people and their families confused, demoralized and distressed. Not only is the experience of FEP highly traumatic and stressful, but FEP's aftereffects may carry a burden which may sometimes last for years. For instance, young people who have experienced FEP have described feeling a loss of self, a sense of alienation from the world and from who they were before the episode. Family life and friendships may also be disrupted, as young people have reported drifting away from previous social circles for reasons that include stigma, depression, anxiety, and the presence of negative symptoms. Upon resolution of the acute phase of illness, some young people may experience residual symptoms—especially negative symptoms—which continue to impair their daily lives (Boydell, Stasiulis et al. 2010, McCarthy-Jones, Marriott et al. 2013, Vodušek, Parnas et al. 2014). However, while suffering may be part of the experience of FEP, many individuals recover; in addition, some who have recovered or are in the processes of recovering may feel that they have experienced positive outcomes as a result of FEP.

The experience of positive outcomes following traumatizing events or illnesses (e.g., war, the death of a child, cancer etc.) and their associated negative mental health outcomes—such as depression, anxiety and post-traumatic stress disorder—have been well-documented in multiple systematic reviews and meta-analyses (Barskova and Oesterreich 2009, Bostock, Sheikh et al. 2009, Hefferon, Grealy et al. 2009, Sawyer, Ayers et al. 2010, Vishnevsky, Cann et al. 2010, Meyerson, Grant et al. 2011). These reviews have synthesized findings on the positive outcomes following illnesses using the rubric of posttraumatic growth (PTG), incorporating in this rubric the positive changes which have resulted from experiencing illness, trauma and tragedy (Calhoun and Tedeschi 2006, Barskova and Oesterreich 2009, Bostock, Sheikh et al. 2009). A defining feature of PTG is that it constitutes *permanent* and actual, or *veridical* positive change in people experiencing trauma, tragedy or illness; changes which constitute PTG are pervasive, stable, and seen to be wholly transformative. Facets of PTG include reappraising life and personal priorities (e.g., acquiring new values, developing a new appreciation for life, giving up control, etc.); developing personal strengths of character (e.g., increasing empathy, developing a survivor identity, gaining wisdom, etc.); engaging in existential re-evaluation (e.g., increasing spirituality, gaining awareness of the shortness of life, establishing a legacy, etc.); and developing a new awareness of the body (e.g., improving ones diet, exercising more, finding ways to reduce stress, etc.) (Hefferon, Grealy et al. 2009). Similarly, stress-related growth also comprises positive changes in response to stress in one or more areas, typically with respect to lifestyle and behavior; however, such changes may be less transformative than the changes constituting PTG; *may* or *may* not be permanent; and may be linked to stressful, but not necessarily traumatic, experiences. Aspects of stress-related growth include broadening perspectives, developing new coping strategies, and developing personal and social resources. In contrast, benefit finding refers to the *perception* that positive changes have occurred in response to adverse life events. These perceptions may reflect veridical changes, or a person’s attempt to cope with distress, or illusions of growth. There remain significant disagreements on whether or not positive outcomes reported following any type of adversity reflect reality and there are disagreements concerning the conceptual boundaries (and similarities) separating PTG, stress-related growth, and benefit finding. Even in the face of attempts to achieve consensus around these conceptual boundaries, the majority of published studies exploring positive outcomes following negative experiences—be they trauma or stress—have measured PTG

Despite the extensive state of knowledge on PTG following many negative human experiences, the state of knowledge concerning PTG following a first episode of psychosis (FEP) is less clear. The apparent paucity in the literature on PTG following FEP is problematic since FEP usually occurs at a critical juncture in a young person's life; namely, when important vocational, social and educational trajectories are being formed (Birchwood, Todd et al. 1998). Knowledge users—including youth who have experienced FEP, families of youth who have experienced FEP, as well as service providers—may benefit from the positive message contained in narratives of those who have experienced PTG following FEP inasmuch as such narratives may instill hope in those who suffer, thereby positively influencing those important trajectories. Without a clear picture of PTG following FEP, knowledge translation of this kind may be difficult, further highlighting the need for synthesized information on the subject.

The unclear state of the literature on PTG following FEP may be due to a number of reasons. The first reason is that there is a general negative view of life post FEP and the focus in research is on symptoms or objective functional outcomes in lieu of PTG, which is more subjectively defined. A second reason is that PTG may be reported using differently worded and/or construed concepts, such as resilience, recovery, or self-actualization in addition to stress-related growth and benefit finding. A third reason may be that PTG has not been extensively studied in the domain of psychosis. Alternatively, PTG may have been studied, but not given great attention in research reports; with any mention of PTG only appearing spontaneously in results sections.

In order to clarify the state of knowledge on PTG following FEP, our objective was to conduct a scoping review of the scientific, peer-reviewed psychiatric and psychological literature to answer the following research question: what is the state of knowledge describing PTG following FEP? A second purpose of this review was to inform a full, mixed studies review to be conducted at a later stage.

Methodology

A scoping review was undertaken following the guidelines proposed by Arksey and O'Malley (Arksey and O'Malley 2005) as a precursor to a fuller systematic review examining the research question. For this scoping review, we sought to engage in literature mapping to discern the location and magnitude of the scientific peer-reviewed research addressing our research question. We also sought to identify gaps and parameters in the scientific literature to establish future research.

The review methodology was structured according to the six stages identified by Akrsey and O'Malley (Arksey and O'Malley 2005), namely, 1) identifying the research question; 2) identifying relevant studies; 3) selecting studies 4) charting of data; 5) collating, summarizing and reporting results; and 6) consultation with stakeholders.

Identifying the research question

The first step of the review was to develop a research question that would make a significant contribution to the scientific knowledge around FEP. More importantly, we chose a question which we felt would be meaningful to service users in treatment for FEP.

Several meetings were held with international experts on FEP and youth mental health to develop the research question, which is "what is the state of knowledge describing PTG following FEP?". The research question was described to individuals with lived experience of dealing with psychosis to gain their feedback. The question was also presented to families of youth with psychosis, psychiatrists, case managers, psychologists, social workers, nurses, research assistants and students at the Prevention and Early Intervention Program for Psychosis; Canada's leading specialized early intervention service located in Montreal in order to validate the importance and utility of the questions and to generate ideas on key concepts related to the subject. Two meetings were held with different stakeholders, and feedback from all participants was taken into consideration.

Identifying relevant studies

Eligibility Criteria. Studies were included in the review if they were peer-reviewed journal articles published in scholarly journals between the years 1980 and 2013. This time criterion is consistent with the emergence of the FEP movement, which is approximately 20 years old. Personal narratives, conference abstracts, books, book chapters, dissertations, editorials and other grey literature were not considered (refer to “Strengths and limitations” section for some comments and reflections regarding this exclusion criterion). Quantitative, qualitative, and mixed methods studies were included, as were systematic reviews and meta-analyses. Studies with males and females of all ages who were experiencing a FEP associated with any diagnosis were eligible for inclusion. Studies of family members, friends and/or treatment providers of persons with FEP were also eligible. Only English studies written in English were included.

Information Sources and Identification Process. A library scientist (AL) from McGill University was responsible for constructing search terms in collaboration with the first author (GJ) and applying them to relevant databases. The librarian scientist searched 85 key words (Table 1) both directly (for specificity) and indirectly (for breadth) relevant to PTG following FEP. The search strategy also included search terms related to stress-related growth and benefit finding to determine if these concepts, rather than PTG, would be more salient to uncover studies of positive outcomes following FEP. Because articles on FEP are usually indexed in PubMed, PsycINFO, and Embase, only these three databases were searched. The keywords and search terms were generated by the first author, in consultation with staff at Prevention and Early Intervention Program for Psychosis, experts in the field of FEP and youth mental health and the librarian scientist. The final list was produced and agreed upon through consensus by all study authors. A second librarian was consulted to validate the keywords and search strategies used. A complementary search using Google Scholar, PubMed, PsycINFO and Embase using the key words “post-traumatic growth” “thriving” “benefit-finding” and “positive change” in connection with “early or first-episode psychosis” was performed to retrieve any additional articles. Twenty one additional researchers with internationally recognized expertise in FEP research were consulted to obtain any articles related to this topic that had not yet been published or had been missed. Articles were uploaded into EndNote version 10.

Study selection

Study Selection Process. Screening was independently conducted by two reviewers using EndNote version 10. The first screening was performed to ascertain whether titles and abstracts of articles explicitly mentioned key words related to PTG (e.g., post-traumatic growth, thriving, benefit-finding, etc.), or if they explicitly mentioned some form of positive change arising through an experience of FEP. The full-text content of all articles that were determined relevant in the first screening were subsequently screened. Specifically, all included articles were read in their entirety by two reviewers to determine whether or not they described PTG following FEP. Disagreement was resolved by consulting with a third author. Once a final list of articles was determined, the articles were charted to aid summarizing the results and to identify a more precise direction for a full systematic review to eventually follow the scoping review.

Charting the data

A data-charting form was created in Excel (Table 2) and data were charted by two individuals through an iterative process whereby key items (e.g., title and author of article;

journal where article appeared; time elapsed since FEP; methodological approach, etc.) were first listed, followed by a discussion and re-evaluation of which items should be kept and excluded, followed by further charting.

Results sections of identified papers were then coded and summarized into themes for easy depiction. We coded and thematically analyzed all qualitative data and summarized all quantitative data. One individual coded each paper, and a second person was consulted to validate themes.

Collating, summarizing and reporting the results

Of 4,612 articles originally identified, 58 were included in the full-text review, and 14 were deemed after full-text review as being relevant to the research question of interest. Articles were excluded on the bases of not being directly related to PTG (n = 2279); being duplicates not properly excluded during the original duplicate deletion procedure (n = 74); being grey literature, conference abstracts, books/book chapters, dissertations or editorials (n = 1866); and not being published in English (n = 335). Of the final 14 articles, five were found through screening titles and abstracts, while nine were found through a general internet search. (Figure 1).

Of the 21 additional experts consulted for articles relevant to PTG following psychosis, 7 responded. None of the recommended articles was judged to be directly pertinent to the identified research focus of this scoping review.

Characteristics of Included studies. All included articles were published between 2000 and 2013. The majority of studies were published by research groups in Western countries, namely, England (n = 7), Canada (n = 3), Australia (n =1) and New Zealand (n = 1). The remaining articles were published in China (n = 1) and Brazil (n = 1). PTG was the key conceptual framework describing positive change following psychosis in only two articles

(Dunkly, Foulds et al. 2007, Pietruch and Jobson 2012). In many of the remaining articles, PTG following FEP was described by the authors as a part of the recovery process (n = 7) (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, Eisenstadt, Monteiro et al. 2012, McGrath, Peters et al. 2013, Windell and Norman 2013). Both articles which used PTG as a key concept also drew on the recovery paradigm (Dunkly, Foulds et al. 2007, Pietruch and Jobson 2012). Other articles described PTG within the context of (i) the help-seeking process, such that participants identified unintended positive benefits of seeking help for FEP (Anderson, Fuhrer et al. 2013); (ii) specialized early intervention services treating FEP, such that participants described the early intervention treatment team as being instrumental in promoting a positive sense of self (Lester, Marshall et al. 2011); and (iii) through experiences of service engagement (Cadario, Stanton et al. 2012). Finally, two studies focused on the positive impact of FEP on friends (Brand, Harrop et al. 2010) and families (Newman, Simonds et al. 2011). None of the studies described benefit-finding or stress-related growth.

Methodologies of Included Studies. Qualitative methodologies were the most frequent approach used in articles (n = 11), followed by mixed methods (n = 1), which included one study featuring a combination of case studies with a quantitative approach (n = 1), and one study using a quantitative approach. Qualitative data were most commonly guided by a grounded theory approach (n = 5), followed by a qualitative descriptive approach (n = 2), phenomenological approach (n = 2), and narrative analysis (n = 1). The qualitative analysis framework for two studies was not clearly stated (Table 3). Among qualitative and mixed methods studies, semi-structured and unstructured interviews were the most common qualitative data collection technique (n = 11), with only one study employing focus groups (Lam, Pearson et al. 2011).

Participant Characteristics of Included Studies. Among studies reporting on the clinical status of included participants with FEP (n= 7), all participants were described as clinically stable during assessments. The duration of time between participants' FEP and the time of assessment in each study ranged from 6 months to several years. In studies where the gender and ethnicity of participants was described (n = 9), the majority were white males; in studies describing diagnosis of participants (n = 8), the majority had a diagnosis of a schizophrenia-spectrum disorder.

Themes of PTG found in Qualitative Studies. Taken together, a range of experiences related to PTG were reported by participants in the included qualitative studies. An important theme among service users was that their FEP motivated them to develop positive character traits such as greater empathy, maturity, and resilience (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, Eisenstadt, Monteiro et al. 2012, McGrath, Peters et al. 2013, Windell and Norman 2013). This theme is reflected in the words of one participant who noted, "If I hadn't had this experience then I would have never learnt how to deal with stress"(Cadario, Stanton et al. 2012). A second theme which emerged related to individuals making positive lifestyle changes following FEP (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, McGrath, Peters et al. 2013, Windell and Norman 2013), such as learning new skills, and increasing sleep and exercise. What follows is a quote illustrative of this theme: "I've grown from the whole thing and I've found…a new passion for this photography" (Windell and Norman 2013). Other themes included developing a stronger connection with family and a wiser understanding of friendship (Romano, McCay et al. 2010, Lester, Marshall et al. 2011, Anderson, Fuhrer et al. 2013). For instance, one participant reported, "I have a fortunate situation of having a pretty caring, loving family on all ends, immediate and external. So I'm sure it strengthened it in some sense…”(Anderson, Fuhrer et al. 2013), while another said “Now I know which ones [friends] I can sit down and talk with, which ones are just party friends” (Lam, Pearson et al. 2010). An important theme pertained to the integration of the psychotic experience into the self in a meaningful and positive way, reflected by one participant who stated “If you’ve got a mental illness, deal with it, try and live with it … it’s not a setback, it’s like an ability, it’s part of you…” (Cadario, Stanton et al. 2012). Experiencing greater religiosity during a FEP was remarked upon by one participant who mentioned: “I think that, erm, I was being guided by God throughout this time. There was too many things that went right for me” (Perry, Taylor et al. 2007). Finally, authors of three papers (Romano, McCay et al. 2010, McGrath, Peters et al. 2013) described many persons with FEP having developed a greater appreciation for life and for the value of helping others, as reflected in the following statement: “Through the illness experience, participants learned to appreciate life and to appreciate the value of helping others”(Lam, Pearson et al. 2010). Of note, one qualitative study was framed by the concept of reflexive function, defined as the capacity to infer mental states and to use those states to interpret behaviour regarding early attachment relationships (Braehler and Schwannauer 2012). In this study, participants with high reflexive function were more likely to show evidence of PTG following their psychosis, such as acceptance and integration, self-compassion, creative self-expression, integration with older peers, and developing new peer groups.

Among the included qualitative studies, two focused on the social supports of persons with FEP and pertained to our research question of PTG following FEP. In one study focused on siblings of persons with FEP, (Newman, Simonds et al. 2011) some siblings said they had found new meaning in life by helping others because of their loved one’s FEP. Others had developed greater empathy towards people, as described by one participant: “It’s kind of like made me very sort of like, personal experience, it's made me wanna help people really with it and help the whole, like put more, like get more research for it I guess". In a second study, friends identified (Brand, Harrop et al. 2010) having a closer relationship with a friend who experienced FEP and felt their friend was a stronger person as a result of their FEP. The following are pertinent quotes, "Well I think we're as close as anyone could ever be" and "He's a stronger person now, he's got a much better attitude".

Themes related to PTG in Quantitative Studies. The single quantitative study examined predictors of PTG following FEP. Predictors included the impact of the trauma induced by FEP (i.e., the degree of post-traumatic symptoms following the experience), the willingness to disclose trauma (i.e., the urge or reluctance to talk about a FEP), the actual disclosure of trauma (i.e., amount of time a participant spent talking about their FEP with people) and processes of recovery (i.e., intrapersonal and interpersonal tasks that facilitate recovery)(Pietruch and Jobson 2012). Their results revealed that PTSD symptoms, recovery and actual self-disclosure positively predicted PTG, while a reluctance to disclose negatively predicted PTG.

Themes related to PTG in Mixed Methods Studies. The mixed methods study (Dunkly, Foulds et al. 2007) had a sample size of two, and presented no quantitative results relevant to positive outcomes experienced following FEP. In the qualitative arm of this study, participants described having grown from FEP, such that they experienced greater appreciation of life, improved relations with others, new possibilities in life, and had developed strengths of character.

Consultation exercise

A consultation exercise was undertaken at the end of the review to obtain feedback from potential knowledge-users. The results from the scoping review were thus presented at a meeting which included psychiatrists, psychologists, nurses, social workers, occupational therapists, researchers, research assistants and trainees from three specialized early intervention services for FEP in Montreal. Those in attendance thought that a focus on positive outcomes following FEP as embodied in this scoping review could have a meaningful impact on the lives of service users with FEP. Clinicians expressed interest in learning how to integrate what had been presented into their clinical practice. Furthermore, feedback was provided on ways to build upon the scoping review and pursue additional directions in the subsequent, full systematic review. Main suggestions for the subsequent review were to include scholarly peer-reviewed articles published in French; to consult with specific groups such as the Hearing Voices Network; to consider first-person accounts and grey literature as sources of knowledge and to more comprehensively include the FEP literature on key concepts such as recovery and resilience.

Discussion

The negative impacts of FEP on affected persons, friends, families and society are significant and should not be understated (Rinaldi, Killackey et al. 2010, Foley and Morley 2011, Pompili, Serafini et al. 2011). However, in addition to suffering, the experience of psychosis may provide individuals with an opportunity for PTG. Although PTG following physical illness has been well described in the literature (Barskova and Oesterreich 2009, Bostock, Sheikh et al. 2009, Meyerson, Grant et al. 2011), the status of knowledge concerning PTG following FEP is unclear. As a first step to completing a full systematic review, we conducted a scoping review to determine the overall landscape of scientific knowledge concerning PTG following FEP. The results from this review indicated a paucity of research directly describing positive outcomes, such as PTG, stress-related growth, and benefit-finding following FEP (Dunkly, Foulds et al. 2007, Pietruch and Jobson 2012). Most research related to the topic of positive outcomes following psychosis was instead embedded within the recovery literature and was investigated principally through qualitative approaches. With the exception of one study which explicitly examined positive outcomes, other mentions of positive outcomes were embedded within qualitative articles.

Because of the nature of the data reviewed, which included excerpts from larger parts of text (that, for qualitative studies, reflect the inductive and deductive processes of qualitative research) and second-order, author reflections about participants, determining if a study described PTG rather than stress-related growth or benefit finding (reflecting actual or perceived growth) was not possible. This task was made more difficult because none of the study authors (except one quantitative study) defined the positive outcomes experienced by participants as PTG, stress-related growth, or benefit finding. It was therefore impossible to determine if participants had *actually* experienced PTG, or if the positive outcomes they reported were illusory, or a coping mechanism. Rather than assume that the positive outcomes reported were illusory or a coping strategy, we inferred that reports of PTG reflected actual changes rather than perceptions of change, and that based on the traumatic nature of FEP, positive outcomes could arguably be conceptualized as PTG, as opposed to stress-related growth. Meanwhile, we fully acknowledge that the first-episode of psychosis may not have been traumatic for some participants and the positive outcomes experienced by them could have been more in line with stress-related growth or even illusory. While such limitations are difficult to circumvent using any literature review methodology, future primary research investigating positive outcomes following FEP should attempt to determine if participants have experienced PTG, stress related growth, or benefit finding.

Of the included studies, 12 captured experiences of PTG from the perspective of people with lived experience of FEP, whereas two centered on the experiences of friends and siblings.

These studies revealed that following FEP, the participants developed new, healthy personality traits; integrated their experience of FEP into a coherent continuous narrative of their selves; appreciated life more; developed stronger connections with friends and families; felt a stronger connection to God; and made positive lifestyle changes. Siblings and friends of people with lived experience of FEP also reported PTG in themselves and in their loved ones. Overall, these findings are similar to domains of growth observed following physical illness (Hefferon, Grealy et al. 2009). Of note, the theme of integrating psychosis with the self is related to an integrative recovery style (i.e., an awareness of the continuity of mental activity and personality from before, during, and recovering from FEP), as opposed to a sealing over recovery style (i.e., an attempt to view the psychotic experience as an isolated, interruptive event that is best forgotten about)(Pietruch and Jobson 2012). Research on integration of psychosis following FEP may therefore be pertinent to PTG; the second phase of this review will therefore attempt to include studies on integrative recovery styles.

That the majority of articles describing PTG employed qualitative methods is noteworthy given the historical hierarchies of power subsumed in quantitative research. Such research has traditionally been regarded as using a deductive approach designed to disconfirm null hypotheses, and, in many circumstances, with little input from participants themselves. Conversely, qualitative research uses a more inductive approach, and allows for participants to generate new themes outside the expectations of the interviewer, creating knowledge grounded on experience (Lawson 1997). Because PTG was revealed by participants themselves in qualitative studies, PTG may be important in the aftermath of FEP, and should be investigated further through a range of methodologies.

Because descriptions of PTG were found mostly in the recovery literature, one question that arises is whether PTG is indeed part of the recovery construct or a distinct experience. According to (Carver 1998), recovery implies to a return to a pre-existing level of functioning, with PTG occurring a step beyond recovery. However, multiple definitions of recovery exist within psychosis research. It has often been defined as being in symptomatic and functional remission according to standardized clinical measures (Jaaskelainen, Juola et al. 2013), a definition that is somewhat consistent with Carver's conceptualization of recovery (Carver 1998). However, other specific measures of recovery such as the Recovery Assessment Scale (Corrigan, Salzer et al. 2004) capture additional, more nuanced aspects of the recovery process, such as feeling hope for the future. The increasingly dominant view, based on subjective perspectives of recovery captured through qualitative methods (Windell, Norman et al. 2012), is that the definition of recovery is inherently subjective. For some, positive outcomes as a result of psychosis may be key to recovery, whereas for others, returning back to a life which resembled a pre-illness existence may be key to recovery. Hence, whether or not PTG and recovery are distinct or similar may also vary depending on individual perceptions, and may need to be systematically investigated in the future.

The small number of studies related to PTG indicates that more research on the subject is needed, especially because it may be important to those with lived experience of FEP as demonstrated by its spontaneous emergence as a theme in the qualitative studies. Given that only two studies with quantitative data were found, and that PTG was not explored directly in qualitative articles, there is a need for a direct examination of PTG following FEP. Furthermore, additional research should address other positive outcomes associated with, and following FEP, which have not traditionally been covered by the rubric of PTG (e.g., developing a positive relationship with auditory hallucinations, etc.).

Strengths and Limitations

Strengths of this scoping review include its focus on a meaningful and potentially clinically relevant research question, its involvement of multiple stakeholders operating within the framework of specialized early intervention for FEP. To our knowledge, no other review using any other methodology has been conducted examining PTG following FEP. Furthermore, few studies have focused on the potential positive aspects of FEP. Overall, results contribute to a more nuanced understanding of FEP and its aftermath, one that takes into consideration growth alongside suffering.

One limitation of this study was that it did not cover the breadth of most scoping reviews, and few publications were retained. Our choice of examining scientific peer reviewed journal articles to the omission of other sources of knowledge (e.g., personal narratives, grey literature, books, etc.) was guided by the rationale that benefits following FEP are a somewhat novel, unexplored and controversial concept. By exploring scientific writings, over more anecdotal work, we could potentially argue with some confidence that the scientific method has lent credibility and validity to the findings we synthesized, strengthening the validity of a positive aftermath following FEP. Reviewing the scientific literature is thus a more conservative approach. Still, this is the only study to synthesize evidence on the positive aftermath following FEP, and helps to dispel the generally negative outlook individuals have towards psychotic illness.

Future Directions

A comprehensive systematic review will be conducted, informed by the results from this scoping review and the recommendations that emerged during the consultation exercise when results were presented to various pertinent stakeholders. A specific search strategy will be employed during the systematic review process to retrieve qualitative, quantitative and mixed methods studies on recovery, because this was shown to be an important key concept related to PTG. Due to the diversity of methodologies, a mixed methods study review will be conducted using a qualitative convergent design so as to not lose the meaning ascribed to PTG by participants. In addition, the primary author is in the process of conducting a primary mixed methods study exploring PTG following FEP. We will attempt to address the various issues surrounding PTG, stress-related growth and benefit finding discussed within our mixed studies review and mixed methods study.

Table 1: Keywords and Search Terms Applied

1. (first adj3 psychos*).mp.
2. (first adj3 psychotic).mp.
3. (early adj3 psychos*).mp.
4. (early adj3 psychotic).mp.
5. (initial adj3 psychos*).mp.
6. (initial adj3 psychotic).mp.
7. or/1-6
8. Resilience, Psychological/
9. exp social environment/
10. exp Family/
11. Mental Health/
12. exp Adaptation, Psychological/
13. quality of life/
14. morale/
15. resilien*.mp.
16. strong*.mp.
17. robust*.mp.
18. resistant.mp.
19. spirit*.mp.
20. tough.mp.
21. endur*.mp.
22. empower*.mp.
23. enabling.mp.
24. embolden*.mp.
25. encouragement.mp.
26. inspiration.mp.
27. inspire.mp.
28. courage*.mp.
29. morale.mp.
30. strength.mp.
31. happy.mp.
32. happiness.mp.
33. pleasant*.mp.
34. enjoy*.mp.
35. satisf*.mp.
36. pleasur*.mp.
37. pleasing.mp.
38. comfort*.mp.
39. reassuran*.mp.
40. well being.mp.
41. wellbeing.mp.
42. content*.mp.
43. hearten*.mp.
44. benefi*.mp.
45. useful.mp.
46. value.mp.
47. valuable.mp.
48. helpful.mp.
49. favorable.mp.
50. favourable.mp.
51. advantag*.mp.
52. constructive.mp.
53. benevolen*.mp.
54. caring.mp.
55. meaning.mp.
56. significan*.mp.
57. importan*.mp.
58. consequen*.mp.
59. adjust*.mp.
60. adapt*.mp.
61. open to experience.mp.
62. quality of life.mp.
63. qol.mp.
64. life chang*.mp.
65. life experienc*.mp.
66. (positive and (product or adjustment or adaptation or psychology)).mp.
67. recovery.mp.
68. empath*.mp.
69. neutral.mp.
70. harmless.mp.
71. awareness.mp.
72. greatness.mp.
73. self actuali*.mp.
74. promotion.mp.
75. creativ*.mp.
76. madness.mp.
77. pride.mp.
78. proud.mp.
79. holistic*.mp.
80. ((posttraumatic or stress) and growth).mp.
81. thriv*.mp.
82. blessing*.mp.
83. transformation*.mp.
84. or/8-83
85. 7 and 84

Table 2: Questions Applied when Charting the Data

Study Characteristics
What is the title of the publication?
Who are the authors of the publication?
Which year was the publication published in?
In which journal does the publication appear?
In what field was the article published in (e.g., psychology, psychiatry)?
What are the aims of the study?
What are the key concepts described in the study?

Participant Characteristics
What is the mean age of participants included in the study?
How many males and females were included in the study?
What is the most frequent diagnosis reported in the study?
What is the most frequently reported ethnicity in the study?
Where participants in the study recruited from inpatient or outpatient services?
Which country were participants recruited from?
How much time has elapsed from the onset of the FEP to when data was collected?
Is the sample used described as clinically stable?

Methodology, Data Collection and Results
Is the study qualitative, quantitative, or mixed methods?
How was data collected?
How was data analyzed?
What predictor variables were included in the study?
What outcome measures were included in the study?
What are the relevant results from the study?

Table 3: Charting of Data

ID	Title	Authors	Year	Journal
1	A qualitative analysis of influences on recovery following a first episode psychosis	Deborah Windell; Ross MG Norman	2012	International Journal of Social Psychiatry
2	A qualitative investigation of first-episode psychosis in adolescence	Eva Cadario; Josephine Stanton; Puti Nicholls; Sue Crengle; Trecia Wouldes; Matt Gillard; Sally Nicola Merry	2011	Clinical Child Psychology and Psychiatry
3	Experience of recovery from a first-episode psychosis	Paula Eisenstadt; Vera B Monteiro; Matheus JA Diniz; Ana C Chaves	2012	Early Intervention in Psychiatry
4	Recovering an emerging self: exploring reflective function in recovery from adolescent-onset psychosis	Christine Braehler; Matthias Schwannauer	2012	Psychology and Psychotherapy: Theory, Research and Practice
5	The process of recovery in women who experienced psychosis following childbirth	Laura McGrath; Sarah Peters; Angelika Wieck; Anja Wittkowski	2013	BMC Psychiatry
6	"There are too many steps before you get to where you need to be": help-seeking by patients with first-episode psychosis	Kelly K Anderson; Rebecca Fuhrer; Ashok K Malla	2013	Journal of Mental Health
7	Views of young people in early intervention services for first-episode psychosis in England	Helen Lester; Max Marshall; Peter Jones; David Fowler; Tim Amos; Nagina Khan; Max Birchwood	2011	Psychiatric Services
8	What does recovery from psychosis mean? Perceptions of young first episode patients	Mary ML Lam; Veronica Pearson; Roger MK Ng; Cindy PY Chiu; CW Law; Eric YH Chen	2010	International Journal of Social Psychiatry
9	"You've got to have a positive state of mind": An interpretative phenomenological analysis of hope and first episode psychosis	Beth M Perry; Damian Taylor; Samantha K Shaw	2007	Journal of Mental Health
10	Reshaping an enduring sense of self: the process of recovery from a first episode of schizophrenia	Donna M Romano, Elizabeth McCay; Paula Goering; Katherine Boydell; Robert Zipursky	2010	Early Intervention in Psychiatry
11	Posttraumatic growth and recovery in people with first episode psychosis: an investigation into the role of self-disclosure	Magdalena Pietruch; Laura Jobson	2011	Psychosis: Psychological, Social and Integrative Approaches
12	Understanding adaptation to first episode-	Jane E Dunkley; Glen W Bates	2007	The Australasian Journal of

	psychosis: the relevance of trauma and posttraumatic growth			Disaster and Trauma Studies
13	A narrative analysis investigating the impact of first episode psychosis on siblings' identity	Sharon Newman; Laura M Simonds; Jo Billing	2011	Psychosis: Psychological, Social and Integrative Approaches
14	What is it like to be friends with a young person with psychosis? A qualitative study	Rachel M Brand; Chris Harrop; Lyn Ellett	2010	Psychosis: Psychological, Social and Integrative Approaches

ID	**Country of Research Group**	**Aim(s) of study**	**Conceptual Frameworks**	**Percent Male**
1	Canada	To examine factors that enhance or impede recovery from the perspective of individuals receiving specialized early intervention care following their first episode of psychosis	Recovery	76.7%
2	New Zealand	To provide a description of the meaning of the first psychotic episode for the adolescent and their primary caregiver, and the experience of accessing effective treatment	Phenomenology of FEP and experiences of service engagement	58%
3	Brazil	To understand the recovery experience of patients from a first episode psychosis programme in Sao Paulo Brazil	Recovery	75%
4	England	To investigate the processes involved in how young people with adolescent onset psychosis adapt to psychosis and how processes of reflective function influence the adaptation process	Recovery	50%
5	England	To develop a theoretical understanding of recovery from psychosis following childbirth	Recovery	0
6	Canada	To describe the experiences of patients with first episode psychosis on their pathway to care and to identify factors that	Pathways to care	75%

		help or hinder help seeking efforts		
7	England	To describe the views over time of young people referred to early intervention services, particularly as they relate to the importance of their relationships	Value of specialized early intervention services	66%
8	China	To explore the experience of first episode psychosis from the patients' perspective and the meaning they attach to the illness and their recovery	Recovery	50%
9	England	To investigate the personal experiences of participants following a recent first episode of psychosis, and explore influences on feelings of hope	Unclear, possibly hope or recovery	100%
10	Canada	To investigate the ways in which individuals with first episode schizophrenia describe their process of recovery and how identified individuals describe their perceptions of and roles in the participant's process of recovery	Recovery	50%
11	England	To explore the relationship of trauma, disclosure, and recovery on post traumatic growth following psychosis	Post-traumatic growth; recovery	65%
12	Australia	To explore the utility of a trauma framework/perspective in understanding recovery from FEP, and to see whether constructs pertinent to trauma and posttraumatic growth emerged in people’s accounts of recovery	Post-traumatic growth; recovery	50%

13	England	The aim was to explore the impact of having a sibling with psychosis on siblings' sense of self and their identity development and the tools they adopt within the families	Impact of psychosis on siblings of service-users	50%
14	England	To understand the social impact of psychosis from the perspective of friends of people with psychosis	Impact of psychosis on friends of service-users	42%

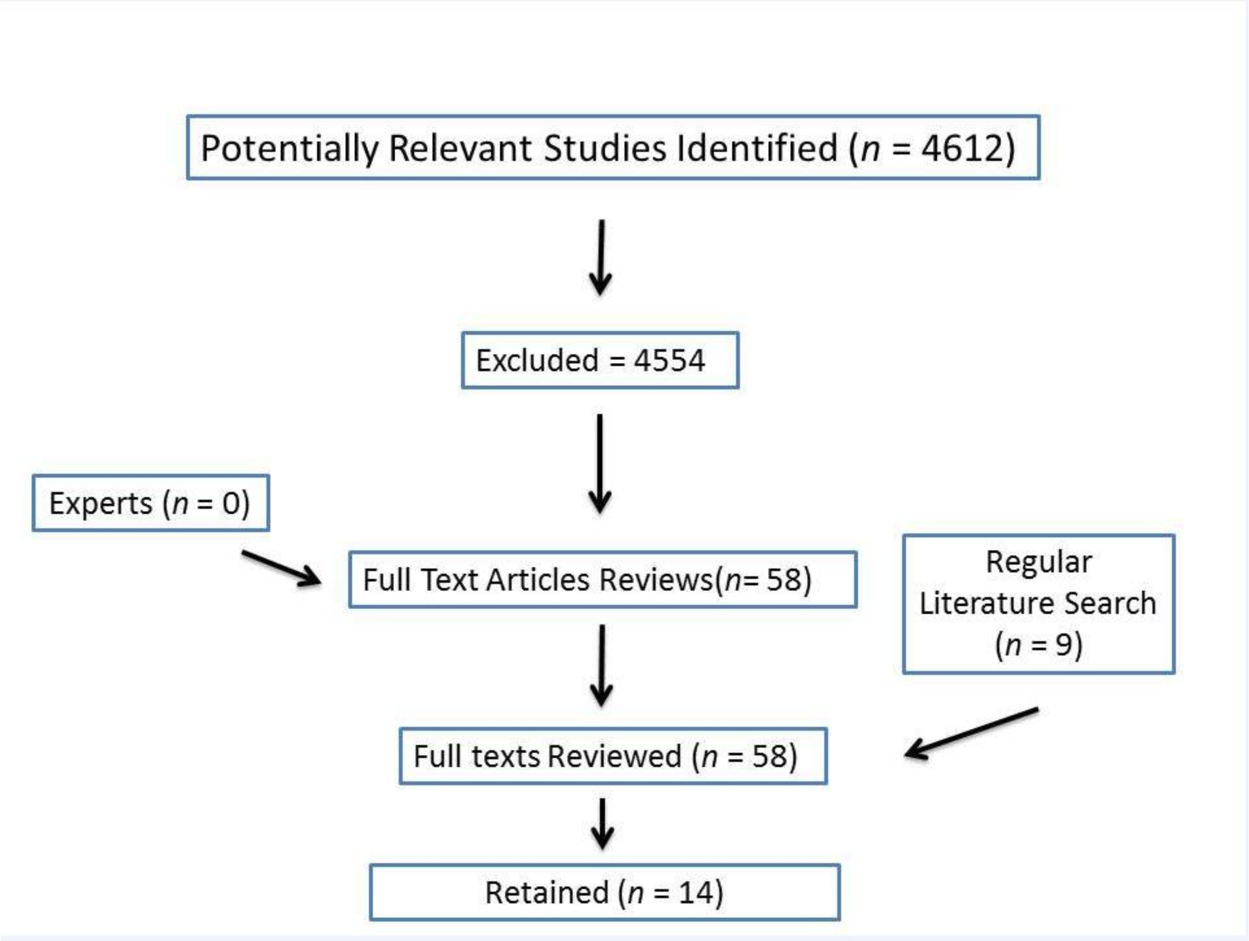
ID	**Mean age of participants**	**Ethnicity (Mode)**	**Diagnosis (Mode)**	**Time since episode/treatment onset**
1	25.87	Not Mentioned	Schizophrenia	3-5 years
2	Between 15 and 18	European	Schizophrenia	“Months to years”
3	23	Not mentioned	Schizophrenia	6 months -2 years
4	18.6	Not Mentioned	50% Schizophrenia	2.5 (Median) since first episode
5	30-54	White British, living in England or Wales	Puerperal Psychosis	Participants recruited at different stages of recovery
6	22.5	Majority born in Canada	Not Mentioned	5.5 years (Median) since onset of treatment
7	22	Majority White, British	Not Mentioned	First interview conducted within 6 months of treatment onset; second interview was 12 months later
8	25.18	Cantonese-speaking Chinese	Schizophrenia	Not mentioned
9	21.8	White British	Not mentioned	7.2 months (Mean) since onset of FEP
10	23.5	Caribbean and Caucasian	Schizophrenia	1-3 years since treatment onset
11	25.67	Not mentioned	Not mentioned	9.8 Months since FEP
12	23.5	Not Mentioned	Bipolar disorder with psychotic features	Up to 8 months since FEP
13	20.75	White British	Non-clinical Sample of siblings	Siblings of service-users were unwell for 1-3 years

14	21	White British	Non-clinical Sample of Friends	Friends of service-users were unwell for 14.4 months (Mean)

ID	Clinically Stable?	Methodology	Data Collection	Data Analysis
1	Not mentioned	Unspecified qualitative method	Semi-structured interviews	Thematic analyses
2	Yes	Unspecified qualitative methods	Combination of unstructured and semi-structured interviews	General inductive approach
3	Participants were stable with respect to type and dose of medication for at least 6 months	Phenomenological approach	In-depth and semi-structured interviews	Phenomenological analysis
4	Yes	Grounded theory approach; Cross-sectional survey approach	Open Interviews; Adult Attachment Interview; Reflective Functioning Scale	Constant comparative method
5	Not mentioned	Constructivist grounded theory	Semi-structured interviews	Constant comparative method
6	Yes	Qualitative descriptive approach	Unstructured and semi-structured in depth interviews	Content analysis
7	Not mentioned	Constructivist grounded theory	Semi-structured interviews	Constant comparative method
8	Not mentioned	Qualitative descriptive approach	Focus groups	Thematic analyses
9	yes	Interpretive phenomenological Approach	Semi-structured interviews	An "idiographic approach"

10	Yes (they identified as recovering)	Constructivist grounded theory approach	Semi-structured interviews	Constant comparison method
11	Yes	Cross-sectional survey design	Impact of Events Scale—Revised; Disclosure of Trauma Questionnaire; Actual Self-Disclosure Measure; Process of Recovery Questionnaire; Post-Traumatic Growth Inventory	Multiple regression
12	Not clear	Cross -sectional survey design; Case study design	Recovery Style Questionnaire; The Positive and Negative Syndrome Scale; Semi Structured Interviews	Not clear for quantitative arm; case study analysis for qualitative arm
13	Not relevant	Narrative methodology	Semi-structured interview	Various narrative analyses
14	Not relevant	Constructivist grounded theory	Semi-structured interviews	Constant comparative method

Figure 1: Study selection process



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Chapter Three

Positive changes experienced after a first episode of psychosis a systematic review

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Abstract

Objective: While the negative consequences associated with first-episode psychosis (FEP) have been well investigated, relatively less is known about the positive changes that people may experience following FEP. Also, existing literature is disparate and in need of a careful synthesis. Such a synthesis can inspire the design of mental health services which foster strengths, hope, and optimism. Our objective was to synthesize the literature on 1) how positive change is experienced following FEP by affected persons, their families, and friends; and 2) the individual, social, and structural factors facilitating positive change.

Methods: A librarian-assisted systematic review of quantitative, qualitative, and mixed methods studies published in English between 1970 and 2015 was conducted. Articles identified from three databases (PubMed, PsycINFO, Embase) and using additional search strategies were screened by two reviewers. Results sections were open-coded and analyzed using thematic synthesis.

Results: Of the 2,777 studies identified, 40 were retained. Our synthesis showed that, following FEP, service users, their families, and friends experienced positive changes at the *individual* (e.g., more insight and clarity), *interpersonal* (e.g., improved relationships), and *spiritual* levels (e.g., greater religiosity). In addition to being facilitated by mental health services, these positive changes were enabled by personal (e.g., motivation), social (e.g., family support) and spiritual (e.g., prayer) factors.

Conclusions: Suffering is a core experience of FEP from which a range of positive changes in services users, their families and friends can follow. It may be beneficial for mental health services to specifically strive to promote these positive changes.

Introduction

Psychotic disorders are among the most severe mental health problems, leading to immeasurable suffering (Rossler, Salize et al. 2005, Whiteford, Degenhardt et al. 2013), particularly in first-episode psychosis (FEP) when youths first experience what can be a frightening illness. The consequences of psychosis are particularly serious given that its onset is usually during late adolescence and young adulthood, a critical developmental period for the attainment of important educational, occupational and relational milestones.

Understandably then, knowledge on the aftermath of psychosis focuses on its negative consequences such as its deleterious effects on functioning, cognition, and quality of life. As such, evidence-based services and interventions have largely drawn on knowledge of the negative aftermath of psychosis. Conversely, little is known about whether and how people experience positive changes following their FEP. Even less is known about what factors facilitate such positive change (Jordan, Pope et al. 2016).

It may seem surprising that psychosis could lead to positive changes. However, studies examining the consequences of a range of psychologically traumatic events and “physical” health problems (e.g., cancer) have described positive changes in their aftermath (Linley and Joseph 2004, Barskova and Oesterreich 2009, Bostock, Sheikh et al. 2009, Hefferon, Grealy et al. 2009). These changes have been conceptualized as posttraumatic growth, stress-related growth, or benefit-finding, and represent changes in individuals beyond a return to their “baseline” level of functioning. Such changes may include a stronger sense of self, a greater appreciation for life, greater spirituality, and better relationships following health problems (Tedeschi and Calhoun 2004, Joseph and Linley 2006, Zoellner and Maercker 2006). Likewise, there have been three reports of positive changes among individuals who have had psychosis for many years and their families or carers (Williams 2012, Mapplebeck, Joseph et al. 2015).

To date, there has been no systematic review on positive change arising from FEP and the facilitators of such change (Jordan, Pope et al. 2016). Such a knowledge synthesis would be congruent with recent calls for designing and using services and interventions that are strengths-based and focus on optimism and hope, especially during the early phases of psychosis (Shiers, Rosen et al. 2009, Linley, Joseph et al. 2011, McGorry, Bates et al. 2013). In addition, this knowledge may show young people that there is more to the experience of FEP than suffering, and that in addition to experiencing caregiver burden and strain, there may also be positive effects for families, carers and friends.

To provide an account of the current state of knowledge on the positive changes people may experience following FEP, we conducted a systematic review of qualitative, quantitative and mixed methods studies. Our objectives were to synthesize the evidence on (1) how positive change is experienced following FEP by people with lived experience of FEP, their families and friends, and (2) the individual, social and structural factors which facilitate positive change.

Methods

Informed by our scoping review which found that that positive change following FEP was most often investigated using qualitative methods and described within the literature on recovery, and that positive change occurred among service users, their families and friends (Jordan, Pope et al. 2016), we conducted a systematic review of qualitative, quantitative and mixed methods studies, i.e. a mixed studies review. This review ensured that the methodological (i.e., qualitative research in FEP) and conceptual (i.e., recovery) areas likely to yield a greater number of articles to answer our research questions were tapped.

Our review followed the guidelines for conducting a mixed studies systematic review, as detailed in the Toolkit for Mixed Studies Reviews (Pluye and Hong 2014), which is based on

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher, Shamseer et al. 2015).

Formulating a review question

Our research questions were developed following SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, and Research type) guidelines for formulating mixed studies review research questions (Cooke, Smith et al. 2012). The research questions were formulated based on extant research and consultations with youth with lived experience of psychosis, their family members, and clinicians and researchers in early intervention for psychosis. There was consensus among stakeholders that our research questions were relevant, understudied, and deserving of investigation.

Defining eligibility criteria

The potential for FEP to lead to positive change may be met with skepticism, as it seems counterintuitive to the bulk of research focused on the negative aspects of psychosis. Thus, it became important to increase confidence in the findings of our review. We therefore only considered scientific, peer-reviewed research using clearly described methodologies. This included English-language, peer-reviewed journal articles and conference abstracts. Specifically, only (a) qualitative studies focused on FEP outcomes and (b) studies on recovery in FEP, whether qualitative, quantitative or mixed-methods in design, were eligible for inclusion in our review. Gray literature and other systematic reviews were excluded; however, reference lists of relevant systematic reviews were consulted to identify potentially relevant primary studies. Articles defining recovery exclusively as being in symptomatic and functional remission were excluded, since their focus was on a return to *normalcy*, not positive change beyond normalcy.

Identifying sources of information

An extensive search strategy was developed jointly by a university librarian and the authors. To increase the reliability of the search, a second university librarian examined and provided feedback on the search strategy. The McMaster University Health Information Research Unit's qualitative search strategies (Unit) were applied to three databases considered highly likely to yield qualitative studies on FEP (Embase, PsycINFO and Medline). These search strategies have been validated and can retrieve qualitative research with 92% specificity and sensitivity (Unit). The databases were searched for literature published between January 1970 (when the majority of research on first-episode psychosis began to emerge) and March 2015.

Additional search strategies included hand searches of key journals identified during the scoping review (Jordan, Pope et al. 2016) (i.e., *Early Intervention in Psychiatry* and *Psychosis: Psychological and Integrated Perspectives*); conducting additional Google Scholar, PsycINFO, PubMed and CINAHL searches; using backward and forward citation tracking with Google Scholar and SCOPUS; examining monthly citation alerts emailed to the primary author; receiving monthly updates on PubMed-indexed qualitative research from a research assistant over the course of the study; and consultation with experts. Two pertinent studies of posttraumatic growth retrieved during the scoping review phase were included as they were not found in this second systematic review phase (Dunkly, Foulds et al. 2007, Pietruch and Jobson 2012). All keywords used during the search are available in Supplementary Table 1.

Identifying potentially relevant studies

Articles were downloaded as EndNote files and uploaded into DistillerSR, a specialized software that facilitates article screening for systematic reviews (Partners 2016).

Selecting relevant studies

Two reviewers independently screened each article for inclusion/exclusion using screening checklists over two phases. A third reviewer was consulted to resolve disagreements when necessary.

First, abstracts (n = 2777) were screened for keywords used to describe recovery in FEP (e.g., “recover”) and/or keywords related to qualitative research methodology (e.g., “interviews”), with very high agreement between the two reviewers (Kappa = .93).

Two reviewers then independently read the results sections of each included article (n = 358) to identify any description of positive changes following FEP. We only considered an article relevant during this phase if there was *explicit* mention, by study participants or the authors, of any positive changes *directly* arising from or after the experience of FEP. Segments of text mentioning positive change were examined and compared by two or more reviewers until consensus was achieved (Kappa = .83). A flow chart of the screening process is available in Supplementary Table 2.

Appraising the quality of studies

Each included article was critically appraised by three independent reviewers using the Mixed Methods Appraisal Toolkit (Pluye, Robert et al. 2011), a validated, widely used critical appraisal tool designed to ascertain the methodological quality of quantitative, qualitative and mixed methods articles. The toolkit consists of 19 questions (e.g., “Is appropriate consideration given to how findings relate to the context?”; “Are measurements appropriate?”) that produce an overall score ranging from 0% (no criteria met) to 100% (all criteria met). Final quality appraisal scores were arrived at by consensus.

Synthesis design

Our synthesis used a convergent qualitative synthesis design, whereby the quantitative findings of included articles (e.g., numbers) were transformed into qualitative data (e.g., words) utilizing an open coding method used in qualitative research. This approach allowed us to keep our synthesis closer to the findings of many of the original articles, since 37 of the 40 included articles used qualitative methods.

Once data were transformed and a complete qualitative dataset was developed, we conducted a thematic synthesis (Thomas and Harden 2008) using ATLAS.ti 7.

To be faithful to the findings of various studies and the interpretations of their respective authors, we prioritized inductive and semantic approaches. First, one author coded the results sections of each included study sentence-by-sentence. Codes were then grouped together to form more focused codes which were defined in a coding manual (Boyatzis 1998). As recommended by Thomas and Harden (2010), four authors then grouped focused codes into analytical themes (i.e., pertaining to the research questions) or descriptive themes (i.e., pertaining to the content of articles that did not relate to the research questions but helped contextualize them) (Thomas and Harden 2008). When constructing themes, we considered the frequency of their representation in the dataset and their importance (Braun and Clarke 2006). Themes were then refined so that they best described and fit the data both within and across studies. Once our final list of themes was compiled, two reviewers (in consultation with the senior author) read the results sections of each article to validate the themes, followed by a final consensus. Analytic and descriptive themes were combined to form a comprehensive synthesis of the study findings.

Measures undertaken to ensure rigor in the analytic process included keeping detailed memos, reflexive notes, an audit trail, and a journal to assist with the analysis and to facilitate an awareness of how the synthesis was shaped by the first author’s personal stance (i.e., that of an emerging researcher deeply influenced by critical disability studies, psychology, political science, and personal positive experiences with youth with FEP) (Braun and Clarke 2006). We also compared our insights with theoretical models of positive change developed by the authors of the reviewed articles.

Results

Characteristics and quality appraisal of the included studies

Forty articles were retained after screening and synthesized (Supplemental Table 2). The majority of studies (n = 37) employed qualitative methods, one exclusively used quantitative methods and two used both qualitative and quantitative methods. A total of 715 participants were included across studies; however, due to the nature of using secondary data, it is impossible to know the absolute number of participants who experienced positive change in these studies. The average age of service users was 24.82 (SD = 4.61). Most studies (n = 36) were conducted with participants living in the Western world (i.e., Australia, Canada, Denmark, England, Finland, New Zealand, Norway, the US, Slovenia) who identified with various ethnic, racial and cultural backgrounds (e.g., White, Black Caribbean, Bangladeshi, Māori, etc.). Four studies were based in non-Western countries (i.e., Brazil, China, Indonesia, South Africa). Participants of various socioeconomic backgrounds and representing various stakeholder groups (service users, families and friends) were featured in the studies.

Family members were identified in 10 studies as “a close relative” (Barker T, Lavender N et al. 2001); carers “(Tanskanen, Morant et al. 2011); primary caregivers (Cadario, Stanton et al. 2012); a primary caregiver “apart from a health, social or voluntary care provider (which included parents, grandparents, spouses/partners and aunts/uncles)” (McCann, Lubman et al. 2011); siblings (Sin, Moone et al. 2008, Sin, Moone et al. 2012); foster parents and parents (Gearing, DeVylder et al. 2014, Nilsen, Frich et al. 2014); spouses and other family (Subandi 2015); and parents and previous and current long term romantic partners (Dunkley and Bates 2014). Friends were identified in one study as “friends who service users thought could best describe their friendship"(Brand, Harrop et al. 2010). Twenty studies reported having included individuals up to five years after the onset of FEP (n = 10) or of treatment (n = 10). The remaining studies did not provide information on exactly when assessments were conducted after the onset of illness. Study and participant characteristics are presented in Tables 1 & 2.

Quality appraisal scores for each article are presented in Table 1. Most studies (n = 13) met 50% of the quality appraisal criteria. Eleven studies met 100% of the criteria, nine studies met 75 % of the criteria, and seven studies met 25% of the criteria. We decided to retain articles with lower quality appraisal scores because they also featured rich quotations describing positive change and because we wanted to be inclusive given the novel nature of our inquiry.

Synthesis of included studies

Our analysis yielded three themes which illustrate the ways in which service users, their families and friends experienced positive change following FEP and four themes pertaining to the factors facilitating such change. These *analytical* themes directly relate to our research questions. Themes identified/present in each study are shown in Table 1.

We also identified one theme describing the broader, negative experiences associated with FEP which were not explicitly associated with positive changes in the included studies. This *descriptive* theme does not *directly* answer our research questions but serves to contextualize the analytical theme findings.

Descriptive theme: Broader, negative experiences associated with FEP

The included studies detailed negative contexts, consequences and experiences associated with FEP. Such suffering seemed essential to the experience of FEP. Positive change, our study's focus, followed this suffering.

Many studies described FEP’s negative impact on the psychological lives of participants. This included cognitive difficulties (Kilkku, Munnukka et al. 2003, Dunkly, Foulds et al. 2007, Brown 2011, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, Connell, Schweitzer et al. 2014, Gearing, DeVylder et al. 2014) and negative emotions (Barker T, Lavender N et al. 2001, Kilkku, Munnukka et al. 2003, Larsen 2004, Mackrell and Lavender 2004, Hirschfeld, Smith et al. 2005, MacDonald, Sauer et al. 2005, Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Brand, Harrop et al. 2010, Ashcroft, Barrow et al. 2011, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Newman, Simonds et al. 2011, Tanskanen, Morant et al. 2011, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, Eisenstadt, Monteiro et al. 2012, Hon 2012, Sin, Moone et al. 2012, McGrath, Peters et al. 2013, Windell and Norman 2013, Bourdeau, Lecomte et al. 2014, Connell, Schweitzer et al. 2014, de Wet, Swartz et al. 2014, Dunkley and Bates 2014, Gearing, DeVylder et al. 2014, Vodušek, Parnas et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015) that were difficult to cope with (Barker T, Lavender N et al. 2001, Brand, Harrop et al. 2010, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, McGrath, Peters et al. 2013, Dunkley and Bates 2014). Some participants had difficulty accepting that they or their relatives had experienced FEP (Barker T, Lavender N et al. 2001, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Windell and Norman 2013, Gearing, DeVylder et al. 2014) and struggled with making sense of the experience of FEP (Barker T, Lavender N et al. 2001, Kilkku, Munnukka et al. 2003, Dunkly, Foulds et al. 2007, Brand, Harrop et al. 2010, McGrath, Peters et al. 2013, Connell, Schweitzer et al. 2015). Additionally, service users and families described help-seeking barriers, negative help-seeking experiences (Barker T, Lavender N et al. 2001, Dunkly, Foulds et al. 2007, Brand, Harrop et al. 2010, Brown 2011, Harris, Collinson et al. 2011, Tanskanen, Morant et al. 2011, Cadario, Stanton et al. 2012, Anderson, Fuhrer et al. 2013, Subandi 2015) and dissatisfaction with care received (Barker T, Lavender N et al. 2001, Kilkku, Munnukka et al. 2003, Larsen 2004, Dunkly, Foulds et al. 2007, Brand, Harrop et al. 2010, Krupa, Woodside et al. 2010, Brown 2011, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Tanskanen, Morant et al. 2011, Bradshaw, Wearden et al. 2012, Cadario, Stanton et al. 2012, Eisenstadt, Monteiro et al. 2012, Hon 2012, Lester, Khan et al. 2012, Anderson, Fuhrer et al. 2013, Stewart 2013, Windell and Norman 2013, Dunkley and Bates 2014, Gearing, DeVylder et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015). Many service users reported no longer feeling in control of their lives and destiny (Kilkku, Munnukka et al. 2003, Hirschfeld, Smith et al. 2005, Dunkly, Foulds et al. 2007, Brown 2011, Harris, Collinson et al. 2011, Braehler and Schwannauer 2012, Hon 2012, Anderson, Fuhrer et al. 2013, McGrath, Peters et al. 2013, Windell and Norman 2013, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015). Many participants described a profound loss of self (Barker T, Lavender N et al. 2001, Hirschfeld, Smith et al. 2005, MacDonald, Sauer et al. 2005, Dunkly, Foulds et al. 2007, Krupa, Woodside et al. 2010, Brown 2011, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Lester, Marshall et al. 2011, Tanskanen, Morant et al. 2011, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, Sin, Moone et al. 2012, McGrath, Peters et al. 2013, Windell and Norman 2013, Bourdeau, Lecomte et al. 2014, Connell, Schweitzer et al. 2014, Gearing, DeVylder et al. 2014, Vodušek, Parnas et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015) and a loss of or difficulties establishing connections with others (Barker T, Lavender N et al. 2001, Mackrell and Lavender 2004, Hirschfeld, Smith et al. 2005, MacDonald, Sauer et al. 2005, Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Brand, Harrop et al. 2010, Krupa, Woodside et al. 2010, Brown 2011, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Newman, Simonds et al. 2011, Tanskanen, Morant et al. 2011, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, Hon 2012, Sin, Moone et al. 2012, McGrath, Peters et al. 2013, Bourdeau, Lecomte et al. 2014, Connell, Schweitzer et al. 2014, de Wet, Swartz et al. 2014, Dunkley and Bates 2014, Gearing, DeVylder et al. 2014, Vodušek, Parnas et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015). Some became reluctant to attend religious institutions or avoided spiritual practices out of fear of a resurgence of unpleasant inner experiences (Larsen 2004, Subandi 2015). Negative experiences were sometimes perceived as impeding the recovery process (Braehler and Schwannauer 2012, Windell and Norman 2013, Connell, Schweitzer et al. 2014, Connell, Schweitzer et al. 2015).

Objective 1: Positive changes experienced following FEP among service users, families, and friends

Following FEP, service users, family members, and friends experienced: 1) *Individual-level positive change*; 2) *Interpersonal positive change*; and 3) *Religious/spiritual positive change*.

Analytic theme: Individual-level positive change

FEP was described in 39 studies as leading to individual-level positive change, i.e., changes occurring in the psychological core of individuals, and at the levels of personality and lifestyles. This theme was developed through combining three sub-themes: a) *Insight and clarity; b) Personality, outlook, and skills; and c) Health, lifestyle, and interests*.

Insight and clarity

Studies described how service users, families, and friends developed new insights (Hirschfeld, Smith et al. 2005, MacDonald, Sauer et al. 2005, Lam, Pearson et al. 2011, Nilsen, Frich et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015), and obtained greater clarity about the self and others, following FEP. FEP was perceived as an opportunity to reassess one's life (MacDonald, Sauer et al. 2005, Dunkly, Foulds et al. 2007, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Windell and Norman 2013, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015). It helped service users realize that time is precious (MacDonald, Sauer et al. 2005, Lam, Pearson et al. 2011, Dunkley and Bates 2014) and should not be wasted (Connell, Schweitzer et al. 2015); and that even adversities could be leveraged to good ends (McGrath, Peters et al. 2013). Furthermore, service users found new meaning in life after experiencing FEP (Kilkku, Munnukka et al. 2003, Hirschfeld, Smith et al. 2005, Harris, Collinson et al. 2011, Newman, Simonds et al. 2011, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, McGrath, Peters et al. 2013, Connell, Schweitzer et al. 2014, Connell, Schweitzer et al. 2015), through assigning a positive, constructive meaning to their experiences (Connell, Schweitzer et al. 2015); viewing psychotic experiences as worthy of integration with aspects of the self (Kilkku, Munnukka et al. 2003, Harris, Collinson et al. 2011, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, McGrath, Peters et al. 2013, Connell, Schweitzer et al. 2015); and finding new meaning in existence itself (Hirschfeld, Smith et al. 2005, Newman, Simonds et al. 2011). Following FEP, service users and families felt wiser (Mackrell and Lavender 2004, Hirschfeld, Smith et al. 2005, MacDonald, Sauer et al. 2005, Lam, Pearson et al. 2011) and said they had greater self-understanding and acceptance (Barker T, Lavender N et al. 2001, Kilkku, Munnukka et al. 2003, O'Toole, Ohlsen et al. 2004, Hirschfeld, Smith et al. 2005, Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Ashcroft, Barrow et al. 2011, Brown 2011, Harris, Collinson et al. 2011, Newman, Simonds et al. 2011, Braehler and Schwannauer 2012, Cadario, Stanton et al. 2012, Eisenstadt, Monteiro et al. 2012, Bourdeau, Lecomte et al. 2014, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014, Nilsen, Frich et al. 2014, Vodušek, Parnas et al.

2014, Subandi 2015). Studies also described how service users developed new value systems (MacDonald, Sauer et al. 2005, Sin, Moone et al. 2008, Krupa, Woodside et al. 2010, Lam, Pearson et al. 2011, Connell, Schweitzer et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015) with greater emphasis on the importance of others (Sin, Moone et al. 2008) and less emphasis on materialism (Subandi 2015), substance use (Krupa, Woodside et al. 2010, Connell, Schweitzer et al. 2014), and what they felt were society's arbitrary role expectations (Lam, Pearson et al. 2011, Subandi 2015). Finally, some studies described service users and their family members as reporting improved, clearer, more open thinking following FEP (Lam, Pearson et al. 2011, Newman, Simonds et al. 2011, Lester, Khan et al. 2012); becoming more imaginative (Hirschfeld, Smith et al. 2005); feeling "smarter" (Lam, Pearson et al. 2011); and being less prone to obsessive thinking (Ashcroft, Barrow et al. 2011). Service users also reported better metacognitive capacities (Ashcroft, Barrow et al. 2011); being more reflective (Ashcroft, Barrow et al. 2011, Dunkley and Bates 2014); having more foresight (Lam, Pearson et al. 2011); and feeling happier and more in touch with their feelings (Harris, Collinson et al. 2011, Vodušek, Parnas et al. 2014, Subandi 2015).

With respect to new insights about others, the experience of FEP highlighted to service users and family members the goodness, importance, qualities, and roles of family and friends (MacDonald, Sauer et al. 2005, Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Lam, Pearson et al. 2011, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Braehler and Schwannauer 2012, Anderson, Fuhrer et al. 2013, Stewart 2013, Dunkley and Bates 2014). They gained better insight into who their true friends were (MacDonald, Sauer et al. 2005, Dunkly, Foulds et al. 2007, Lam, Pearson et al. 2011). Both service users and family members became more aware of others caring for them (MacDonald, Sauer et al. 2005, Lam, Pearson et al. 2011, Anderson, Fuhrer et al. 2013, Stewart 2013, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014); realized that others can offer support in times of need (McCann, Lubman et al. 2011, Dunkley and Bates 2014); and gained a new appreciation for the value of helping others (Lam, Pearson et al. 2011, Newman, Simonds et al. 2011, McGrath, Peters et al. 2013), especially those experiencing mental health concerns (Newman, Simonds et al. 2011, McGrath, Peters et al. 2013, Stewart 2013).

Personality, outlook and skills

Studies described FEP as a transformative experience leading service users to develop a new, improved identity (Barker T, Lavender N et al. 2001, Lester, Marshall et al. 2011, Sin, Moone et al. 2012, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015) and a stronger self (Brand, Harrop et al. 2010, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Pietruch and Jobson 2012, Sin, Moone et al. 2012, Connell, Schweitzer et al. 2014, de Wet, Swartz et al. 2014, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015). They now felt more authentic and closer to their inner core (Barker T, Lavender N et al. 2001, Larsen 2004, Connell, Schweitzer et al. 2014, Vodušek, Parnas et al. 2014). Following FEP, service users and families experienced self-development (Barker T, Lavender N et al. 2001, Larsen 2004, Sin, Moone et al. 2008, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Sin, Moone et al. 2012, Dunkley and Bates 2014, Vodušek, Parnas et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015), and became more mature and responsible, especially with respect to their roles within the family (Hirschfeld, Smith et al. 2005, Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Brown 2011, Lam, Pearson et al. 2011, Newman, Simonds et al. 2011, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, Windell and Norman 2013, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014, Nilsen, Frich et al. 2014). They also described becoming self-reliant

(Barker T, Lavender N et al. 2001, O'Toole, Ohlsen et al. 2004, Dunkly, Foulds et al. 2007, Bourdeau, Lecomte et al. 2014, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015); acquiring personal control (Ashcroft, Barrow et al. 2011, Dunkley and Bates 2014, Vodušek, Parnas et al. 2014); and becoming more willing to deal with problems. Becoming independent from others through a process of individuation was described as a key dimension of positive change by service users in two studies (Barker T, Lavender N et al. 2001, Dunkly, Foulds et al. 2007).

Furthermore, studies described how, after FEP, some individuals had a better attitude (Brand, Harrop et al. 2010), demeanor (Dunkly, Foulds et al. 2007), and sense of confidence (Kilkku, Munnukka et al. 2003, Hirschfeld, Smith et al. 2005, Harris, Collinson et al. 2011, Lam, Pearson et al. 2011, Braehler and Schwannauer 2012, Hon 2012, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014, Nilsen, Frich et al. 2014, Connell, Schweitzer et al. 2015, Subandi 2015); were happier (Subandi 2015) and more open to experiences and emotions (Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Brand, Harrop et al. 2010, Lester, Marshall et al. 2011, Bourdeau, Lecomte et al. 2014, Dunkley and Bates 2014, Nilsen, Frich et al. 2014, Subandi 2015); were more empathetic (Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Lam, Pearson et al. 2011, Sin, Moone et al. 2012, McGrath, Peters et al. 2013, Dunkley and Bates 2014) and kinder (Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Lam, Pearson et al. 2011, McCann, Lubman et al. 2011, McGrath, Peters et al. 2013, Dunkley and Bates 2014); knew more about their own resources and how they reacted and dealt with stress (Kilkku, Munnukka et al. 2003); and were better able to handle stress and negative emotions (Kilkku, Munnukka et al. 2003, O'Toole, Ohlsen et al. 2004, Sin, Moone et al. 2008, Ashcroft, Barrow et al. 2011, McCann, Lubman et al. 2011, Sin, Moone et al. 2012, McGrath, Peters et al. 2013, Connell, Schweitzer et al. 2014, Gearing, DeVylder et al. 2014, Nilsen, Frich et al. 2014, Subandi 2015). Finally, service users described learning new skills (Windell and Norman 2013) such as time and resource management (Lam, Pearson et al. 2011)

Health, lifestyle, and interests

Following FEP, service users improved their quality of life by making their lives simpler, more enjoyable and more meaningful (Dunkly, Foulds et al. 2007, Krupa, Woodside et al. 2010, Windell and Norman 2013, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015); by reducing substance use (MacDonald, Sauer et al. 2005, Krupa, Woodside et al. 2010, Cadario, Stanton et al. 2012, Windell and Norman 2013, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014), taking better care of themselves (Windell and Norman 2013), practicing better sleep habits (Windell and Norman 2013) exercising (Lam, Pearson et al. 2011, Subandi 2015); and setting valued goals (e.g., becoming physically fit) (Dunkley and Bates 2014). Service users also felt that the experience of FEP opened up possibilities that would otherwise have been not available (Brown 2011, Pietruch and Jobson 2012, Dunkley and Bates 2014, Vodušek, Parnas et al. 2014) and led to new activities (Windell and Norman 2013) and better functional roles like new employment avenues (McGrath, Peters et al. 2013, Subandi 2015). Some service users described developing new interests (Dunkly, Foulds et al. 2007, Windell and Norman 2013, Dunkley and Bates 2014) such as photography (Windell and Norman 2013).

Analytic theme: Interpersonal positive change

Twenty studies reported how the experience of FEP may have positively influenced service users' and families' relationships and the place they occupied within society. This theme comprised two subthemes: *relationships with family and friends,* and *place/role in society.*

Relationships with family and friends

Studies described how FEP led to improved, closer, deeper, more valued, and stronger family bonds (Dunkly, Foulds et al. 2007, Sin, Moone et al. 2008, Brown 2011, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Newman, Simonds et al. 2011, Braehler and Schwannauer 2012, Pietruch and Jobson 2012, Sin, Moone et al. 2012, Anderson, Fuhrer et al. 2013, McGrath, Peters et al. 2013, Connell, Schweitzer et al. 2014, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015) and improved bonds between service users and friends (Brand, Harrop et al. 2010, Lam, Pearson et al. 2011). FEP also led families to become more resilient to struggles through improvements in communication (Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Braehler and Schwannauer 2012, Sin, Moone et al. 2012, Nilsen, Frich et al. 2014); problem-solving (Sin, Moone et al. 2008, Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Sin, Moone et al. 2012, Dunkley and Bates 2014); and coping and emotional regulation (McCann, Lubman et al. 2011, Sin, Moone et al. 2012). Studies also described how families spent more time together (Krupa, Woodside et al. 2010, Dunkley and Bates 2014)and became more harmonious (Dunkley and Bates 2014), considerate (McCann, Lubman et al. 2011, Newman, Simonds et al. 2011, Sin, Moone et al. 2012), caring, and willing to put effort into their relationships with each other (Dunkley and Bates 2014).

Some studies reported how service users let go of unhealthy relationships. These included romances that had come to be seen as unhealthy (Larsen 2004) and friendships now perceived as less valuable, harmful, unstable and superficial (Mackrell and Lavender 2004, MacDonald, Sauer et al. 2005, Lam, Pearson et al. 2011). Service users also described shedding relations with friends whom they perceived as lacking empathy (Mackrell and Lavender 2004). In contrast, service users described rekindling valuable relationships with individuals with whom they had lost touch before experiencing FEP (Lam, Pearson et al. 2011) and establishing precious new friendships (Braehler and Schwannauer 2012), including with others who had experienced psychosis (Anderson, Fuhrer et al. 2013, Windell and Norman 2013).

Place/role in society

Studies described how, following FEP, service users and family members gave back to others by supporting individuals who had experienced psychosis or other mental health problems through peer support (McGrath, Peters et al. 2013, Stewart 2013). Families also reported raising awareness about mental illnesses and challenging the stigma of mental illness within their family and in society at large (Sin, Moone et al. 2012) (Newman, Simonds et al. 2011).

Analytic theme: Religious/spiritual-level positive change

Four studies reported how FEP led service users to experience increased levels of spirituality and religiosity(Tanskanen, Morant et al. 2011, Pietruch and Jobson 2012, Connell, Schweitzer et al. 2015, Subandi 2015) which service users, carers and authors identified and is consistent with models of posttraumatic growth or how spiritual groups may experience growth following adversity (Tedeschi and Calhoun 2004). For instance, service users prayed more (Subandi 2015) and became more involved in religious institutions (Tanskanen, Morant et al. 2011, Connell, Schweitzer et al. 2015, Subandi 2015). One service user reported positive religious experiences, such as a spiritual opening up of the heart, while another felt that FEP enabled him to repent and accept his destiny (Subandi 2015) which he perceived as beneficial.

Objective 2: Facilitators of positive changes following FEP

Facilitators of positive change were derived from one cross-sectional quantitative study (Pietruch and Jobson 2012) and from study authors' reflections and participant quotations in the qualitative studies; we only included factors and processes described specifically as facilitating positive change. These factors were 1) *Personal factors*, 2) *Social factors* 3) *Religious/spiritual factors*, and 4) *Factors related to mental healthcare*.

Analytic theme: Personal factors reported as facilitating positive change

Personal factors facilitating positive change were related to psychological processes, skills and coping strategies employed to deal with FEP and facilitate recovery.

Psychological processes facilitating positive change included experiencing a sense of hope for the future (McCann, Lubman et al. 2011, Connell, Schweitzer et al. 2015); developing greater awareness of the world (Hirschfeld, Smith et al. 2005); making sense of and actively contemplating how the impact of FEP could be positive (Kilkku, Munnukka et al. 2003, Larsen 2004, Newman, Simonds et al. 2011, Connell, Schweitzer et al. 2014); a heightened sense of agency (Dunkley and Bates 2014); and having the capacity to infer the mental states of others (Braehler and Schwannauer 2012, Connell, Schweitzer et al. 2014). Studies also described how positive changes were facilitated by being more mature (Nilsen, Frich et al. 2014); more motivated to achieve goals (Newman, Simonds et al. 2011, McGrath, Peters et al. 2013, Dunkley and Bates 2014, Connell, Schweitzer et al. 2015, Subandi 2015); more determined to deal with current and future difficulties (Newman, Simonds et al. 2011, Connell, Schweitzer et al. 2015); by actively strategizing for recovery (Connell, Schweitzer et al. 2015); proactively deciding and attempting to effect positive change (MacDonald, Sauer et al. 2005, Connell, Schweitzer et al. 2015); and becoming passionate about helping others (Newman, Simonds et al. 2011, McGrath, Peters et al. 2013).

Skills employed by service users to facilitate positive change included improved self-care to support recovery efforts (Windell and Norman 2013, Subandi 2015); developing or re-discovering talents and abilities (Windell and Norman 2013); and improving physical their living conditions (Subandi 2015). Engaging in valued ongoing or new functional activities (such as school or work) was also linked to positive change among service users (Braehler and Schwannauer 2012, Windell and Norman 2013). Coping strategies facilitating positive change included those learnt through specific interventions and others acquired by service users on their own. They included developing strategies to deal with disturbing thoughts; thinking about thinking (metacognition); identifying the positive aspects of adverse situations (Connell, Schweitzer et al. 2015); and having a positive attitude (McCann, Lubman et al. 2011). Furthermore, being able to communicate, discuss and disclose one's thoughts and feelings were also linked to positive change (Lester, Marshall et al. 2011, McCann, Lubman et al. 2011, Braehler and Schwannauer 2012, Pietruch and Jobson 2012, Connell, Schweitzer et al. 2014, Nilsen, Frich et al. 2014).

Finally, the process of recovery (Kilkku, Munnukka et al. 2003, Braehler and Schwannauer 2012, Pietruch and Jobson 2012, Connell, Schweitzer et al. 2015) was also reported to contribute to positive change. An integrative recovery style (Braehler and Schwannauer 2012, Pietruch and Jobson 2012), that integrates psychotic experiences into a coherent life narrative contributed more to positive change than a sealing-over style that attempts to forget about psychotic experiences (McGlashan, Levy et al. 1975).

Analytic theme: Social factors reported as facilitating positive change

Studies described positive change as being facilitated by social factors such as stronger connections with community (Subandi 2015) and having one's beliefs about mental illness challenged by others. Caregivers being there for services users (Windell and Norman 2013, Dunkley and Bates 2014) and having qualities like honesty, trust, trustworthiness, and genuine interest (McCann, Lubman et al. 2011), were linked to positive change among service users. In caregivers, the process of caring for a loved one with psychosis facilitated positive change (McCann, Lubman et al. 2011, Newman, Simonds et al. 2011).

Analytic theme: Religious/spiritual factors reported as facilitating positive change

The very few studies describing how religious/spiritual factors facilitate positive change revealed that prayer (de Wet, Swartz et al. 2014), attending religious services (e.g., church) (Tanskanen, Morant et al. 2011), and reading scripture (e.g., the Quran) were important in this regard (Subandi 2015).

Analytic theme: Aspects of mental healthcare services reported as facilitating positive change

Factors related to mental healthcare services were the most frequently endorsed facilitators of positive change within the included studies. They included factors related to service delivery, various interventions that individuals and family members partook of and information provided by mental health professionals.

Service users reported positive change as having been facilitated by services that emphasized self-efficacy (Barker T, Lavender N et al. 2001), participation in activities (Lester, Khan et al. 2012), recovery (Windell and Norman 2013), hope, (Stewart 2013) self-acceptance (O'Toole, Ohlsen et al. 2004), and stress management (Harris, Collinson et al. 2011). Services that placed less emphasis on diagnosis, but instead stressed each individual’s specific experience and narrative (Stewart 2013), also facilitated positive change. While service users described hospital-based services less positively, their dislike for such care was sometimes perceived as having “sensitized” them to be more appreciative of better care (Stewart 2013).

Because of its recognized value in treating FEP, medication was seen as facilitating positive change (Bradshaw, Wearden et al. 2012, Lester, Khan et al. 2012). Positive change was also seen as having been facilitated by family interventions focused on problem-solving (Nilsen, Frich et al. 2014). Learning new ways of coping, such as through mindfulness meditation (Ashcroft, Barrow et al. 2011), was linked to positive change (Lester, Marshall et al. 2011). Peer support services facilitated positive change through the reciprocal nature of the relationship between peers and the normalizing, non-threatening environment in which it occurred (Harris, Collinson et al. 2011, Lester, Marshall et al. 2011, Stewart 2013). Alcoholics Anonymous and Narcotics Anonymous were specifically mentioned as peer-based programs that brought about positive change (Krupa, Woodside et al. 2010). Finally, receiving meaningful and pertinent information about FEP and its treatment from mental healthcare professionals was also important (Kilkku, Munnukka et al. 2003).

Discussion

This study aimed to synthesize scientific and peer-reviewed qualitative, quantitative, and mixed methods literature about positive change following FEP as experienced by service users, their families, and friends; and the factors/processes that facilitate such positive change. It revealed that service users, their families and friends experienced positive change at the individual, interpersonal and religious/spiritual levels along with the suffering that is inherent in FEP. Until now, no systematic review has examined positive change following a serious mental illness. Our synthesis can make early intervention services for psychosis more concordant with their foundational philosophy of offering evidence-informed, strengths-based services that emphasize optimism (Bertolote and McGorry 2005).

The domains of positive change described were consistent with domains found in investigations of positive change following other adversities (Linley and Joseph 2004, Barskova and Oesterreich 2009, Bostock, Sheikh et al. 2009, Hefferon, Grealy et al. 2009), with the most frequently endorsed aspect pertaining to developing new insights and shifts to one’s self. The similarities between positive changes experienced following physical and mental health problems support Frank's findings that passages through suffering various adversities follow archetypal patterns that can be framed as illness, chaos, and quest narratives (Frank 1995). Within Frank's conceptualization, our findings of positive change seem to fall largely within the archetype of quest narratives.

A key positive change was that FEP spurred service users and families to give back to society by becoming peer support workers and engaging in activism. While "giving back" as a positive change may follow other adversities, this dimension has not usually featured in current conceptualizations of post-adversity positive change (Tedeschi and Calhoun 2004, Joseph and Linley 2006, Zoellner and Maercker 2006). Our synthesis thus meaningfully extends the spectrum of post-adversity positive change.

While psychosis is generally associated with significant cognitive impairments (Aas, Dazzan et al. 2014), service users in a few of the studies we reviewed reported clearer thinking, greater perspective-taking and feeling smarter following FEP. Such improvements may relate to heightened clarity of goals and values rather than improvements in cognitive functioning per se. Nonetheless, it may be valuable to further investigate these subjective perceptions of changes in cognition and their role in contributing to recovery.

Families and friends of service users reported experiencing positive changes following their loved one's FEP, despite also experiencing caregiving burden. Although based on few studies, this finding is consistent with other studies showing that posttraumatic growth occurs in family members of individuals who have experienced several psychotic episodes (Morton, White et al. 2015) or other traumas (Duran 2013), and suggests that being there for a person who is suffering can be rewarding.

Our synthesis suggests that positive changes were facilitated by factors within individuals, their social and religious/spiritual lives, and the structural and relational aspects of the care they received. This is consistent with ecological models of resilience (Ungar, Ghazinour et al. 2013) as well as facilitators of positive change following other traumas (Linley and Joseph 2004).

The most frequently perceived facilitator of positive change after FEP was receiving care seen as appropriate, positive and strengths-enhancing, usually at early intervention services. Perhaps this is because a majority of our included studies recruited participants from early intervention services. However, other studies have shown that programs offering broad-spectrum, high-quality mental health services and supports are perceived as important by service users (Fava and Tomba 2009, Lal, Ungar et al. 2015, Sanders, Munford et al. 2015) , further strengthening our conclusion. Of note, studies of positive change following other types of adversities do not point to the primacy of treatment or services as a facilitator.

While the majority of our studies provided information about the phenomenology of positive change, fewer studies reported on factors facilitating it. Given that our synthesis is based largely on qualitative studies, these facilitators should not be viewed as causally related (in a quantitative sense) to aspects of positive change. However, they do represent avenues for further research.

Facilitators were sometimes difficult to distinguish from aspects of positive change themselves. For instance, a commitment to improving relationships was a positive change that led to a more peaceful home environment. This in turn served as a facilitating factor promoting further growth in the interpersonal sphere. Positive change in one domain may also spur positive change within another domain. Thus, positive change and its facilitators can form a virtuous circle, wherein each gain facilitates the next one. Positive changes may also increase an individual's capacity to cope with future challenges (e.g., by becoming closer to family, an individual may receive new support in the face of future life challenges).

The relationship between recovery and positive change was not unidirectional. At times, positive change seemed synonymous with recovery, echoing work by Jacobson and Greenley (Jacobson and Greenley 2001). In other instances, recovery was seen as promoting positive change, consistent with the theoretical framework that posttraumatic growth is a state beyond recovery (Carver 1998, Tedeschi and Calhoun 2004). In yet another scenario, positive change promoted recovery. While it may be difficult to distinguish between positive change and recovery, it may be more meaningful to simply defer to service users' own conceptions of recovery and positive change, or to view the relationship between recovery and positive change as fluid.

It is important to bear in mind that youth represents a critical developmental period wherein young people often grapple with their aspirations, values, identity and place in society. Given this, youth with FEP may already be on a path of change, suggesting that positive changes following psychosis may result from interactions between responses to psychosis and the normal developmental processes.

Implications for service delivery

Regardless of any positive change it may precipitate, psychosis remains a devastating and traumatic illness for many individuals and their loved ones, and one that we do not seek to characterize as desirable. However, our synthesis provides an evidence base for services striving to promote growth among service users. Positive changes should be fostered by services because, in addition to being valuable on their own, they may be resilience-enhancing and lead to better outcomes. Knowing that positive change can occur following FEP, services can offer specific interventions that can both create conditions conducive to positive change and capitalize on these changes. Simply making it a point to inform service users and families/friends that positive change is known to occur after adversity could improve their outlook and, thereby, possibly their outcomes.

Strengths

This review deals with a subject which has hitherto received little attention and has the potential to shift the narrative around psychosis. Adopting a rarely used but apt methodology, we maintained a high level of rigor and conducted a synthesis which remained close to the data presented in the articles. Finally, the majority of included studies were of relatively high methodological quality.

Limitations

We recognize that grey literature, particularly first-person accounts, could have yielded rich data on our subject of interest (Perry 1974, Williams 2012). However, choosing a more conservative approach, we included only peer-reviewed, scientific evidence.

Furthermore, most of the primary studies reviewed were not specifically conducted to discover aspects or facilitators of positive change. We still chose to include such studies to arrive at the most comprehensive possible synthesis of literature on our topic of interest.

Although we present religion/spiritualty as positive changes and facilitators, it should be noted that these are very poorly studied dimensions of positive change following FEP. Little is known about the extent to which FEP precipitates change in the sphere of religion/spirituality, whether such change is viewed as positive, and whether persons with a religious/spiritual outlook are likelier to experience positive change following FEP.

The majority of studies reviewed included samples drawn from early intervention services. As such, our findings may be more pertinent to individuals receiving these services than to those receiving standard care. However, our findings are consistent with those of many other studies reporting positive change. Finally, it was impossible to draw any conclusions on the frequency at which particular positive changes occurred. This may be a feature of qualitative systematic reviews in general.

Future directions

This review highlights the need for detailed, prospective and high-quality investigations of positive change following FEP. Future research should be explicitly designed with the objective of examining positive change from the perspectives of service users, and their families, friends, and treatment providers. Such investigations could benefit from the inclusion of qualitative methods suited to elucidating subjective experiences and quantitative methods that can determine the extent to which positive change occurs, at what point in the course of illness it occurs, how it is manifested, at what frequency its manifestations occur, what factors facilitate it and its relationship with other outcomes such as recovery, resilience and remission. Such a mixed methods study is currently being conducted by the authors (Jordan, Malla et al. 2016).

Table 1: Study characteristics

Study	Country	Quality Appraisal	Study Aims	Approach	Data Collection	Themes
Barker et al.,2001 (Barker T, Lavender N et al. 2001)	United Kingdom	75%	To explore the narratives used to explain the process of developing schizophrenia	Grounded Theory	Semi-structured Interviews	*Aspects*: Individual-level *Facilitators:* Services
MacDonald et al., 2005 (43)	Australia	100%	To explore experiences of social relationships during the recovery from FEP	Phenomenological Approach	Open-ended interview	*Aspects:* Individual-level *Facilitators:* Personal
Mackrell et al., 2004 (44)	United Kingdom	100%	To explore peer relationships before, during and after the onset of FEP in people recovering from FEP	Grounded Theory	Semi-Structured Interviews	*:* *Aspects:* Individual-level Interpersonal *Facilitators:* NA
O'Toole et al., 2004 (64)	United Kingdom	25%	To explore experiences of a FEP intervention and establish aims seen as effective for future service planning	Interpretative Phenomenological Analysis	Focus Groups	*:* *Aspects:* Individual-level *Facilitators:* Personal, Services
Connell et al., 2014 (38)	Australia	75%	To explore experiences of the early stages of recovery from FEP	Interpretative Phenomenological Analysis	Semi-structured Interviews	*:* *Aspects:* Individual-level, Interpersonal *Facilitators:* Personal
Krupa et al., 2010 (60)	Canada and Australia	75%	To explore activity and social participation following a first episode	Constructivist Grounded Theory	Semi-structured Interviews; Document	*Aspects:* Individual-level *Facilitators:*

			of psychosis		Analysis	Services:
Vodušek et al., 2014 (45)	Slovenia	25%	To explore the emotional experience of a first episode of psychosis	Phenomenological Approach	Open-ended interviews	*Aspects:* Individual-level *Facilitators:* NA
Tanskanen et al., 2011 (28)	United Kingdom	50%	To explore experiences of onset of FEP and help seeking for FEP	Thematic Analysis	Semi-structured Interviews	*Aspects:* Spiritual *Facilitators:* Spiritual
Windell et al., 2012 (46)	Canada	50%	To examine perceptions of what influences recovery following a FEP	Thematic Analysis	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal, Social, Services
Anderson et al., 2013 (59)	Canada	50%	To explore pathways to care and factors that influence help-seeking	Qualitative Descriptive Approach	Unstructured and semi-structured, in-depth interviews	*Aspects:* Individual-level Interpersonal *Facilitators:* NA
Stewart et al., 2012 (61)	Australia	100%	To explore the process of engagement in treatment following a FEP	Grounded Theory	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Services:
Eisenstadt et al.,	Brazil	25%	To understand the	Phenomenological	Semi-structured	*Aspects:*

2012 (47)			experience of recovery following a FEP	Approach	interviews	Individual-level *Facilitators:* NA
Harris et al., 2011 (48)	United Kingdom	75%	To explore service-user experiences of being in contact with early intervention services and the impact of that contact	Interpretative Phenomenological Analysis	Semi-structured interviews	*Aspects:* Individual-level *Facilitators:* Services
Ashcroft et al., 2012 (49)	United Kingdom	100%	To explore experiences of receiving mindfulness therapy within an early intervention program for psychosis	Grounded Theory	Semi-structured interviews	*Aspects:* Individual-level *Facilitators:* Services
Braehler et al., 2011 (41)	United Kingdom	100%	To investigate how people adapt to psychosis and the influence of reflective function on adaptation	Constructivist Grounded Theory	Semi-structured interview, adult attachment interview, reflexive functioning scale	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal
Hon, 2012 (50)	United Kingdom	100%	To gain an understanding of medication-taking practices	Grounded Theory	Semi-structured interviews	*Aspects:* Individual-level *Facilitators:* NA
Bradshaw et al., 2011 (62)	United Kingdom	100%	To develop and evaluate a healthy living intervention	Framework Analysis	Semi-structured Interviews	*Aspects:* Individual-level *Facilitators*: Services
Lester et al., 2012 (63)	United Kingdom	75%	To explore perspectives of early intervention services and primary care over time	Constructivist Grounded Theory	Semi-structured interviews	*Aspects:* Individual-level *Facilitators:* Services
Cadario et al., 2011(29)	New Zealand	75%	To examine the experience of FEP and the experience of accessing treatment	General inductive approach	Unstructured and semi-structured interviews	*Aspects:* Individual-level *Facilitators:* NA

Sin et al., 2012 (31)	United Kingdom	25%	To explore the needs of siblings of people receiving early intervention services for FEP	Thematic Analysis and Framework Analysis	Semi-structured Interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* NA
Lam et al., 2012 (55)	China (Hong-Kong)	50%	To explore the meaning of FEP and meanings related to illness and recovery	A combination of various qualitative methods	Focus Groups	*Aspects:* Individual-level, Interpersonal *Facilitators:* NA
Lester et al., 2011(52)	United Kingdom	50%	To describe views of people referred to early intervention services within the context of their relationships	Constructivist Grounded Theory	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal, Services
Brown, 2011 (403)	Canada	100%	To understand way that FEP affects occupational performance	Thematic Analysis	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* NA
McCann et al., 2011 (30)	Australia	75%	To explore the experience of caregiving for persons with FEP	Interpretative Phenomenological Analysis	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal, Social
Sin et al., 2008 (32)	United Kingdom	50%	To explore the experiences and needs of siblings of persons who experienced a FEP	Phenomenological Approach	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* NA
Hirschfield et al., 2005 (53)	United Kingdom	75%	To explore the lives of young men before, during and after having had a FEP	Constructivist grounded theory	Semi-structured interview	*Aspects:* Individual-level *Facilitators:* Personal
Larsen, 2004 (42)	Denmark	100%	To examine how	Person-centered	Documentary	*Aspects:*

			individuals generate meaning following experiences of a FEP	ethnographic approach	analysis, individual interviews, focus groups, surveys, time registration forms, written narratives	Individual-level, Interpersonal, Spiritual *Facilitators:* Personal Services
Kilkku et al., 2003(39)	Finland	100%	To describe how people who experienced a FEP experienced information-giving and the meaning of information-giving	Phenomenological Approach	Unstructured interviews	*Aspects:* Individual-level *Facilitators:* Personal, Services
Newman et al., 2011 (54)	United Kingdom	50%	To explore the impact of a FEP on siblings ‘experience of self, identity development, and family roles	Narrative Analysis	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal, Social
Nilsen et al., 2014 (34)	Norway	50%	To explore the benefits of receiving a psychoeducational family intervention following a FEP	Systematic Text Condensation	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal, Services
Bourdeau et al., 2015 (55)	Canada (Quebec)	25%	To explore the links between recovery stages, symptoms, function and narrative development among people who had experienced a FEP	Mixed Methods; content analysis for qualitative data; descriptive discriminant analysis and t- tests for quantitative; unspecified method of integrating qualitative and quantitative findings	Psychosocial Rehabilitation Toolkit; Social Functioning Scale; BPRS-Expanded; California Verbal Learning Test; Trail Making Test (A & B); structured interview	*Aspects:* Individual-level *Facilitators:* NA

					(Indiana Psychiatric Illness Interview)	
Subandi et al., 2015 (35)	Indonesia	75%	To explore the process of recovery from a FEP in a Javanese cultural setting	Ethnographic	Unstructured interviews	*Aspects:* Individual-level, Interpersonal, Spiritual *Facilitators:* Personal, Spiritual
Gearing, et al., 2014 (33)	United States of America	50%	To examine pathways in youth self-determination and self-management of treatment for FEP	Content Analysis	Semi-structured interviews	*Aspects:* Individual-level *Facilitators:* NA
de Wet et al., 2015(56)	South Africa	50%	To understand the experience of recovery from FEP in persons living in South Africa	Interpretative Phenomenological Analysis	Semi-structured interviews	*Aspects:* Individual-level *Facilitators:* Spiritual
Connell et al., 2015 (57)	Australia	50%	To understand the process of change in self and its relationship to recovery	Interpretative Phenomenological Analysis	Interviews (not specified)	*Aspects:* Individual-level, Spiritual *Facilitators:* Personal
Brand et al., 2011 (37)	London	100%	To explore the meaning of friendship for friends of people who have experienced a FEP	Constructivist Grounded Theory	Semi-structured interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* NA
Dunkley et al., 2015 (36)	Australia	50%	To explore accounts of posttraumatic growth following a FEP	Interpretative Phenomenological Analysis	Semi-structured Interviews	*Aspects:* Individual-level, Interpersonal *Facilitators:* Personal, Social, Services
McGrath et al., 2013 (58)	United Kingdom	50%	To develop a theoretical understanding of	Constructivist Grounded Theory	Semi-structured Interviews	*Aspects:* Individual-level,

			recovery from FEP following childbirth			Interpersonal *Facilitators:* Personal, Social
Pietruch et al., 2012 (20)	United Kingdom	25%	To investigate the relationship between post traumatic growth and self-disclosure of posttraumatic stress symptoms and recovery	Quantitative Descriptive Study	Actual self-disclosure measure; Posttraumatic Growth Inventory; Process of Recovery Questionnaire	*Aspects:* Individual-level, Interpersonal, Spiritual *Facilitators:* Personal
Dunkley et al., 2007 (21)	Australia	25%	To examine recovery from FEP in terms of trauma and posttraumatic growth	Quantitative: descriptive statistics; Qualitative: thematic analysis	Quantitative: Recovery Style Questionnaire; the Positive and Negative Syndrome Scale; Qualitative: semi-structured interviews	*Aspects:* Individual-level *Facilitators:* NA

Table 2: Characteristics of participants in the included studies

Authors	Diagnosis	Ethnicity	Sex	Stakeholders	Age	Sample size
Barker et al., 2001(30)	Schizophrenia	N/A	*Service users:* N=6 males, N= 2 females *Family:* N=2 females, N=6 males	Service users, family members	Service users M = 37.5	N=8 Service users N=8 Family members
MacDonald et al., 2005 (46)	FEP	Caucasian (n = 6)	N=1 female, N=5 males	Service users	*M* = 21.99	N=6
Mackrell et al., 2004 (47)	Psychotic disorder; Schizophrenia; Polymorphic disorder with symptoms of schizophrenia; Bipolar disorder (n not specified)	Black Caribbean (n = 2), Black African (n = 2), White British (n = 2), Japanese (n = 1), White Irish (n = 1), Canadian (n = 1), Portuguese (n = 1), Mixed from Sierra Leone (n = 1)	N=5 females N=6 males	Service users	NA	N=12
O'Toole et al., 2004 (67)	Schizophrenia (n = 10),	Mixed (n = 2), White (n = 5),	N=3 females N=9 males	Service users	*M* = 26.58	N=12

	Schizoaffective (n = 2)	Asian (n = 2), African/ Caribbean (n = 3)				
Connell et al., 2014 (41)	FEP	N/A	N=6 females N=20 males	Service users	*M* =21	N=26
Krupa et al., 2010 (63)	FEP	20 living in Canada; 5 living in Australia	N=8 females N=17 males	Service users	*M* = 25.7	N=25
Vodusek et al., 2014 (48)	"Non-affective psychosis"	N/A	N=8 females N=12 males	Service users	*M* = 22.1	N=20
Tanskanen et al., 2011 (31)	FEP	*Service-users* = White British = 3, White other = 4, Black African = 3, Black Caribbean = 5, Asian Bangladeshi = 4, Mixed race = 2; *Carers* = [5 White British; 2 White other; 1	*Service users*: N=6 females, N=15 males; *Carers*:N=8 females, N=1 male	Service users, carers	Service users *M* = 26.5; Carers range = 26-68	N=21 Service users N=9 Carers

		Black Caribbean; 1 Mixed Race				
Windell et al., 2012 (49)	Schizophrenia (n = 16); Schizoaffective (n = 8); Psychosis NOS (n=3); Substance-induced (n = 2); Bipolar disorer (n=1)	N/A	N=7 females N=23 males	Service users	*M* = 25.87	N=30
Anderson et al., 2013 (62)	N/A	N/A	N=4 females N=12 males	Service users	*M* = 22.5	N=16
Stewart et al., 2012 (64)	Schizophrenia (n = 14);, Schizoaffective (n = 6); Depression (n = 6); Bipolar disorder (n=3); Brief psychotic episode (n = 1)	Born overseas (Hong Kong, Greece, Spain, and Fiji) (n = 4) , first-born Australians from immigrants (n = 21), first born Australians from non-immigrants (n	N=15 females N=15 males	Service users	NA	N=30

		= 5)				
Eisenstadt et al., 2012 (50)	Paranoid schizophrenia (n = 8)' Schizoaffective (n = 3); Schizophreniform (n = 2); Catatonic schizophrenia (n = 1); Psychosis NOS (n = 1); Persistent delusional disorder (n = 1)	N/A	N=4 females N=12 males	Service users	*M* = 20.13	N=16
Harris et al., 2011 (51)	N/A	N/A	N=3 females N=5 males	Service users	*M* = 29.25	N=8
Ashcroft et al., 2012 (52)	"Persistent difficulties with either positive symptoms, or anxiety, or both"	White British (n = 9)	N=2 females N=7 males	Service users	*M* = 25.56	N=9
Braehler et al., 2011 (44)	Schizophrenia-like (n = 4); Schizoaffective (n = 1); Bipolar	N/A	N=4 females N=4 males	Service users	*M* = 18.6	N=8

	Disorder (n = 2); Psychotic Depression (n = 1)					
Hon, 2012 (53)	Schizophrenia (n = 6); Schizoaffective (n = 3); Bipolar Disorder (n = 3)	N/A	N=5 females N=7 males	Service users	*M* = 25.16	N=12
Bradshaw et al., 2011 (65)	N/A	British white (n = 8), Black African (n = 2) South Asian (n = 3)	N=3 females N=10 males	Service users, health professionals	*M* = 25.5	N=13
Lester et al., 2012 (66)	N/A	White British (n = 16), Pakistani (n= 2), Indian (n = 2), Mixed (n = 1)	N=7 females N=14 males	Service users	*M* =23.28	N=63 baseline N=21 at follow-up
Cadario et al., 2011(32)	Schizophrenia (n = 8); Bipolar disorder (n=4)	New Zealand European (n =7), New Zealand Māori (n = 4), New Zealand Māori/Cook Island Māori	*Service users:* N=5 females, N=7 males *Carers*: N=11 females,N=1	Service users, primary caregivers	*Range* = 15 - 18	N=12 Service users N=12 Carers

		(n = 1)	male			
Sin et al., 2012 (34)	N/A	White British (n = 18), Black African (n =2), Asian (n = 5), Mixed (n = 6)	N=22 females N=9 males	Siblings	*M* = 22.7	N=31
Lam et al., 2012 (55)	Paranoid schizophrenia (n = 4); "Unspecified psychosis" (n = 1); Acute psychotic disorder (n = 1)	Cantonese speaking Chinese (n = 4)	N=3 females N=3 males	Service users	*M* = 25	N=6
Lester et al., 2011(54)	N/A	White British (n = 25), White other (n = 1), Irish (n = 1), Pakistani (n = 3), Indian (n = 2), Black Caribbean (n = 1), Black African (n =	N=10 females N=24 males	Service users	*M* = 22	N=63 baseline N=36 at follow-up

		1)				
Brown, 2011 (43)	N/A	N/A	N=3 females N=2 males	Service users	*Range* = 24-29	N=5
McCann et al., 2011 (33)	N/A	English speaking (n = 16), Vietnamese speaking (n = 1), English & Tagalong speaking (n = 1), English and Spanish speaking (n = 1), English and Romanian speaking (n=1)	N=17 females N=3 males	Primary caregivers	*Range* = 21-76	N=20
Sin et al., 2008 (35)	N/A	White British (n = 7), Asian, Pakistani (n = 1), Black, African (n = 1), Mixed (n = 1)	N=8 females N=2 males	Siblings	*M* = 22.8	N=10

Hirschfield et al., 2005 (56)	N/A	English (n = 5), South African Irish born (n = 1)	N=6 males	Service users	*M* = 23.3	N=6
Larsen, 2004 (45)	N/A	N/A	NA	Service users, health professionals	NA	N=15
Kilkku et al., 2003(42)	N/A	N/A	NA	Service users	NA	N=7
Newman et al., 2011 (57)	N/A	White British (n = 4)	N=2 females N=2 males	Siblings	*M* = 20.75	N=4
Nilsen et al., 2014 (37)	Schizophrenia (n = 10); Schizoaffective (n = 1); Psychosis NOS (n = 1)	White (n = 9), Asian (n = 3)	*Service users: N*=7 females,N=5 males *Family*:N=8 females, N=6 males	Service users, family members	Service users *M* = 26.78 Family members *M* = 56	N=12 Service users N=14 Family Members

Bourdeau et al., 2015 (58)	Schizophrenia (n = 29); Psychosis NOS (n = 4); Bipolar disorder (n = 4); Schizoaffective (n = 3); Psychotic depression (n = 3); Substance-induced psychosis (n = 1)	Caucasian (n = 36), African/Caribbean (n = 9), Asian (n = 1), Latin American (n = 1)	N=11 females N=36 males	Service users	*M* = 26	N=47
Subandi et al., 2015 (38)	FEP	Javanese	N=6 females N=1 male	Service users, family members	NA	N=7
Gearing, et al., 2014 (36)	Schizophrenia (n = 3); Bipolar disorder (n = 5); Major depression; (n = 1), Psychosis NOS (n = 2)	Caucasian (n = 6), Hispanic (n = 3), Asian (n = 2), African-American (n = 1)	*Service users:* N=6 females,N=6 males *Family*: N=13 females N=3 males	Service users, family members	Service users *M* = 19.3, Family members *M* = 53.1	N=12 Service users N=16 Family Members
de Wet et al., 2015(59)	Schizophrenia (n = 5); Schizophreniform (n = 2)	"Coloured" †(n = 6), White (n = 1)	N=3 females N=4 male	Service users	*M* = 35.29	N=7

Connell et al., 2015 (60)	Bipolar disorder (n = 5); Schizophrenia (n = 3); Schizophreniform (n = 2); Substance-induced psychosis (n = 2)	Country of birth: Australia (n = 10), "Overseas" (n=2)	N=3 females N=9 male	Service users	*M* = 21	N=12
Brand et al., 2011 (40)	N/A	White British (n = 5) , Black British (n = 1), Mixed European (n = 1)	N=4 females N=3 male	Friends	*M* = 21	N=7
Dunkley et al., 2015 (39)	FEP	N/A	*Service users:*N=3 females,N=7 males *Romantic partners*: N= 2 females *Parents:*N= 4 females	Service users, romantic partners, family members	Range: 22-28	N=10

			N=1 male			
McGrath et al., 2013 (61)	Puerperal psychosis (n = 11); Postpartum depression with psychotic features (n = 1)	White British (n = 12)	N=12 females	Service users	*M* = 35.6	N=12
Pietruch et al., 2012 (23)	N/A	N/A	N=12 females N=22 males	Service users	*M* = 25.67	N=34
Dunkley et al., 2007 (24)	Bipolar disorder (n = 2)	N/A	N=1 female N=1 male	Service users	*M* = 23.5	N=2

Table 1: Keywords and Search Terms Applied

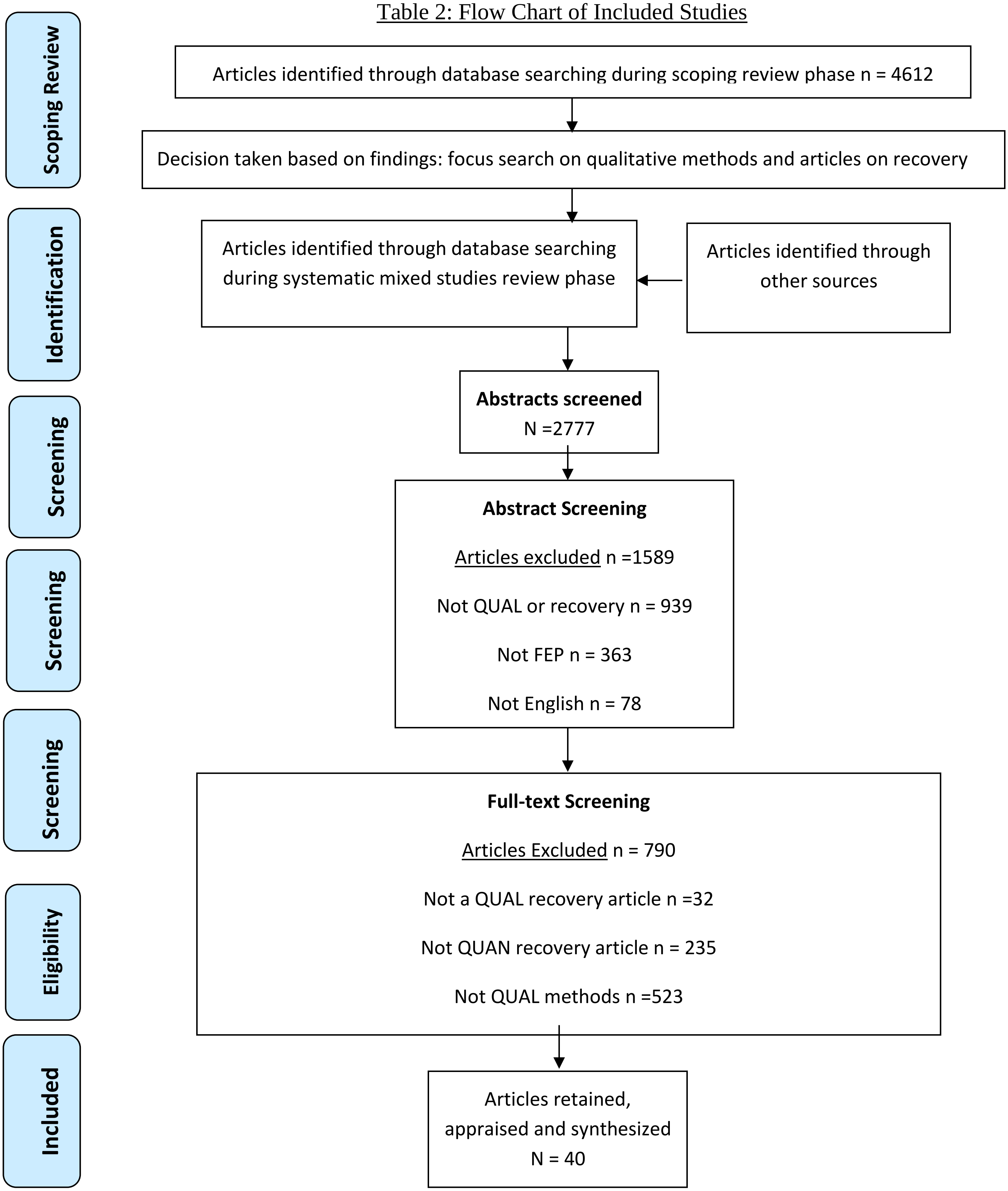
Keywords

1. (first adj3 psychos*).mp.
2. (first adj3 psychotic).mp.
3. (early adj3 psychos*).mp.
4. (early adj3 psychotic).mp.
5. (initial adj3 psychos*).mp.
6. (initial adj3 psychotic).mp.
7. or/1-6
8. Resilience, Psychological/
9. "Power (Psychology)"/
10. exp social environment/
11. exp Attitude to Health/
12. exp Family/
13. Mental Health/
14. exp Adaptation, Psychological/
15. quality of life/
16. morale/
17. life change events/
18. resilien*.mp.
19. strong*.mp.
20. robust*.mp.
21. resistant.mp.
22. spirit*.mp.
23. tough.mp.
24. endur*.mp.
25. empower*.mp.
26. enabling.mp.
27. embolden*.mp.
28. encouragement.mp.
29. inspiration.mp.
30. inspire.mp.
31. courage*.mp.
32. morale.mp.
33. strength.mp.
34. happy.mp.
35. happiness.mp.
36. pleasant*.mp.
37. enjoy*.mp.
38. satisf*.mp.
39. pleasur*.mp.
40. pleasing.mp.
41. comfort*.mp.
42. reassuran*.mp.
43. well being.mp.
44. wellbeing.mp.
45. content*.mp.
46. hearten*.mp.
47. benefi*.mp.
48. useful.mp.
49. value.mp.
50. valuable.mp.
51. helpful.mp.
52. favorable.mp.
53. favourable.mp.
54. advantag*.mp.
55. constructive.mp.
56. benevolen*.mp.
57. caring.mp.
58. meaning.mp.
59. significan*.mp.
60. importan*.mp.
61. consequen*.mp.
62. adjust*.mp.
63. adapt*.mp.
64. open to experience.mp.
65. quality of life.mp.
66. qol.mp.
67. life chang*.mp.
68. life experienc*.mp.
69. (positive and (product or adjustment or adaptation or psychology)).mp.
70. recovery.mp.
71. empath*.mp.
72. neutral.mp.
73. harmless.mp.
74. awareness.mp.
75. greatness.mp.
76. self actuali*.mp.
77. promotion.mp.
78. creativ*.mp.
79. madness.mp.
80. pride.mp.
81. proud.mp.
82. holistic*.mp.
83. ((posttraumatic or stress) and growth).mp.
84. thriv*.mp.
85. blessing*.mp.
86. transformation*.mp.
87. or/8-86
88. 7 and 87
89. (surviv* or recover*).mp.
90. 7 and 89
91. exp empirical research/ or exp health services administration/
92. (qualitative or empirical or grounded or ethno* or naturalistic or phenomenologic* or interview* or experience* or theme*).mp.
93. 7 and 92
94. 90 or 93
95. 94 not 88

Additional Keywords

“First episode psychosis” OR “early psychosis” OR “early psychotic” OR“qualitative” OR phenomenology” OR “discourse analysis” OR “ethnograph” OR “narrative” OR “narratives” OR “lived experience” OR “lived experiences” OR “in-depth interview” OR “in-depth interviews” OR “grounded theory” OR “focus group” OR “lived experience” OR “open-ended” OR “thematic analyses” OR “themes” OR “theme” OR “purposive sample” OR “purposive sampling” OR “content analysis” Post traumatic growth" OR “thrive” OR “thriving” OR “benefit” OR “benefits” OR “recover” OR “recovering” OR “recovery” OR “survive” OR “surviving” OR "integration" OR "sealing over" OR "recovery style questionnaire"

Table 2: Flow Chart of Included Studies



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Chapter Four: Paradigms Guiding this Dissertation

Scientific knowledge is situated and generated within paradigms, or systems of basic beliefs about the fundamental nature of the world and reality (Guba and Loncoln 1994). Although paradigms are not always distinct entities, quantitative research is generally conducted under positivist or post-positivist paradigms; and qualitative research is usually conducted under relativist paradigms, such as social constructivism, critical realism, constructionism, etc. (Guba (Guba and Lincoln 2005).

Since mixed methods research involves combining different methods, choosing an appropriate paradigm under which to conduct mixed methods research is challenging. Some argue that because quantitative and qualitative methods are traditionally rooted in different paradigms, combining both methods in one study is philosophically impossible (Denzin 2010). The typical paradigm of choice for mixed methods researchers is pragmatism, which is based on the premise that researchers should use whatever method is at their disposal to answer a research question (Creswell and Plano Clark 2011). While pragmatism has been widely applied, there may also weaknesses inherent in adopting a pragmatic paradigmatic stance; for instance, it has been argued that pragmatism is an easy way of circumventing the philosophical problems inherent in mixing methods (Johnson and Onwuegbuzie 2004, De and Lowe 2011).

Overarching paradigm: Dialectical Pluralism

An alternative paradigm for mixed methods studies is dialectical pluralism (Johnson 2012, Johnson 2017), which is the overarching metaparadigm guiding this study. Dialectical pluralism is a metaparadigm that builds on the practice of using back-and-forth reasoning as a way of generating knowledge (Johnson 2017); on prior work on dialectic philosophy (Greene and Caracelli 1997, Greene 2007, Greene and Hall 2010); and on the notion that pluralism is desirable for a society. Rather than ignoring the philosophical issues that arise when combining paradigms as in the case of pragmatism, dialectical pluralism is a metaparadigm that allows researchers to engage with multiple methods, perspectives, standpoints and values. Conducting research using dialectical pluralism requires researchers to dialogue with differing paradigms and their respective ontologies (i.e., what researchers think is the nature of reality), epistemologies (i.e., theories of knowledge), methodologies (i.e., how researchers acquire knowledge) and axiologies (i.e., what researchers value) to create a more meaningful whole. Rather than ignoring the tensions inherent in using multiple paradigms, researchers using dialectical pluralism must learn to thrive off such tensions. The paradigm of dialectical pluralism is therefore appropriate when employing convergent mixed-methods designs, where multiple methods and paradigms can be used simultaneously (Johnson 2012, Johnson 2017).

As a metaparadigm, dialectical pluralism is associated with ontological, epistemological, methodological and axiological guidelines that shape how to “dialogue” with different paradigms and methods. Ontologically, dialectical pluralism assumes multiple realities and that multiple statements made about reality can be true. Hence, reality can be both empirically observable and generated through interpretation depending on the phenomenon (Hacking 2000). These multiple ways of viewing reality can produce a richer understanding of reality. Epistemologically, dialectical pluralism requires researchers to dialogue and use multiple theories of knowledge to determine what is pertinent to a given study. Doing so will yield deeper, more meaningful knowledge relative to knowledge generated through the application of one epistemology alone. Methodologically, researchers should consider using multiple research methods and concepts to determine the most appropriate methods for a given study. Both divergence and convergence of findings generated through various methods are expected and encouraged. Establishing validity under dialectical pluralism requires that researchers ensure that the validity of qualitative, quantitative and mixed methods is maintained. Thus, all validity types should be used when appropriate. Axiologically, dialectical pluralism requires the transparent presentation of what a research project values or its valuation of various aspects (Johnson 2012, Johnson 2017).

Values guiding this project

The values guiding this project relate to the commitment I have to improving the lives of persons who have experienced psychosis; promoting social justice; and challenging authority when doing so is aligned with my values or when it can improve society. I believe that my research can improve the lives of persons who have experienced psychosis by providing them with hope for the future and the knowledge that they could potentially improve their lives following as FEP. To promote social justice, I ensured that my work gave voice to perspectives that are often lacking; remaining open to the diversity of perspectives shared by participants, even if I disagreed with or felt uncomfortable with those perspectives; and recognizing that positive changes are embedded within larger contexts that can limit people's potential to live full lives. By focusing on positive sequelae following psychosis, which counters prevailing narratives about the ontology and aftermath of FEP, I was able to challenging authority. In doing so, however, I was mindful that my work did not result in "inspiration porn" for "sane" people (Grue 2016). I did so by contextualizing the research questions in broader social contexts when possible, and by not describing participant experiences as though they were exotic or magical.

Constructivism and Post-positivism

While dialectical pluralism was the overarching metaparadigm guiding the project, a constructivist paradigm guided the qualitative component of the empirical mixed methods studies, while a post-positivist paradigm guided systematic mixed studies review and the quantitative component of the empirical mixed methods studies (Guba 1990, Guba and Loncoln 1994). Ontologically, constructivism is a paradigm which views reality as multiple and based in various social interactions. Epistemologically, the researcher and subject matter are related, or linked, and data are thought to arise from co-created meanings. Methodologically, constructivism is “dialectical”, that is, created through back-and-forth exchanges between the subject matter and the researchers. In terms of axiology, constructivism holds that creating knowledge inherently involves a process of valuation (Guba 1990, Guba and Loncoln 1994).

I adhered to the tenets of constructivism in the qualitative component of this study by listening to participants and analyzing data without assuming the existence of an objective truth or benchmark for what positive change should be; by co-creating constructions through interviewing participants and analyzing data, and then merging these constructions with knowledge in the field; as well as by actively reflecting on my own position in this research process.

Unlike constructivism, the ontology of post-positivism is that reality does exist, but how reality is understood depends on the perspective of the observer. Epistemologically, post-positivism also acknowledges that observers cannot be separated from their subjects, but that one can get close to objective truth by being as objective, bias- and value-free as possible. Methodologically, post-positivism is concerned with falsifying hypotheses; manipulating study variables; conducting investigations in natural environments; and identifying insider perspectives to phenomena. Finally, post-positivism holds that values have no place in an investigation and that biases should be kept in check (Guba 1990, Guba and Loncoln 1994, Guba and Lincoln 2005).

I was consistent with the tenets of post-positivism when carrying out the systematic mixed studies review by not overly interpreting findings presented in the included studies; and relying on multiple perspectives to validate themes. I was consistent with the tenets of post-positivism by using standardized, validated scales to measure subjective perspectives of constructs; carrying out the quantitative component within the early intervention service where participants received treatment; and by taking several measures to reduce bias (e.g., handing out questionnaires in a standardized order, using a verbal script when recruiting, etc.).

Conducting a study under one overarching paradigm and two additional paradigms required me to perform almost daily paradigm shift (Kuhn 2012) in how I viewed reality, the nature of knowledge, ways to collect data, and my role in the project. Hence, I found it crucial to keep track of my thoughts and perspectives in a reflexive diary while I carried out my project. Doing so ensured that I continued to carry out my project rigorously and reflexively.

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Chapter Five: How reflexivity was applied in the current project

In employing mixed methods, researchers use qualitative and quantitative methods to address one or more research questions (Creswell and Plano Clark 2011). In using qualitative methods, researchers are encouraged to be aware that they often bring their own subjective experiences into their work, thereby shaping the creation of the knowledge produced. Such subjective experiences may include researcher's own life histories, theoretical frameworks, and views. Being transparent about one's subjective experiences is known as reflexive practice, and is considered an important way of enhancing the rigour and trustworthiness of qualitative research (Jootun, McGhee et al. 2009, Berger 2015). While reflexive practice is typically only used when carrying out the qualitative component of a mixed methods study, reflexive practice may be useful when negotiating the tensions involved in using mixed methods (De and Lowe 2011, Walker, Read et al. 2013) since working with different paradigms and methods can often be challenging (Creswell and Plano Clark 2011); and transparency about such challenges may result in more trustworthy work.

In adopting dialectical pluralism, researchers must be comfortable living with tensions involved in using multiple paradigms that may share little in common; methods that are philosophically grounded in different interpretations of reality and truth; and analytical techniques that may or may not embrace the subjective experiences of researchers (Johnson 2012, Johnson 2017). In this study, working through these issues was a delicate and difficult act that was made easier by engaging in reflexive practice.

In engaging in reflective and reflective practice, I kept a detailed journal within which I reflected on the multiple selves I brought to this study. I structured this journal around the framework for highlighting reflexivity described by Reinharz (Reinharz 1997) and Ferrari

(Ferrari 2010). The specific "selves" I reflected upon included my *brought self*, my *situationally created self*, and my *research-based self*.

In reflecting upon my *brought self*, I chronicled my ethnicity, socioeconomic status, and educational background. I reflected upon my political orientation; my views on spirituality and religion and my spiritual and religious beliefs; as well as my own personal experiences of using medical services. In reflecting upon my *situationally created self*, I chronicled my role as a Doctoral student in the Department of Psychiatry at McGill University; my role as a research assistant working at the Prevention and Early Intervention Program for Psychoses, which was the study site for this project; and the tensions inherent in occupying these different roles. For instance, I was often exposed to information about participants during clinical rounds, and felt the need to isolate that information from what participants had revealed to me in order to fully honor their subjective experiences. In reflecting upon my *research-based self*, I chronicled the sources from which I received doctoral funding; my evolution as a researcher who learned to embrace qualitative research; the difficulties I encountered in using multiple methods and paradigms; as well as the challenges I faced when attempting to understand why the quantitative results of my study diverged from the qualitative findings. For example, I often felt like I needed to fully engage with either quantitative or qualitative material, rather than partially engage with both types of research, in order to maintain consistency of thought.

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Chapter Six

Posttraumatic growth following a first episode of psychosis: a mixed methods research protocol using a convergent design

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Abstract

Background. The suffering people experience following a first episode of psychosis is great, and has been well-investigated. Conversely, potential positive outcomes following a first episode of psychosis have been under-investigated. One such outcome that may result from a first episode of psychosis is posttraumatic growth, or a positive aftermath following the trauma of a first psychotic episode. While posttraumatic growth has been described following other physical and mental illnesses, posttraumatic growth has received very little attention following a first episode of psychosis. To address this research gap, we will conduct a mixed methods study aimed at answering two research questions: 1) How do people experience posttraumatic growth following a first episode of psychosis? 2) What predicts, or facilitates, posttraumatic growth following a first episode of psychosis? **Methods.** The research questions will be investigated using a mixed methods convergent design. All participants will be service-users being offered treatment for a first episode of psychosis at a specialized early intervention service for young people with psychosis, as well as their case managers.. A qualitative descriptive methodology will guide data-collection through semi-structured interviews with service-users. Service-users and case managers will complete questionnaires related to posttraumatic growth and its potential predictors using quantitative methods. These predictors include the impact a first episode of psychosis on service-users' lives, the coping strategies they use; the level of social support they enjoy; and their experiences of resilience and recovery. Qualitative data will be subject to thematic analysis, quantitative data will be subject to multiple regression analyses, and results from both methods will be combined to answer the research questions in a holistic way.

Discussion. Findings from this study are expected to show that in addition to suffering, people with a first episode of psychosis may experience positive changes. This study will be one of few to have investigated posttraumatic growth following a first episode of psychosis, and will be the first to do so with a mixed methods approach.

Keywords: First episode psychosis; posttraumatic growth; coping; social support; resilience; recovery; mixed methods

Background

A first episode of psychosis (FEP), which is typically characterized by the onset of experiences such as hallucinations and delusions, is often a traumatic experience that leaves young people feeling alienated from themselves and the world around them, and often results in disrupted occupational, educational and social trajectories (Malla and Payne 2005, Tarrier, Khan et al. 2007, Tandon, Keshavan et al. 2008). However, as has been documented with various traumatic events including life-threatening physical health problems, war, abuse, natural disasters, death of loved ones, etc., positive changes (such as developing stronger connections with others, or becoming more mature, learning how to better handle stress) can occur alongside and following illness or trauma (Tedeschi and Calhoun 2006).

Such positive changes as a result of illness have been referred to as posttraumatic growth (PTG). On the one hand, it could be argued that PTG forms part of the recovery process from conditions such as FEP; they have been described by service-users as a component, or process of, recovery (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, Pietruch and Jobson 2012, McGrath, Peters et al. 2013, Windell and Norman 2013); and have been theorized by some to be a transformational form of recovery (Jacobson and Greenley 2001). On the other hand, it could also be argued that PTG represents a state beyond recovery (described as a return to normal, or baseline functioning, as was suggested by Carver (Carver 1998). Some have also described PTG as resilience (for reference, see (Tedeschi and Calhoun 2006)); however, PTG may be separate from the concept of resilience, or evidence of resilience; with personal, social, cultural and institutional factors (which may constitute resilience) laying the foundations for PTG. Conversely, growth may also be resilience-enhancing; for instance, an individual who develops stronger relationships with parents may come to have better social support the next time such support is needed.

While PTG has been explored in relatively older individuals with multiple-episodes of psychosis, or more chronic psychotic disorders over several years (Mapplebeck, Joseph et al. 2015), few studies have examined the phenomenon of PTG in younger people in treatment for a FEP. Studying PTG in a younger population is important because young people are in the stages of forming important educational and occupational trajectories, as well as negotiating identity issues. Having a positive narrative that young people may draw from may inspire hope in those who suffer, and may help young people, their families and treatment provider's structure care in such a way as to promote PTG.

To date, only two studies which have explored PTG following FEP have used quantitative approaches (Dunkly, Foulds et al. 2007, Pietruch and Jobson 2012). Of these, only one examined predictors of PTG (which included recovery, trauma and self-disclosure) (Pietruch and Jobson 2012). Both were based on very small convenience samples (one study had a sample size of 34, while the other had a sample size of 2; and in the second study, quantitative measures were included as part of a case study not guided by a clear methodology).These methodological issues may limit the generalizability and validity of their findings. Furthermore, only one qualitative study has explored the phenomenon of PTG, and revealed that through FEP, participants developed improved relationships with others; experienced enhanced perspective taking, confirmation of the character of others; a greater appreciation of life; new possibilities; and a stronger sense of self. However, the authors did not explore what participants felt facilitated PTG (Dunkley, Foulds et al. 2007).

PTG-like processes have been described in other qualitative studies; however, the aim of these studies was not to discover PTG in participants, but rather to elucidate other aspects or processes important for young people who have recently experienced FEP. These include studies on the process of recovery from FEP (in which participants described recovery more in terms of a return to normal, and less so in terms of PTG) (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, McGrath, Peters et al. 2013, Windell and Norman 2013); the experience of first seeking treatment for FEP (Anderson, Fuhrer et al. 2013); an evaluation of a specialized early intervention service treating FEP (Lester, Marshall et al. 2011); and experiences of what it is like to be a family member of a young person with FEP (Newman, Simonds et al. 2011). Findings from these studies yielded information on how people have grown from FEP, namely, that they appreciated life more, experienced increased spirituality, developed new interests, and strengthened bonds with others. However, the lack of focus on PTG in these qualitative studies may have resulted in a narrower depiction of PTG following FEP than would have resulted from a study focused specifically on PTG.

While independent qualitative and quantitative studies have their own strengths, combining both methods to address research questions may also be beneficial (Creswell and Plano Clark 2011). For instance, including a qualitative component into a study may yield the benefit of producing a richer, more nuanced account of a phenomenon; conversely, applying quantitative methods may yield the benefits of testing models predicting PTG or associations of PTG with possibly inter-connected concepts (e.g., resilience and recovery). Hence, a methodological approach which addresses the shortcomings of studies on PTG conducted so far by including a larger sample of well-characterized persons with psychosis and by leveraging a mixed methods approach may significantly advance our understanding of PTG following FEP.

Such a study of the aspects and facilitators of PTG following FEP may help service-users, their loved ones and treatment teams foster PTG; may help counter the highly stigmatizing views society holds about people who have experienced FEP; and may provide a strong, much needed message of hope about the experience of psychosis.

In summary, the study's larger aims are to investigate both aspects of PTG following FEP (e.g., better relationships with others, experiencing a stronger self, etc.) and facilitators/predictors of PTG (e.g., coping, social support, etc.), using a mixed methods approach.

Research Questions

Qualitative Research Questions: 1) What are the aspects of PTG service-users experience following a FEP 2) What do service-users perceive as facilitating aspects of PTG following FEP?

Quantitative Research Questions: 1) What aspects of PTG are most frequently endorsed by service-users following FEP? 2) Which factors predict PTG following a FEP?

Methods

The research questions will be investigated using a mixed methods approach [20] so that we can capture objectively the extent to which PTG and its various components are endorsed by persons with FEP and also understand subjectively how PTG is experienced following a FEP. Similarly, while the quantitative measures will allow us to determine the extent to which postulated factors predict PTG, using qualitative methods will yield subjective perceptions of the role played by these factors. Additional aspects (beyond those hypothesized) may also emerge in the qualitative analyses as influencing whether and how individuals experience growth following a FEP, which will be considered.

The project will employ a convergent design (Creswell and Plano Clark 2011, Koskey and Stewart 2014) that entails conducting separate qualitative and quantitative methods integrated at all steps of the research process.

For this project, quantitative and qualitative methods will be mixed at the level of research questions, data collection, data analysis, and interpretation of results. We will conduct both study methods simultaneously.

Ethical approval for this project was granted by the McGill University Institutional Review Board (which has jurisdiction at both recruitment sites). All eligible participants will be explained the study protocol and those who agree will sign informed consent forms prior to participation.

Qualitative Methods of the Study. In-depth, semi-structured, individual interviews lasting approximately an hour will be conducted in either English or French. The aim of the interviews will be to elucidate subjective experiences of PTG and to capture what participants feel enabled them to grow. In addition, we will also explore any negative consequences resulting from FEP, and be open to additional ways participants have grown as well as additional facilitators of PTG, to capture a more nuanced understanding of participants' experiences. Interviews will be audiotaped and transcribed verbatim. A qualitative descriptive approach will guide all aspects of the qualitative methods we employ to derive a comprehensive description of participants' experiences that is both deep and meaningful (Sandelowski 2010).

Throughout the study, the primary investigator will be reflexive and aware of how his perceptions and beliefs intersect at various junctures with the project to actively guide the project. These perceptions and beliefs emerge from having had previous experience working within the context of a disability studies framework which considers "pathology" to be a variation in human functioning which can be celebrated (Jaarsma and Welin 2012), and having had highly positive and rewarding experiences helping individuals with psychotic disorders. In terms of the design of this protocol, an awareness of the disability studies framework helped conceptualize the role that enabling environments play in influencing the extent to which people may be able to achieve PTG.

Quantitative Methods of the Study. Questionnaires assessing PTG and five hypothesized predictors of PTG (i.e., the impact that FEP had on service-user’s lives, coping strategies, levels of social support, and experiences of recovery and resilience) will be administered to service-users recruited. In addition, each service-user’s case manager will complete an adapted third-person version of the Posttraumatic Growth Inventory (Figure 1).

Recruitment Criteria and Setting

Participants will include service-users being offered treatment for a FEP and key treatment providers (i.e., their case managers) recruited from two specialized early intervention services for FEP in the McGill University Network - the Prevention and Early Intervention Program for Psychoses (PEPP) at the Douglas Mental Health University Institute and at the McGill University Health Centre. These programs are located in the lower west and central parts of Montreal, Quebec, respectively, treat all potential cases of FEP in their respective catchment area, and together serve a population of over 500,000 people. Individuals are accepted for treatment if they are experiencing a FEP not attributable to substance use or an organic brain condition (e.g., epilepsy); are between the ages of 14 and 35; have not previously taken antipsychotic medication for more than 30 days; have an IQ above 70; and are able to communicate in either English or French. Service-users are treated for between two and five years, during which they are offered close follow-up through intensive case management and antipsychotic medication. In addition to case management, other psychosocial services are provided as needed such as cognitive behavioral therapy for social anxiety (Iyer, Jordan et al. 2015).

In addition to being followed at PEPP, potential participants must be clinically stable (defined through consensus by psychiatrists and case managers at weekly meetings as not being in a relapse); must have received treatment for a minimum of one and a maximum of five years; and must be between the ages of 18 and 35. We chose to focus on this age range because of known differences between adolescents and adults on a range of early clinical and functional indicators [25]. Younger individuals also have different needs and are at different developmental junctures compared to older individuals.

Sampling Strategy and Power Calculations

When employing qualitative methods, we will recruit participants who have experienced some degree of growth following their FEP using a purposive sampling technique (as evaluated by their case manager and/or psychiatrist). A maximum variation strategy will be employed, and we will attempt to ensure that both genders and a range of SES backgrounds are well-represented in our sample, as gender and SES have been shown to influence PTG (Vishnevsky, Cann et al. 2010). We estimate that between 10 and 15 participants will be recruited. Given that this project is being completed within the scope of a doctoral progam, we may not be able to reach the point of theoretical saturation.

When employing quantitative methods, we will recruit all service-users at PEPP who meet study recruitment criteria. In order to achieve 80% power, a sample size of 92 participants will be needed to obtain a moderate effect size (f^2=.15) in a multiple regression analysis (i.e., the main analysis we will perform) with five predictor variables tested at an alpha level of .05.

Since no previous study that has examined PTG included the predictors of interest in this study, our power estimations were based on an assumption of a moderate effect size, which is consistent with effect sizes generally observed in behavioral sciences (Cohen 1988), and with meta-analyses examining PTG following non-psychotic illnesses (Sawyer, Ayers et al. 2010). An 80% power level was chosen—relative to a higher power level—to decrease the chances of making a type-1 error. Power was calculated using G*Power version 10.

Measures and Procedures

Qualitative Interview Guide. A semi-structured interview guide developed by the primary investigator will be used to conduct in-depth interviews. The interview guide was validated through feedback from service-users and their family members, as well as case managers, psychiatrists, and research evaluators at PEPP. Each stakeholder group made suggestions and modifications to the content of the guide.

The guide contains open-ended questions to help the interviewer probe why participants felt they sought help at PEPP; the ways which those experiences led to changes to the self, relationships with others, new life possibilities, appreciation for life, and spirituality. The guide will also help ascertain what participants feel has facilitated PTG, and will probe for whether or not participant’s thought coping, social support, experiencing recovery or other aspects of resilience (such as one’s connection to their cultural practices) helped them achieve PTG. Probes will be phrased in an open-ended format, and will help the us determine the subjective experience of PTG following FEP and facilitators of PTG to ensure that mixing at the level of data collection can occur. However, we will remain open to participants discussing areas of growth or facilitators of growth outside what is being specifically assessed in the guide. Also, the interview guide is expected to evolve following each interview, leading to modifications in the guide. Summary notes of interviews will also be produced following each interview, which will include notes related to the research questions; aspects of the interview which the interviewer found interesting or challenging and worthy of reflection; as well as the ease at which the interviewee spoke, and seemed comfortable describing their experiences.

Quantitative Measures. Decisions on which measures to use were based on existing literature on factors important for the development of PTG following physical illnesses (Linley and Joseph 2004, Tedeschi and Calhoun, 2006, Sawyer, Ayers et al. 2010, Yu, Peng et al. 2014) and input from consultations with clinician-scientists and clinicians at PEPP. Thus far, studies have shown that experiences perceived as mildly or severely negative do not foster growth, while experiences perceived as moderately negative do (Tedeschi and Calhoun 2006). Other important factors predictive of PTG following physical illnesses include having adaptive strategies to cope with adversity as well as people to draw on in times of need (Yu, Peng et al. 2014). Being recovered may also be important (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, McGrath, Peters et al. 2013, Windell and Norman 2013). Being resilient, defined by some as the ability to bounce back from stressful situations, has also been found to be important (Zerach, Solomon et al. 2013, Yu, Peng et al. 2014).

The included measures are well-established, have previously been used in psychosis populations, and are well-validated and reliable. All questionnaires have been translated into French in line with the World Health Organization's ((WHO) 2015) instructions for translation and adaptation of instruments. Pen-and-paper or online versions in either English or in French will be administered depending on the preference of the participants and modality of completion (pen-and-paper vs. online) will be noted.

Posttraumatic Growth. PTG will be measured using the Posttraumatic Growth Inventory (Tedeschi and Calhoun 1996), which is the most widely used, validated scale to measure PTG following traumatic illness or events (Linley and Joseph 2004). The PTG Inventory is a 21-item scale which assesses growth in five domains, namely: relating to others (e.g., having compassion for others), developing new possibilities (e.g., I established a new path in life), personal strength (e.g., knowing I can handle difficulties), spiritual change (e.g., I have a stronger religious faith), and appreciation for life (e.g., my priorities about what is important in life). As done in prior research examining outsider perspectives of PTG (Moore, Gamblin et al. 2011), the questionnaire has been adapted to the third person for case managers to fill out with reference to the PTG experienced by their clients (e.g. “my client established a new path in life?”).

Predictors of Posttraumatic Growth. The impact of psychosis will be measured using the Subjective Experiences of Psychosis Scale, which is a well-validated, service-user generated scale that measures both the positive (e.g., feelings of empowerment) and negative impacts (e.g., feelings of depression) that psychosis can have on an individual’s life. Individuals will be asked to separately rate the positive and negative impact of psychosis on 31 items using a 5-point Likert scale. Participants will be classified as being mildly, moderately or very negatively impacted by FEP by separating average ratings on the negative impact subscale into three discrete categories representing being mildly, moderately and greatly affected.

Coping will be measured using the Brief COPE scale (Carver 1997) which is a validated, 21-item measure of coping strategies abbreviated from the original scale (Carver, Scheier et al. 1989). The scale measures 14 different coping strategies, namely, active coping (e.g., I’ve been taking action to try to make the situation better); planning (e.g., I’ve been trying to come up with a strategy about what to do); positive reframing (e.g., I’ve been looking for something good in what is happening); acceptance (e.g., I’ve been learning to live with it); humor (e.g., I’ve been making jokes about it); religion (e.g., I’ve been praying or meditating); emotional support (e.g., I’ve been getting emotional support from others); instrumental support (e.g., I’ve been getting help and advice from other people); self-distraction (e.g., I’ve been turning to work or other activities to take my mind off things); denial (e.g., I’ve been refusing to believe it has happened); venting (e.g., I’ve been expressing my negative feelings); substance use (e.g., I’ve been using alcohol or other drugs to make myself feel better); behavioral disengagement (e.g., I’ve been giving up the attempt to cope); and self-blame (e.g., I’ve been criticizing myself).

Social support will be measured with the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem et al. 1988, Dahlem, Zimet et al. 1991), which is a validated, 12-item measure of support received from significant others (e.g., there is a special person who is around when I am in need), family (e.g., my family really tries to help me), and friends (e.g., I have friends with whom I can share my joys and sorrows).

Recovery will be measured using the Recovery Assessment Scale (Corrigan, Salzer et al. 2004), a validated measure of perceptions of recovery following the experience of psychosis. This 41-item (each rated on a 5-point Likert scale) scale measures recovery in 5 domains, namely, personal confidence and hope (e.g., fear doesn’t stop me from living the way I want to), willingness to ask for help (e.g., I know when to ask for help), goal and success orientation (e.g., I have my own plan for how to stay or become well), reliance on others (e.g., even when I don’t believe in myself, other people do) and lack of domination by symptoms (e.g., my symptoms interfere less and less with my life).

Since most valid and reliable measures of resilience are specific to developmental periods (either childhood/youth or adulthood) that do not completely overlap with the age range of the sample to be recruited (i.e., 18-35), two measures of resilience will be used. When measuring resilience in service-users between the ages of 18 and 23 we will use the Child and Youth Resilience Measure—Youth version (Ungar and Liebenberg 2013), across 8 domains; namely, personal skills (e.g., I try to finish what I start); peer support (e.g., I think my friends care about me when times are hard); social skills (e.g., I know where to go in my community to get help); caregiver support (e.g., I feel my parents/caregivers know a lot about me); spiritual life (spiritual beliefs are a source of strength for me); education (e.g., I feel I belong at school); and connection with culture (e.g., I like the way my community celebrates things). When measuring resilience in service-users over the age of 23, the adult version of the Child and Youth Resilience Measure will be used (Ungar and Liebenberg 2013), which measures resilience in the same domains as the child and youth version. Both versions are fairly similar. We will conduct factor analyses of data from the resilience measure filled out by persons below and above 23 years and retain resilience data for those above 23 only if it yields factor scores comparable to those among persons with FEP below the age of 23 and to those in the original factor analysis of the scales.

Covariates. Other potential variables will be considered on the based on their correlations with PTG and if they are described as important during the qualitative interviews. If additional covariates are considered, more participants will be recruited to satisfy power requirements. Potential covariates include demographic factors (e.g., age, gender, level of education, time since FEP), symptomatology (e.g., measured using the Scale for the Assessment of Positive Symptoms (Andreasen 1984) and Scale for the Assessment of Negative Symptoms (Andreasen 1983); functioning (e.g., using the Strauss Carpenter Scale (Strauss and Carpenter 1974, Strauss J.S and Carpenter 1977); premorbid adjustment (e.g., using the Premorbid Adjustment Scale (Cannon-Spoor, Potkin et al. 1982)); and medication adherence (using self-reports, and clinical notes

(Cassidy, Rabinovitch et al. 2010)). These measures are administered at regular intervals throughout follow-up as part of the standard PEPP evaluation protocol (Iyer, Jordan et al. 2015).

Data Analyses

Data analyses will occur in three ways. Separate qualitative and qualitative analyses will be conducted followed by a merging of results from both methods.

Qualitative Data Analyses. The primary investigator will conduct all interviews in English or French depending on service-user preferences. Interviews will be audiotaped and transcribed verbatim (transcripts will included all words, hesitations, laughter and background noise) by an outsourced company and checked for accuracy by at least two researchers. A thematic analysis of transcripts will be conducted, using the inductive and deductive procedure outlined by Braun and Clarke (Braun and Clarke 2006) in order to develop themes related to our research questions. In addition to developing themes to answer the research questions, we will also develop themes outside this scope which may arise through the co-construction of meaning between participants and the analyst; for instance, we may attempt to tease apart differences in how service-users describe their experience of PTG from how they describe recovery, resilience, and facilitators of growth more broadly. The process of coding and building themes using a deductive approach will be informed by literature on PTG.

An inductive and deductive approach to coding will be applied to form initial codes, which will undergo further refinement and additional coding until themes are developed. Two individuals will engage in the coding process and the building of theme. Using multiple coders will help enrich the analysis. Detailed memos will be kept by both coders, which will assist with the interpretative process of the analysis. A thematic map of the interrelationships between themes will be also produced.

The methods described by Braun and Clarke will be used to ensure adequate rigour. These include ensuring that data are transcribed accurately and verified by two individuals; coding thoroughly to ensure the coherence, consistency and distinctiveness of themes and their correspondence with the data; conductive interpretive, rather than superficial, analysis; ensuring a march between extracts and analysis, that the analysis presents a narrative, and that a balance between narrative and extracts exists; giving ourselves time to properly analyze the data; and ensuring the fidelity of the final written report. Finally, we will take steps to ensure that we pay adequate attention to contextual factors shaping the experience of or factors contributing to PTG. Such factors may include the organizational climate of services, and the degree to which they are open, empowering and resilience enhancing; the degree to which participants feel their environments and systems outside of the treatment settings are resilience-enhancing and accessible to them; as well as factors at play within the Quebec healthcare system, which may revolve around the recent re-organization of the healthcare system.

Quantitative Data Analyses. Descriptive statistics will be computed based on the PTG Inventory scores, separately for service-users and case managers. Correlations between any potential covariates and PTG Inventory scores will be computed. A multiple stepwise regression will be conducted to determine predictors of PTG, with potential covariates in the first block, followed by the five hypothesized predictor variables in the second block and PTG as the outcome variable. A factor analysis of items of the PTGI, Child and Youth Resilience Measure, and the Recovery Assessment Scale will also be conducted to distinguish the statistical differences between these constructs.

Mixed Method Data Analysis. Results generated from the qualitative and quantitative methods used will be compared after results from each method are analyzed separately to form an overall interpretation of the experience of PTG following FEP and the factors that facilitate

PTG. Convergence (i.e., similar results from the qualitative and quantitative methods used), and divergence (i.e., contradictory or different results from the qualitative and quantitative methods used) will be examined using two side-by-side comparison tables related to each research question (see Table 1).

In the first table, themes related to PTG following FEP generated from the qualitative analyses, and the means and standard deviations of each subscale of the PTG Inventory derived from quantitative analyses, will be entered in separate columns and ordered according to importance (for themes) or magnitude (based on means and standard deviations). In the second table, factors perceived as important for the development of PTG derived from the qualitative analyses, and significant predictors of PTG derived from the quantitative analyses along with their beta weights, will be displayed in separate columns and ordered according to importance and magnitude, respectively. Convergence and divergence will be interpreted by examining these tables. Specifically, themes which were developed from results using qualitative methods which do not match what was measured using quantitative methods will be discussed and interoperated in terms of how they complement and enrich our understanding of PTG following FEP. An overall picture of convergence and divergence will be presented in the results section, and interpreted in the discussion section.

Discussion

The aim of the proposed study is to understand PTG following FEP, and what psychosocial factors are important for its development. This study is among three studies (Dunkley, Foulds et al. 2007, Pietruch and Jobson 2012)(Dunkley and Bates, 2014) to *directly* explore PTG following FEP since many of studies reporting PTG, or PTG-like processes, have been embedded in studies with aims other than discovering PTG (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Lester, Marshall et al. 2011, Newman, Simonds et al. 2011, Braehler and Schwannauer 2012, Eisenstadt, Monteiro et al. 2012, Anderson, Fuhrer et al. 2013, McGrath, Peters et al. 2013, Windell and Norman 2013). We expect the findings from this study to have greater validity because of the application of a mixed-methods convergent design. Using qualitative methods, our study will capture subjective experiences of PTG that cannot be appreciated using exclusively quantitative approaches. Using quantitative methods, our study will help document the extent to which PTG is experienced in FEP and will help establish a predictive model of factors influencing PTG.

Multiple stakeholders (e.g., service-users, family members and clinicians) have pointed out that the current narrative around FEP can seem disempowering and biased towards the suffering and negative impacts of psychosis. Researchers have also opined that the positive sequelae and growth resulting from adversity are worthy of investigation (Aspinwall and Tedeschi 2010). Findings from this study may therefore give greater hope to service-users with psychosis, and inform hope-inspiring, strengths-based treatment approaches to facilitate positive changes among service-users. Since our sample of service-users will be well-characterized and come from a well-defined catchment area, results generated through the quantitative methods of our study are likely to be highly generalizable. Furthermore, we believe the qualitative results will be analytically generalizable by adding depth to the dominant, medical-model conceptualization of FEP and its aftermath, as our findings will describe both the positive and negative aftermath of FEP. To our knowledge, this is one of few studies to directly examine PTG following FEP using mixed methods as part of its overall methodology, which may be important given that PTG has not been systematically examined previously in FEP.

However, this study will not be without its limitations. The PTG inventory has not been specifically validated for use in FEP. However, the scale has been successfully used and found to be valid with multiple populations in multiple contexts (varying illnesses, varying geographic regions, etc.). This strengthens the argument for the use of this scale in our study. Further, the use of qualitative methods in our study may help to validate the use of PTG Inventory in FEP or make a case for the creation of a FEP-specific scale for PTG.

Our choice of factors to test as predictors of PTG is based on previous PTG research with individuals who had not experienced a FEP. As such, these factors may not be the most pertinent ones. Service user perceptions of what is important for the development of growth following the experience of a psychosis will be elicited by this project, which will address this limitation and suggest further avenues of research.

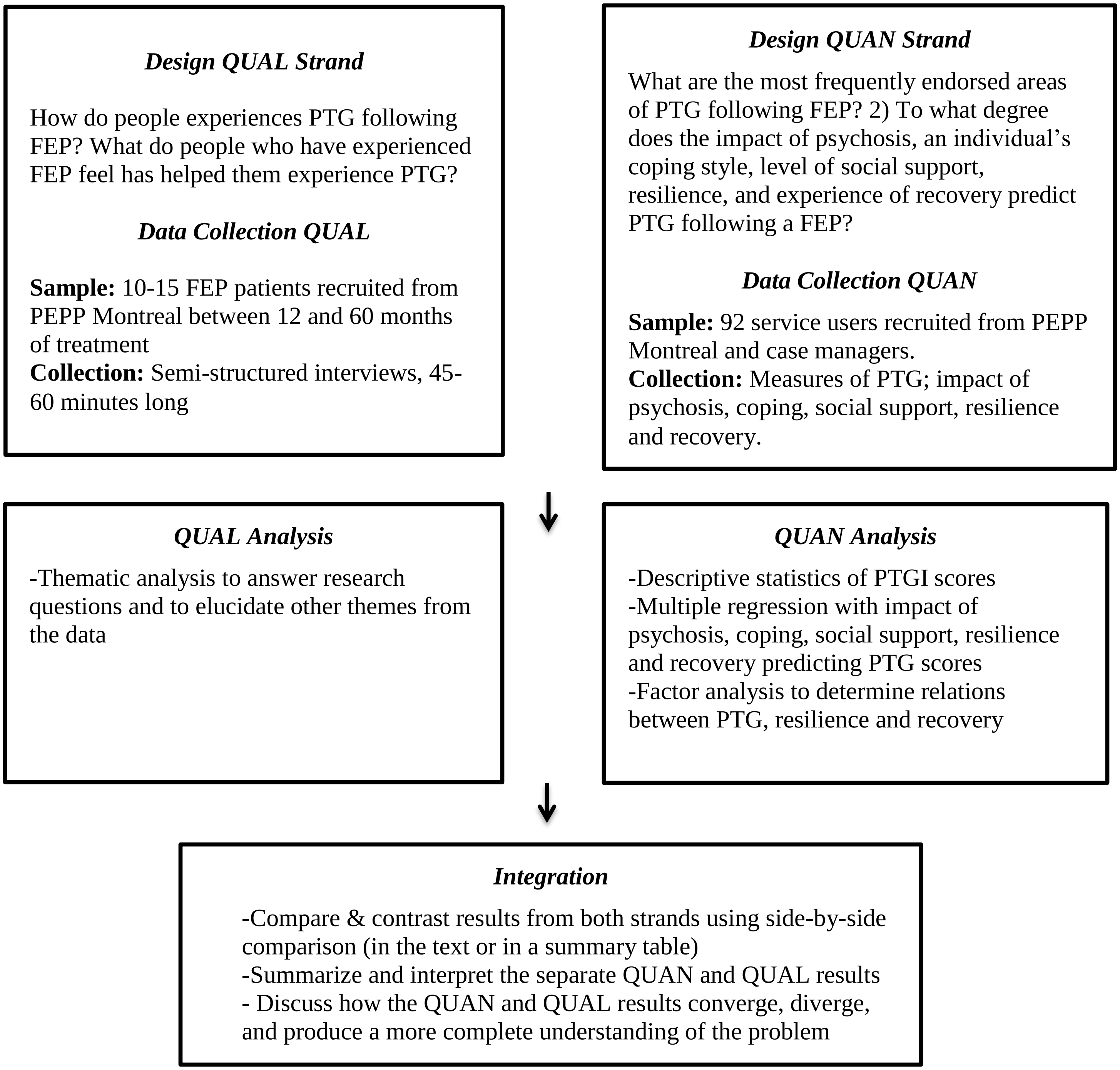
While we believe our study is a needed step in understanding the experience of PTG following FEP, we believe that future studies should explore how other people in service-users' social network's also grow through their loved one's FEP; and how treatment providers themselves may also grow, through providing services to those in need. Such investigations would demonstrate how varying stakeholder groups may benefit from the negative experiences of FEP. Finally, instead of relying on case managers to identify service-users who have experienced PTG, identifying participants who have experienced PTG from their responses to the PTG Inventory for subsequent interviews may result in a greater participant pool for interviews. However, this recruitment process seemed difficult to carry out because this work is being conducted as a Doctoral project.

Table 1: An example of a mixed methods results table

Theme	**Qualitative**	**Quantitative**
	Themes related to Subjective Experiences of Posttraumatic Growth According to Importance	**Endorsement of Domains related to Subjective Experience of Posttraumatic Growth According to Magnitude**
T1	Developing Positive Character Traits	Greater Appreciation for Life
T2	Positive Lifestyle Changes	Developing Positive Character Traits
T3	Stronger Connections with Family	Stronger Connections with Family
T4	Stronger Connections with Friends	Stronger Connections with Friends
T5	Integration of Experience	Positive Lifestyle Changes
T6	Greater Appreciation for Life	Greater Religiosity
T7	Greater Religiosity	
T8*	Becoming more authentic	
T9*	Greater Civic Engagement	
	Themes related to Subjective Experience of Facilitators of Posttraumatic Growth According to Importance	**Predictors of Posttraumatic Growth According to Magnitude of Standardized Beta Coefficients**
T1	Coping	Recovery
T2	Social Support	Coping
T3*	Medication	Social Support
T4*	Symptom Remission	Resilience
T5	Socio Economic Status	Impact of Psychosis
T6	Recovery	
T7	Resilience	
T8	Impact of Psychosis	

*Note: * = Themes which may arise spontaneously*

Figure 1: Study Design



Design QUAL Strand

How do people experiences PTG following FEP? What do people who have experienced FEP feel has helped them experience PTG?

Data Collection QUAL

Sample: 10-15 FEP patients recruited from PEPP Montreal between 12 and 60 months of treatment
Collection: Semi-structured interviews, 45-60 minutes long

Design QUAN Strand

What are the most frequently endorsed areas of PTG following FEP? 2) To what degree does the impact of psychosis, an individual's coping style, level of social support, resilience, and experience of recovery predict PTG following a FEP?

Data Collection QUAN

Sample: 92 service users recruited from PEPP Montreal and case managers.
Collection: Measures of PTG; impact of psychosis, coping, social support, resilience and recovery.

QUAL Analysis

-Thematic analysis to answer research questions and to elucidate other themes from the data

QUAN Analysis

-Descriptive statistics of PTGI scores
-Multiple regression with impact of psychosis, coping, social support, resilience and recovery predicting PTG scores
-Factor analysis to determine relations between PTG, resilience and recovery

Integration

-Compare & contrast results from both strands using side-by-side comparison (in the text or in a summary table)
-Summarize and interpret the separate QUAN and QUAL results
- Discuss how the QUAN and QUAL results converge, diverge, and produce a more complete understanding of the problem

Note. PTG = Post traumatic growth; FEP = First episode psychosis; QUAN = quantitative; QUAL = qualitative

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Chapter Six(b): Addendum to protocol

The protocol for my thesis was drafted in 2014 and published in 2015. Between the time when my protocol was published and the completion of my work, some changes to the protocol were made. Some of these changes reflected shifting realities on the ground where my study was conducted. Other changes were made to ensure that I was able to meet sample size requirements for my study and complete my doctoral degree within the timeframe available to me, and to improve the qualitative component of this project. However, none of the changes to the original protocol were substantive; and I carried out this project using the originally aims, proposed design, methods, and analysis plan.

Overall changes made to the project

1) Originally, I had intended on recruiting from two early intervention services in Montreal. However, as recruitment commenced, I soon realized that I would be able to meet my recruitment targets by recruiting from one site alone. This allowed me additional time to devote to other components of my dissertation, and also reduced potential variance attributable to having more than one study site.
2) I did not include findings comparing case managers and their respective service users for the sake of making this thesis more concise.

Changes made to the qualitative component

1) The Prevention and Early Intervention Program for Psychosis (PEPP) serves individuals whose preferred official language is either English or French. Given this, I specified that I would conduct qualitative interviews in French and English in my protocol. However, all participants chose to complete the interviews in English.

2) There was no mention of the paradigms guiding this project in my protocol. There was also very little information presented on how I would be reflexive. I have given more weight to describing paradigms and my reflexive process in my dissertation (Chapters Four and Five).
3) In the protocol, I stated that I would code all interviews and build themes with the help of another person. In 2016, an undergraduate student helped me code several early interviews. As I developed a clearer understanding of constructivist qualitative methods, I realized that introducing a second coder introduces different paradigmatic and reflexive stances which could prove difficult to negotiate. I also felt like a second coder would not be as familiar with the subject of this work as me. I therefore coded all interviews and built themes independently, and this work is much more internally consistent as a result. Rather than enriching this work through having the perspective of another researcher, this work was enriched by repeatedly coding and re-coding transcripts; repeatedly reading transcripts to arrive at a more global understanding of the phenomena of interest; reading the rich theoretical literature on positive change; sitting with, and thinking deeply about the data; presenting my work to colleagues with expertise in early psychosis; and working closely with my thesis supervisors.

Further clarification and elaboration of qualitative methods

My dissertation elaborates in greater detail on the methods used to carry out the qualitative component - qualitative description - which were briefly described in the published protocol. Qualitative description is rooted in naturalistic inquiry, which was later termed “constructivism” (Guba 1985). The aim of qualitative description is to provide a rich, clear understanding of a phenomenon that is close to the words of participants themselves and not necessarily linked to more abstract theoretical concepts. While it is considered one of the least interpretive methods at the disposal of qualitative researchers, it still requires investigators to interpret and analyze their data. Furthermore, it is considered the least theoretically-driven method, yet qualitative descriptive studies can begin with theory, or at the very least with a researcher's own awareness of what they bring to their studies and how their theories/positions change over the course of the study if needed. Qualitative description is suitable for research questions aimed at investigating the "who", "what", and "where" of a phenomenon. Both content and thematic analyses are suitable and widely used analyses used when employing qualitative descriptive methods. Like other qualitative methods, qualitative description can have hues and overtones of other methods, such as grounded theory or ethnography; and draw from larger theoretical orientations. Finally, the end product of qualitative description is a straightforward yet rich depiction of a topic under investigation (Sandelowski 2000, Sandelowski 2010).

Changes made to the quantitative component

1) In my protocol, I proposed to conduct a confirmatory factor analysis of the two versions of the resilience measure used in the study (The Child and Youth Resilience Measure and the Adult Resilience Measure) (Liebenberg, Ungar et al. 2013) as an exploratory aim. This was not possible due to limitations of sample size (n = 94). We instead examined if participants' responses on the Child and Youth Resilience Measure differed from responses on the Adult Resilience Measure; and if differences in PTG could be attributable to which measure was completed.

2) Similarly, I did not perform a factor analysis of the Posttraumatic Growth Inventory (Tedeschi and Calhoun 1996) and the Recovery Assessment Scale (Giffort, Schmook et al. 1995) due to sample size constraints.

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Chapter Seven

Title: Aspects of positive change following a first episode of psychosis: A mixed methods study using a convergent design

Authors: Gerald Jordan, Ashok Malla, Srividya N. Iyer

Introduction

The onset of psychosis, often a traumatic and devastating mental illness, is marked by significant suffering (McCarthy-Jones, Marriott et al. 2013, Rodrigues and Anderson 2017). Understandably, the majority of scientific research on first episode psychosis (FEP) has focused on its negative aftermath. However, similar to what has been observed following major life-threatening events such as war (Shakespeare-Finch and Lurie-Beck 2014) and illnesses like cancer (Barskova and Oesterreich 2009), persons who experience FEP may also experience positive changes following their experiences (Jordan, Pope et al. 2017, Jordan, MacDonald et al. 2018).

Numerous models and conceptualizations of positive change have been developed. These have construed positive change as an illusion, a coping strategy (Taylor 1983, Taylor and Armor 1996, Taylor, Kemeny et al. 2000) or the result of a meaning-making process (Park 2010, Park 2013). Some evidence suggests that positive change represents a phase within the recovery process (Andresen, Oades et al. 2003); while others have argued that positive change represents a and a state beyond recovery (O'Leary and Ickovics 1995, Carver 1998). The most commonly applied model of positive change is that of posttraumatic growth (PTG), which has been defined as a fundamental, qualitative shift in functioning following a highly negative event or experience (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006). PTG has been conceptualized to follow the shattering of a person’s assumptive world and the struggle of dealing with trauma. Aspects of PTG include a greater appreciation for life, improved ways of relating to others, greater personal strength, greater spirituality, and new life possibilities.

In our scoping review and systematic review on PTG and positive change following FEP, we identified only four studies that had *specifically* focused specifically on positive change following FEP, only one of which exclusively employed quantitative methods (Jordan, Pope et al. 2017, Jordan, MacDonald et al. 2018). Our systematic review (Jordan, MacDonald et al. 2018) identified 37 additional studies where positive change following FEP was described using qualitative methods, most often within the context of an examination of subjective processes of recovery. These changes occurred at the individual (e.g., greater insight and clarity) interpersonal (e.g., improved relationships) and spiritual (e.g., greater religiosity) levels. However, the focus of these studies was not explicitly on positive change following FEP (e.g., for instance, some were focused on investigating experiences of pathways to care, experiences of siblings, etc.).

Our understanding of positive change following FEP through both qualitative and quantitative methods is therefore limited. This knowledge gap is problematic because early intervention services are increasingly implementing strengths-based and resilience-enhancing elements in their services (Shiers, Rosen et al. 2009, Iyer, Jordan et al. 2015). Yet, positive psychology research has largely ignored FEP, leaving services without an adequate evidence base to draw from. Thus, there is a need for further qualitative research on the subjective experience of positive change following FEP, and quantitative research on the extent to which individuals with FEP experience positive change.

To address this knowledge gap, we sought to investigate the aspects of positive changes following FEP in persons receiving care at an early intervention service for psychosis using a mixed methods convergent design. The primary research question addressed by this study was: What are the positive changes service users experience following a first episode of psychosis?

Methods

Study setting

Participants were service users recruited from the Prevention and Early Intervention Program for Psychoses, which is a catchment area-based early intervention service treating all referred cases of FEP in Southwest Montreal, Quebec, Canada. Persons are accepted to the service if they are between the ages of 14 and 35; have an IQ of at least 70; are experiencing a non-affective or affective psychotic disorder that is not due to an organic brain disorder (e.g., epilepsy) or induced entirely by substance use; and have not taken antipsychotic medication for more than 30 days. Treatment consists of antipsychotic medication; recovery-oriented, intensive case management; and psychoeducation. Additional psychosocial services, such as Individual Placement and Support (Becker and Drake 2003); multiple family group therapy; housing services; and psychotherapy, including cognitive behavioral therapy and mindfulness-based approaches, are provided on an as-needed basis (Iyer, Jordan et al. 2015).

Eligibility criteria

To participate in the quantitative component of the study, service users needed to be between the ages of 18 and 40; have completed at least six months but no more than five years of treatment; be fluent in either English or French; and be clinically stable enough to participate in the study (i.e., not be experiencing a relapse based on their treatment team's report). To participate in the qualitative component, service users needed to have met the above criteria for the quantitative component, and had to have been identified by their treatment team (i.e., psychiatrist, case manager, research/symptom evaluator, etc.) as having experienced positive change following their FEP.

Methods and data collection

The study objective was addressed using mixed methods (Jordan, Malla et al. 2016). A mixed methods convergent design was used, whereby separate qualitative and quantitative components were conducted simultaneously, separately, and with equal priority (Creswell and Plano Clark 2011). Mixing of methods occurred at the level of research question so that both the quantitative and qualitative components addressed the same objective; measurement so that both components measured and assessed the same domains; and interpretation of results so that findings from both components could be compared and contrasted. While an independent quantitative or qualitative study could have addressed the study objective, we used mixed methods for its potential to yield a more complete understanding of positive change following FEP. By using mixed methods, we were able to capitalize on the strengths of both qualitative and quantitative approaches.

The study was approved by McGill University’s Research Ethics Board. All participants signed an informed consent form prior to participating. Participants were compensated $10.00 CAN for completing questionnaires; and an additional $30.00 CAN for completing qualitative interviews.

Quantitative Methods. A cross-sectional survey design was used to carry out the quantitative component of the study. The total number of participants was based on a power calculation (Jordan, Malla et al. 2016). To help determine the generalizability of the quantitative findings, we compared demographic and baseline clinical characteristics of the sample to a broader sample of PEPP services users who were eligible but were not included in the study, either because they refused or because they had not been approached to participate in the study due to feasibility considerations.

Quantitative Assessments. Questionnaires could be completed online or using pen and paper, in English or French, depending on a participant’s preference. When French questionnaires were not already available (namely, the Subjective Experiences of Psychosis

Scale)(Haddock, Wood et al. 2011), a research team translated questionnaires into French according to the World Health Organization’s guidelines for scale translation ((WHO) 2015). This entailed translating English questionnaires into French; back-translating French questionnaires into English; and pilot testing French questionnaires with service users to determine their readability and ease of completion.

Participants completed the PTG inventory, which is a well-validated, widely used measure of positive change following adversity (Tedeschi and Calhoun 1996). The PTG inventory measures positive change in five domains/subscales, including relating to others (e.g., I have more compassion for others), personal strength (e.g., I have a greater feeling of self-reliance), appreciation for life (e.g., I can better appreciate each day), spiritual change (e.g., I have a stronger religious faith), and new possibilities (e.g., I developed new interests). Responses are rated on a six-point Likert-type scale, with anchors ranging from “I did not experience this change” to “I experienced this change to a very great degree”. The original scale revealed good psychometric properties (Tedeschi and Calhoun 1996) and robustness against a social desirability bias (Wild and Paivio 2003, Weinrib, Rothrock et al. 2006). In this study, the scale was adapted to assess PTG following participants’ “mental health problem”. GJ provided further instructions, asking participants to rate how they changed as a result of the mental health problem for which they received treatment at PEPP (such as psychosis, hearing voices, etc).

To determine participant`s perspectives of what their mental health problem was, we also analyzed results from one open-ended question of the Subjective Experiences of Psychosis Scale, which is a reliable, well-validated scale assessing the impact of psychosis on various domains (Haddock, Wood et al. 2011). Specifically, participants were asked to think about and write out what they would call the experiences for which they received treatment at PEPP (e.g., psychosis, illness, etc.).

A demographic questionnaire was used to record relevant sociodemographic characteristics such as age, gender, income, etc. (Table 1). The Circumstances of Onset and Relapse Schedule, a semi-structured interview, was used to assess the age of onset of psychosis and the duration of untreated psychosis (Norman, Malla et al. 2004), defined as the delay in weeks between the onset of psychosis and the commencement of adequate treatment with an antipsychotic, defined as one month of taking medication. The Scale for the Assessment of Positive Symptoms (Andreasen 1984) and Scale for the Assessment of Negative Symptoms (Andreasen 1983), were used to assess positive and negative symptoms, respectively. Diagnoses were made using the Structured Clinical Interview for DSM-IV within the first three months of follow-up by trained staff. SCID-IV diagnoses were based on consensus between the research team, an experienced psychiatrist, and interviewer. All clinical characteristics were assessed by trained evaluators at multiple time-points over participants' two year follow-up.

Qualitative Methods. A qualitative descriptive approach was used to carry out the qualitative component of the study. The aim of qualitative description is to provide a rich account of a phenomenon of interest. Such descriptions are to some degree shaped by interpretation; one or more theories; or the naturalistic background (e.g., their clinical experience, etc.) of the investigators (Sandelowski 2000, Sandelowski 2010). Qualitative data were collected through semi-structured interviews lasting approximately one hour. Participants were purposefully sampled according to whether their treatment team felt they had experienced positive change following FEP. The treatment team was given a presentation on positive change at the beginning of this project where they were explained how positive change may be experienced. As per our protocol (Jordan, Malla et al. 2016), recruitment ended when no new information was obtained (i.e., when we achieved thematic saturation). The purpose of the interviews was to determine how participants came to receive services at PEPP, how they changed as a result of those experiences, and what they felt facilitated such changes. We asked participants to describe overall changes they experienced so that we could capture the broader context of their experiences. In line with the tenets of constructivism (Guba 1990, Guba and Loncoln 1994, Guba and Lincoln 2005), the interviewer used participants' own descriptions of their FEP when conducting interviews, and attempted to develop co-constructed understandings of the interview topics with participants. An interview guide was used during the interviews (Appendix 3). The guide was developed through consultation with service users, clinicians and researchers, and a review of the literature. However, interviews remained open to what participants felt was important to discuss regarding the topics. All interviews were conducted in English. Detailed notes were written following each interview. In addition, recordings of the interviews were audiotaped, transcribed verbatim, and checked for accuracy by two researchers. GJ engaged in extensive reflexive practice (Jootun, McGhee et al. 2009, Berger 2015) to examine the impact of his "multiple brought selves" on the research process (Reinharz 1997, Ferrari 2010).

Results

Quantitative data analysis

As a first step, preliminary analyses were conducted to detect differences in baseline clinical and demographic characteristics between participants (n = 94) and service users who were eligible but were not included in the study sample (n = 110); and if any differences in PTG scores were related to the questionnaire's format [e.g., online (n = 2) vs offline(n = 92)] or language of administration. A comparison between participants who completed qualitative interviews and those who were included in the quantitative component of the study was not made because the aim of qualitative research is to achieve theoretical, and not statistical, generalizability.

Each of the five subscales of the PTG inventory consists of a different number of items. Therefore, descriptive statistics were calculated for the PTG inventory, including the scale and subscale means, standard deviations, ranges, and indications of skewness. Item means (i.e., the average response across the entire PTG inventory and its subscales) were also computed. Consistent with prior reporting of results derived from the PTG inventory (Gianinazzi, Rueegg et al. 2016), responses to items of the PTG inventory were grouped according to whether they reflected "no to a small amount" of PTG (i.e., a score of $\leq$ 3) or a "moderate to great amount" of PTG (i.e., a score of $\geq$ 3). Finally, the ways in which participants described their mental health problem on the Subjective Experiences of Psychosis Scale (Haddock, Wood et al. 2011) were grouped into categories based on similarities in responses and their frequencies were reported (e.g., voices were grouped with hallucinations).

Qualitative data analysis

We conducted a thematic analysis to develop themes containing rich descriptions of the ways participants changed following FEP (Braun and Clarke 2006). The analysis was iterative, often moving from one stage to the next and back again. Transcripts were read and re-read multiple times to develop an overall understanding of the topic and to create a larger narrative from the themes. Entire transcripts were subject to several rounds of thorough, line-by-line, open coding in order to adequately capture all information. Coding of positive change was directed, first and foremost, by what the participants themselves said in the interviews. In addition, coding was informed by theoretical constructions of positive change described within the PTG literature (Perry 1974, Tedeschi and Calhoun 1995, Perry 1999, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006, Park 2010, Park 2013); two systematic reviews on this topic conducted as part of this PhD (Jordan, Pope et al. 2017, Jordan, MacDonald et al. 2018); and our research team's clinical and personal experiences and relationships with young people with FEP. Codes were combined into focused codes, categories and themes. Themes were reviewed and compared to codes and text to check for internal consistency. Analytical memos, thoughts, reflections, and reflexive notes were read and reflected upon, to help shape the analyses. While an inductive approach was generally favoured (i.e., bottom-up), the analysis was also partially shaped by the theoretical and experiential influences described above. In general, semantic themes (i.e.,, linked to the "surface meanings" of the data, which were closely linked to participants' own descriptions of their experiences) were developed, yet a latent approach (i.e., which dives deeper than the surface meaning to arrive at underlying issues and how data could be best structured) was also used, especially when organizing themes. Finally, while most themes reflected the experience of positive change, we also included themes based on the broader experiences of FEP (i.e., what participants' lives were like prior to their first episode of psychosis, and the negative changes they experienced during or following FEP) to provide greater context to participants' narratives.

Mixed methods data analysis

Once the qualitative and quantitative components were analyzed independently, findings from both components were entered into a mixed methods joint display table. This is a common method of displaying convergence and divergence between findings in mixed methods research (Creswell and Plano Clark 2011, Guetterman, Fetters et al. 2015). In addition, findings from both strands were integrated within a narrative using a weaving approach that involved describing the convergence and divergence between qualitative and quantitative findings (Fetters, Curry et al. 2013). We placed this narrative within the discussion section as per expert recommendations (Guetterman, Fetters et al. 2015).

Participants

263 service users were followed at PEPP during the study period (May 2015 – November 2017). Of these, 147 were approached, 36 declined, and 111 participated. Data from 16 participants were excluded for various reasons (i.e., they did not return questionnaires, did not complete the questionnaires as per the instructions, or they completed pilot versions of the questionnaires); and one participant withdrew consent, yielding a final sample of 94 (Appendix 1). All participants who completed the qualitative component also completed the quantitative component. Of the 263 eligible service users, 14 were identified by the treatment team as having experienced positive change following FEP (an eligibility criterion for the qualitative component) and were approached. One service user declined; 13 completed interviews (saturation of themes was reached by the 13th participant); and one participant withdrew consent from the study, yielding a final sample size of 12 (Appendix 2).

Quantitative results

Preliminary analyses indicated that a greater proportion of females participated in this study relative to service users who were eligible but were not included; χ^2 (1) = 7.37, P = .007. Furthermore, participants had a higher level of negative symptoms upon entry to PEPP relative to service users who were not included; F (1,179) = 4.06, P = .045 (Table 1).

No significant differences in PTG were detected due to questionnaires being completed in English (n = 62) versus French (n = 32), and questionnaires being completed and online (n = 2) versus offline (n = 92).

All participants were diagnosed with a psychosis-spectrum disorder (Table 1). Most participants described receiving treatment because of psychosis (n = 69, 83.1%) on the Subjective Experiences of Psychosis Scale. Other participants indicated receiving treatment at PEPP because they had substance use issues (n = 3); other mental health problems like anxiety or depression (n = 6); conflicts with other people (n = 2); spiritual or religious problems (n = 3); “shit” (n = 1), “stupidity” (n = 1), “individual lifestyle choices” (n = 1), and in one instance, “just an experience” (n = 1).

Descriptive statistics revealed that the average score on the Posttraumatic Growth Inventory was 59.40 (26.81). Scores ranged between 0 and 105 and the distribution of responses was normal (skewness = -.13) (Table 2).

Participants indicated that following FEP, they experienced new ways of relating to others (M = 19.66, SD = 10.00; Min = 0, Max = 35.00), new possibilities (M = 13.96, SD = 6.84; Min = 0, Max = 25), greater personal strength (M = 11.59, SD = 5.48; Min = 0, Max = 20.00), spiritual changes (M = 4.75, SD = 3.70; Min = 0, Max = 10.00), and new appreciation for life (M = 9.40, SD = 4.02; Min = 0, Max = 15.00).

Examining item means of the PTG inventory revealed that participants reported experiencing moderate amounts of PTG across all items (M = 2.92, variance = .06).

Finally, between 50% and 75% of participants endorsed “moderate to great” PTG on each item of the PTG sale. The item assessing stronger religious faith received the lowest level of “moderate to great” endorsement (47.8%) whereas the item assessing a greater appreciation for life received the highest endorsement (72.3%) (Figure 1).

Qualitative results

Participants described what their lives were like prior to, during and following their first episode of psychosis. All participants described experiencing both negative and positive changes in the aftermath of their first episode of psychosis. Themes reflecting positive change included 1) improved self, health and personality; 2) a stronger, more balanced religiosity and spirituality; 3) improved relationships with others; and 4) improved lifestyles, goals, and expectations for the future. Of these, improved self, health and personality and a stronger, more balanced religiosity and spirituality appeared to be the most important themes according to participants. Overall, positive changes were described as being a direct result from having experienced psychosis, and/or a result of receiving mental services at PEPP. For some participants, these changes reflected fundamental *forward shifts* (i.e., resembling fundamental shifts in functioning) from how they were before their FEP. For other participants, such changes reflected efforts on their behalf to *reconnect* with aspects of themselves and their lives that were once important but were long forgotten, or attempts to *solve*, or let go of past ways of being and living (Figure 2). One common type of change, which cut across all themes, involved coming to new realizations that fed into the changes participants experienced.

Theme 1: Life before and during the first episode of psychosis

Participants experienced problems in many domains prior to experiencing their FEP. Nearly all participants described experiencing high, overwhelming levels of stress, depression, numbness and rumination leading up to the FEP, coupled with difficulties expressing their thoughts and feelings. Some felt conflicted over their identities and certain aspects of their personalities. Most described loving—yet sometimes problematic— relationships with friends, family members and romantic partners that took a toll on their lives. Others, however, were isolated, lonely, and were cut off from other relationships. Many were ambivalent about their spirituality, while others were religious or *intensely* spiritual. Finally, while some described points in time when they functioned well, many described experiencing difficulties with school or work prior to the FEP. Others reported living wild, drug-fuelled, and oftentimes anxiety-provoking lifestyles.

> Respondent: "Oh my God. (soft laughter) I was really shut down. I was really afraid of… the opinions of others. I became very . . . [sigh] how can I say . . . very withdrawn from society actually. I was, um – and it's so contrary to who I was before I met this person (ex husband). Uhm, yeah. Oh my God, just so different. Just really someone really shut down emotionally, unable to communicate, unable to express myself the way that I wanted to"
>
> Respondent: "I was wild. (laughter) um, I was wild, I was lost, I was… um (long pause). I felt lost"

Participants often felt that their experience of the mental health problem for which they received treatment at PEPP often intersected with life junctures they were unable to cope with. While the majority felt that their problem was devastating, confusing or terrifying, others saw it as an inherently pleasurable, positive experience. It was also perceived as therapeutic, or useful. For instance, participants remarked that:

> Respondent: "Like if I if I hadn't had that experience (psychosis), like I could probably be dead or in jail or something now"
>
> Respondent: "So it (psychosis) keeps me, it keeps me in check to make sure that I'm, I'm expressing what I need, I'm expressing my boundaries, because that's how I take care of myself, because no one else is going to take care of me actually nobody really gives a shit"

Most participant's descriptions of their problem aligned with psychiatric definitions of psychotic disorders, and by extension, the treatment criteria for PEPP (e.g., hearing voices as a symptom of psychosis). They labeled their problem using similar medical language, often exclusively referring to the problem as psychosis. Others referred to it as a spiritual experience, a rapture/rupture, or their liberation, while also seeing it as psychosis.

> Respondent: “I came to PEPP uh two and a half years ago. um… I got sick. I was diagnosed with psychosis, and I’ve been here ever since”

> Respondent: “It was, kind of, like a spiritual experience, and my body like went numb and I felt like I had like died and then was reborn, like gave birth to myself”

Theme 2: Declines and difficulties following FEP

Following their first episode of psychosis, participants experienced many difficulties with respect to how they felt and thought; understood themselves; related to others; engaged in spirituality; and lived their lives. Sometimes, such difficulties seemed to foster the positive changes that participants described.

For instance, many could no longer connect with emotions or to what they were once passionate about. Others lost the ability to feel; yet some described such numbness as a possible protection against feeling too much, too soon. Many experienced difficulties structuring or holding onto thoughts, which for some, represented a creative opportunity (e.g., for creating art). Others experienced difficulties understanding jokes; knowing how to act, think, or make decisions. Relatedly, some participants described how they no longer felt able to communicate difficult thoughts and feelings. Some participants also experienced difficulties taking care of themselves; while others described struggling with the side effects of antipsychotic medication, such as weight gain. In addition, one participant felt like he no longer knew who he was as a person.

> Respondent: “Before the drug-induced psychosis I had more vocabulary and more like correct syntax to formulate my ideas”

> Respondent: “Well, it’s it’s caused me not to be able to take care of myself for a very long time consistently, so I’m still recovering from that”

In terms of relationships, participants experienced problems connecting with or relating to others following the FEP. Some felt their experience of psychosis had left them profoundly lonely and abandoned by their loved ones. Yet some participants remarked that people who were no longer in their lives had been toxic, superficial, and therefore not worth holding onto.

> Respondent: “Well, socially. Like, I used to have a lot of friends but I no longer socialise with people that much, yeah.”
>
> Respondent: “During my psychosis and after my psychosis, yes, it was difficult for me to uhm to be close to him (spouse) because I thought that he was not telling me the truth about what happened to me”

With respect to how participant’s spirituality changed following the FEP, some described a new reluctance, hesitation or fear of engaging or believing in spirituality or religion. This change stemmed largely from difficulties associated with their psychosis. Such fear sometimes gave way to more grounded forms of spirituality that many participants practiced following the FEP.

> Respondent: “I prayed a lot like before I went to the hospital and I was always asking for a high level of understanding, and I think I like I got to more than my body could handle.”
>
> Respondent: “And I tried to clear, like, stay clear of working with deities, so like gods and goddesses and things. I've done that enough in my psychosis state, I don't need to do it here”

Finally, participants described experiencing difficulties working, being in school, and making ends meet following the FEP. However, these also represented opportunities to change one’s life course for some.

> Respondent: “I always wanted to be a politician, like that's my dream. I feel like that dream just shattered. But then again there's still hope. I don't know what that hope is. I'm still waiting to see what that hope is.”
>
> Respondent: “Yeah. Because I - I'm less productive now - in a day. I used to do a lot in a day. I could go hours and hour without eating, without thinking about anything and just work or just study. And now I can't do that - I study for three hours and I'm fed up and I need to do something else, yeah.”

Theme 3: Improved health, personality, and a stronger sense of self

In addition to the difficulties participants encountered following their first episode of psychosis, participants also experienced positive changes at the level of the self. One component of such change involved experiencing *improved mental health*, and to a lesser extent, physical health. These improvements involved changes from how participants perceived being even before the FEP, and thus seemed separate (yet similar) from clinical recovery. Such changes were often directly attributed to the services they received at PEPP, as well as attempts to solve and rectify old ways of being.

For instance, many described how, following psychosis, they had developed *new* perspectives, knowledge and understandings about mental health and mental health care. This included a new awareness about mental health and mental illness; a new recognition of the importance of taking steps to maintain one's mental health; and a new understanding of the value of mental health services and the valuable role they can play in recovery.

> Respondent: "Yeah I learned my lesson. That's a positive, learning my lesson, stop, stay away from the drugs and stuff after like so many years."
>
> Respondent: "I think I just wasn't aware of it as much and uh it was affected by psychosis, because I never really had time uh to have a lot of experiences with emotions because I uh because this happened in the relatively early stages of my life, so … now... I can say that because of the tough situations I've been in, I've I've I've had an opportunity to be more aware of emotional intelligence

In addition, participants described experiencing a new sense of improved mental wellbeing and health following FEP. Participants described feeling less suicidal, stressed, angry, and preoccupied than ever before (even before the FEP). They described how these emotions gave way to other emotions (e.g., happiness) and greater optimism which were not present before the onset of psychosis. Participants also described experiencing new and improved ways of connecting with, and feeling in control of their emotions. One participant described how he developed greater complexity of thought, while another described how she began thinking in pictures, which was helpful for writing. Finally, a minority of participants described how they experienced improvements in their physical appearance and health following FEP (e.g., by becoming "cleaner" and "more energetic").

> Respondent: "I've been less angry, less inpatient and less anxious and stuff like that, and then a lot calmer and stuff. I think I can think things through. Like, before that I was very impulsive. I acted on impulse and on stuff like that. I didn't know what to do sometimes. I was just panicking."

> Respondent: “Well, I think I might have been – all my life, I’ve never I’ve never felt as mentally stable as I have now”

Participants described how they developed a new, improved capacity to promote or maintain their mental health and deal with life challenges. Many described how they became more communicative, open, expressive and willing to share their thoughts and emotions compared to before the FEP. Participants also described how they learned to better identify, handle and apply their emotions to everyday situations; deal with stress and the unexpected; set aside time to spend with themselves; and let go of small things that they realized did not matter. Many also described how they stopped using illicit substances like marijuana and began taking responsibility for their own mental health.

Interviewer:	Yeah. And what about how you’ve – how you deal with stress now, like since your psychosis?
Respondent:	I cry. [laughs] I just cry.
Interviewer:	And before?
Respondent:	How did I deal with it? Alcohol or a drug.

> Respondent: “And for a problem, and let's say a problem happens ... like now, I don't think oh, I don't have anything ... there's nothing I can do. Yes, there is something I can do. Right now I'm thinking yes, there is something that I can do to improve my situation and to not be stuck to the feeling of being stuck, unless it's lasting.”

In addition to experiencing improvements in mental health, participants also described positive changes with respect to their *sense of self* following the psychosis. Commonly, participants developed greater self-awareness and self-understanding through their experiences; while others gained self-worth and a greater awareness of their own potential to transform into better people.

> Respondent: “I realise that everything matters, like every word that comes out of my mouth, every thought that crosses my mind, like everything has an impact and everything makes a difference, and I didn't have that awareness before”
>
> Respondent: “I felt even ashamed of myself.
> Interviewer: Okay, I'm sorry.
> Respondent: And now I see nothing wrong. There's nothing wrong with being blah, blah, blah, and that's good.”

However, most changes to the self, following FEP, involved developing a stronger sense of self. At times, a stronger sense of self was preceded by breaking off contact with abusive, toxic or authoritative figures in one's life. Participants described how they became more self-confident; self-assured; determined; willing to take risks; pursue what they want from life; and face challenges following FEP.

> Respondent: "And I think that who I am and my sense of self right now is somebody who is a lot more confident, is a lot stronger, and values everything that makes my life possible a lot more than I used to. Because now I know what the alternative is, and the alternative is having. . . constant doubts as to whether or not I deserve to exist, based off the depression that came up. And that means that. . . if I didn't want to be here, I wouldn't be here, so I should have that mentality going into everything that I do."

They described refusing to be mistreated by others; committing to speak their mind even if it meant making others feel uncomfortable; and being resolute or committed to the choices they made.

> Respondent: "before I used to pray and I used to do all that stuff, and I thought like - but you know it's my life, that's a big - big thing that I realised from psychosis - it's my (emphasis on my) life"

Several participants described how they became more self- accepting and authentic following FEP by becoming closer to their core, inner self—including their "old self". They also described how they became more honest and truthful to their thoughts, feelings and values. Relatedly, one participant described becoming more grounded following FEP, which involved being connected to the world of everyday experience and emotion. Others described becoming more responsible, mature, grown up and no longer acting "stupid". Finally, some developed a more refined and kinder personality or identity, as well as values they perceived as better.

> Respondent: Well, it's brought me like a lot closer to who I am and, and . . . yeah, it has changed my personality in the way that I feel like um a much more open and receptive person whereas I was, before I was someone who was really just shut down and self-centred"

> Respondent: "I'm more like grounded and in like, practical lived experience mode, at the moment anyway, and I like that a lot better because I think I was like, too much in my mind and too much in my head before and I wasn't connected to like my heart and I wasn't connected to the ground, and now it's like it all comes from the ground, from the bottom up, and it feels a lot better that way"

Theme 3: Stronger, more balanced religiosity and spirituality

Participants experienced several important changes in their spiritual and religious lives following FEP. These included having important realizations about spirituality, including that spirituality is real, yet should be connected to sound knowledge, verified wisdom or common sense. Some developed new knowledge or understandings about spiritual, existential and religious issues. Such knowledge included realizing the omnipotence of God and that spirituality is everywhere.

> Respondent: Yeah and I also learned about, like God, where God is…It's like you get a glass of water and you put some sand inside. We are the sand and God is, like the water…So that is how ... that is what I found out about where God is. So he's living amongst us and not somewhere in the sky.”
>
> Respondent: “Just realizing that spirituality does exist and uhm there’s certain ways to go around it that have to, that need to make sense with everything else, you know, if it doesn’t line up with uh sound knowledge of what we already know, then there’s a likelihood that if– if there’s no common thread of common sense then – or or some type of – or some type of verified wisdom, then it’s uhm its most likely not relevant at that point.”

In addition to experiencing new spiritual insights, some developed new spiritual beliefs, such as a new-found belief in God. Relatedly, one participant described hearing the voice of God, which offered him comfort and a sense of security. Another participant also occasionally heard voices—but not the voice of God. She vehemently stated that any voice—good or bad—was an unwelcome experience.

Interviewer:	And what about religion or spirituality? Has your connection with religion or spirituality changed through psychosis?
P4:	Uh, well, I believe in God now.
Interviewer:	Before, you didn’t believe in God?
Respondent:	I didn’t believe in anything.

> Respondent: “Well, the voice that I hear, it’s a I can't differentiate whether it's a male or a female because it's like it's coming from the heart, which I believe it's the voice of God. Like, each morning I get up, it tells me, like how are you and this and that and when I try to give up on my faith it will tell me no, like there is something in store for you. Like, to keep on pressing, yeah.

Participants also described how they engaged in new forms of participation in institutionalized religion or spirituality. Specifically, some described going to church more often and developing new connections with communities (specifically, with the Catholic Church or

Wiccan faith). Others described how they broke away from an organized religion that was forced onto them by authoritative figures in their lives, such as an ex-husband or strict parents. Some also described engaging in new spiritual or religious rituals, including prayer and meditation.

> Respondent: "I go every Sunday to … to the church and I feel more closer to, to God and …and I participate more in the (religious) community than before"
>
> Respondent: Yes. Before I was with uh– well, he was a very religious person and very, how do you call – like conventional religion. Just like, you know . . . and so –that wasn't me at all. Um…so I broke out of that for sure and I just kind of – I just kind of appreciate the unknown and believe that kind of, for now, the rest is kind of none of my business and I'm just here to live as fully as I can."

In addition, participants described experiencing increased levels of guidance from, or willingness to be guided by, religious or spiritual elements. For instance, one described a new willingness to abandon control of the unpredictable to the will of God; and another following more closely the guidelines of (Evangelical) Christian moral conduct. One participant described how his spirit contained new knowledge that could offer him guidance in life. For one participant, such knowledge included information on the dangers of popping pills.

> Respondent: My spirit's changed like I know what to do now instead of not knowing what to do, if that makes any sense like…like I know like not to go and do like 25 pills in one night anymore like back in the day I did it like I didn't care. But now I know like okay now I take X amount or take zero and I take zero so.
>
> Interviewer: And what kind of stuff do you feel that God has control over?
> Respondent: I don't know what is going to happen to me tomorrow, maybe I'm going to have another episode or …ehh.. I don't know, that kind of stuff… I don't know, I can't control, I can do my best but if it has to happen it's going to happen and I have to be quiet and I have to, to understand and accept that it's happening and do my best.

Finally, some participants developed more grounded and less zealous approaches to spirituality or religion. Such approaches felt more congruent with being wise and maintaining one's mental wellbeing. These participants commonly described having experienced problems related to spirituality during their first episode of psychosis.

> Respondent: "Whether or not things were real, whether or not it was really happening, whether or not I really just made that happen, because…the effects of my magic there were a little bit more important and were a little bit more affecting of other people…rather than now. Now it's going…to events and celebrating with a community that recognises my magic, so I can still use those terms that I love, and, and have a space where I feel connected."

Theme 4: Improved relationships with others

Many participants experienced improved relationships with others and with society following their experience of psychosis. This included improved ways of thinking about and relating to other people. For instance, participants realized the value of others; the importance of relationships; and that they were loved and cared for by their families. Many also developed stronger, better relationships, and made better friends following FEP. They become more considerate of other people's needs; more receptive to the love and guidance of family; as well as more honest, easygoing and comfortable around others. They also developed an improved capacity to deal with negative aspects of other people. Furthermore, participants felt they had become kinder, more respectful and pleasant with friends and family; more humble; and less judgemental and pushy.

> Respondent: "When I say we have better relationships, it's like these prior months. It's been like two, three months I feel like we have a better relationship because we're seeing each other way more often, and she always, she always, she always been good to me. And I think it's going to be even better in the future."
>
> Respondent: "Yeah. I don't - I used to get mad to, with my mother a lot - I don't anymore. I used to talk to her in a very rude way - I don't anymore."

Often, participants described improving the size and scope of their social networks, as well as increasing the frequency of contact with loved ones. This entailed being with friends and family more often than before their psychosis; developing new friendships; and in one case, gaining full custody of one's child from an estranged ex-husband. In contrast, through realizing the importance of living for oneself, participants let go of the need to fix other people's problems; stopped worrying about other people's well-being; and let loved ones learn from their own mistakes. Relatedly, many participants described letting go of unhealthy relationships following FEP. This involved letting go of relationships deemed superficial or unhealthy; with friends who were not present during their first episode of psychosis; or with people whom they perceived as having exerted power and control over them in the past.

> Respondent: “At first it was difficult for me to.. to meet all my friends after my psychosis… because I had been in soins intensif [intensive care] and I didn’t – they didn’t know all that, but after I – I just realize…and know who was my friends and what was the people that I wanted to tell them what happened. So … now I have the friends that are more close and the friends that are not is like … I … I choose with who I want to be”

> Respondent: “I think it's just how I saw the meltdown happen and the psychosis happen and the fact that I was in the hospital for a month, it just taught me that I can't always think for others. I need to think about myself first.”

Finally, some also described no longer feeling bound by the expectations of other people or by the rules of society. However, one participant now recognized the importance of attending to the politics of social situations, and negotiating them with proper etiquette.

> Respondent: “Like I needed to get a Master's degree, I needed to be in the biggest company, to be working for the biggest company in the world and I needed to that, just to be - just to feel successful and to - to be successful to other people. I don't care about that anymore.”

> Respondent: “I wouldn’t care, I would just go about my business and treat everybody normally and fairly, but I wouldn’t be sensitive to the status quo of the hierarchy, politics of the place. I wouldn’t be sensitive to that at all, but now I’m a lot more sensitive to that, I’ve realized it’s quite important in life to operate accordingly because it does it does affect a lot of things”

Theme 5: Improved lifestyles, goals, and expectations for the future

Many participants experienced improvements in their lives and goals following their first episode of psychosis. Such changes included new perspectives and understandings about life. For instance, some described developing a more positive perspective on life and a greater appreciation of life. Others realized that they wanted to change life directions; and developed new hope for the future coupled with new knowledge on how to achieve new goals.

> Respondent: “I'm happier, in general…Just appreciating life more in general, because before that I was like no, I just want to die and stuff like that”

Often, participants developed new activities, passions, pursuits and goals following FEP. These included new and fun activities such as going to restaurants more often; new occupational possibilities and intellectual pursuits; as well as constructive and prosocial activities aimed at strengthening community supports for others with mental health problems. One participant said, "I go much more to the cinema and we go out with my husband to restaurants and, and that kind of things" and another described integrating "fantasy type ideas about money" that developed during his FEP into valuable, goal directed behavior.

> Interviewer: Okay. What about like things that you do for fun or like other activities that you do, like have that, have those changed because of your psychosis?
> Respondent: I dedicate more time to those things.
> Interviewer: So what kind of things do you – like what kind of things are you referring to?
> Respondent: Eh now I go much more to the cinema and we go out with my husband to restaurants and that kind of things.

In addition to developing new interests, participants described engaging in activities they were already passionate about, yet with renewed passion and greater self-determination. Often, participants described how their approach to art became more emotionally intelligent, featured a greater breadth; became more thoughtful; and for one participant, became "deeper and darker". Another participant described how his experience of FEP made him a more legitimate social activist by being able to draw on the racism he experienced within a "magical realm" that was part of his "delusional" system, making him act and speak from outside a place of privilege. Some described how their tastes and interests—such as types of music—also changed to more closely reflect their values.

> Interviewer: And has your – like your music changed in any way through experiencing psychosis compared to before the psychosis?
> Respondent I think it's become darker and deeper. [responded quickly]
> Interviewer: In what sense deeper?
> Respondent Deeper as in it's more … it reaches in further in terms of – I've had a lot of time to think about things, so it's uh it's sort of more – the ideas are more sought after, they're more explored, they're a bit more explored than they previously were.
>
> Respondent I'm already a, and…I don't think that, I think that feminists speaking from a place where they have never been harassed or never been abused or never been assaulted, don't know the place, like don't know the feeling of a survivor. And, I am (intonation on am) very active in feminist scenes and…I don't think that I could…understand the experience of other survivors unless I was one myself. And a vast majority of my abuse comes from this other world… and I feel like without those experiences, without those…understandings from such a young age and without that kind of…rough, hardening, um…I would be very oblivious or I would only have a textbook, (smacking sound) theoretical perspective on what, a lot of women go through. And, or a lot of . . .

> perceived females go through. And…that means that I'd be speaking from another place of privilege.

In addition to engaging in new pursuits, participants described feeling happier with life. They felt more present and able to go with the flow of life; and like they were constantly progressing and challenging their own limits. Many participants also described how they learned to let go of aspects of their lives which they perceived as stressful; unimportant; or linked to arbitrary social expectations.

> Respondent: "I'm on my way to always greater and better things. I just feel like in my life I'm just – I'm progressing so much, so fast. And every experience that I have just brings me more fulfilment and more enjoyment and more passion in my life and everything just keeps getting better and better."
>
> Respondent: "…and I don't like drinking as much. And I went out last night, and I had a glass of wine, but that was it, you know? And I took sips off of my , my friend's rum and cokes, but that was it. Like I don't – I don't like drink to get drunk anymore, you know?"

Finally, participants described having new goals for the future, which ranged from occupational, educational or financial goals; to engaging in different forms of activism a telling one's story of mental illness to larger audiences. They described working towards their goals with greater focus and self-determination.

> Respondent: "My plan is to give $200 per pay, so $400 per month to uh my student loan, to the government, and um the other - I'll be doing the same - 200 per pay also on - in a banking, uh in a savings account. And by the time I finish paying my student li—my student uh my student loan, I'll have the same amount"
>
> Respondent: "…and from the first time I got to the hospital it was like I wanted to tell my story and to get my story out there, and finding different ways to do that and different ways to express myself, so like from the hospital, painting really helped."

Discussion

The purpose of this study was to investigate aspects of positive change following an FEP using a mixed methods convergent design. Results from the quantitative component of this study revealed that nearly all participants reported some level of posttraumatic growth following FEP on all domains of the PTG Inventory (i.e., relating to others, new possibilities, personal strength, spiritual change, and appreciation for life). On average, participants reported experiencing moderate amounts of positive change. Similarly, findings from the qualitative component reveal that, in addition to experiencing difficulties and suffering associated with psychosis, all participants also experienced a variety of positive changes following the psychosis. Themes developed in this study pertained to life before and during the FEP; difficulties following the FEP; improved health, personality, and a stronger sense of self; stronger, more balanced religiosity and spirituality; improved relationships with others; and improved lifestyles, goals, and expectations for the future.

This study is the first investigation of positive change following FEP among persons receiving care at an early intervention service. Our study is important because it provides evidence that there may be more to the aftermath of FEP than merely suffering. Early intervention services for FEP can draw on findings from this study to better implement strengths-based, recovery-oriented approaches to care (Shiers, Rosen et al. 2009).

Our quantitative results are consistent with other reports showing that positive change is possible following a range of adverse events and experiences (Linley and Joseph 2004, Barskova and Oesterreich 2009, Bostock, Sheikh et al. 2009, Hefferon, Grealy et al. 2009, Meyerson, Grant et al. 2011, Sherr, Nagra et al. 2011, Harding, Sanipour et al. 2014, Grace, Kinsella et al. 2015). Studies of posttraumatic growth following other adversities have revealed that most people experienced positive change of a similar magnitude as to what we have observed (Linley and Joseph 2004, Morris, Shakespeare-Finch et al. 2005, Lelorain, Bonnaud-Antignac et al. 2010). However, ours is the only study to report descriptive statistics on domains and items of the PTG Inventory among persons having experienced an FEP. Notably, our qualitative findings are consistent with those observed in our review of other studies reporting positive changes following FEP (Jordan, MacDonald et al. 2018). As mentioned earlier, these studies were not explicitly focused on examining positive change following FEP. Our study therefore makes a substantial novel contribution in this regard.

We identified both convergence and divergence between qualitative and quantitative findings (Table 3). In most cases, the qualitative findings *expanded* upon the quantitative results. Both sets of findings revealed that most participants described their mental health problem as a psychosis. This may reflect how participants' treatment teams framed their experiences (Larsen 2004); the prevailing cultural understandings around such experiences, which are shaped by the medical model (Jacob 2016) and the study's setting (an early intervention program for psychosis) (Iyer, Jordan et al. 2015).

The qualitative findings revealed that positive changes comprised either entirely new shifts in functioning; or attempts to solve past mistakes; or attempts by participants to reconnect with forgotten aspects of themselves or their lives. The quantitative results did not capture these nuances in positive change. We are unaware of any model or study of positive change that has described these particular manifestations of positive change following adversity.

Moreover, the qualitative findings captured what participants' lives were like before and during the first episode of psychosis; and the declines and difficulties participants experienced with the onset of psychosis. These findings were not captured in the quantitative results. An alternative version of the PTG Inventory is available which measures both posttraumatic growth and depreciation (Baker, Kelly et al. 2008). While this measure has not been used in the context of psychosis, several studies have confirmed that individuals experience both gains and declines following other types of adversity (Hefferon, Grealy et al. 2009, Cann, Calhoun et al. 2010, Allbaugh, Wright et al. 2016, Karagiorgou, Evans et al. 2018). We did not use this version of the PTG Inventory because we were primarily interested in capturing positive change in the quantitative component; and because we felt that this version was too lengthy and would add an extra burden on participants.

Spiritual change was an important and frequently reported area of positive change in participants' narratives, which is consistent with other studies in FEP (Jordan, Pope et al. 2017) and other adversities (Shaw, Joseph et al. 2005). Yet, spiritual change received the lowest endorsement of any domain on the PTG Inventory, which too is consistent with other studies focused on other adversities (Sears, Stanton et al. 2003, Taku, Cann et al. 2015, Schmidt, Blank et al. 2017). This divergence suggests that the PTG Inventory may not be sensitive to spiritual changes. Indeed, the spiritual change domain of the PTG Inventory consists of only two items. For this reason, Tedeschi and Calhoun updated the PTG Inventory to include additional items assessing spiritual and religious growth (Tedeschi, Cann et al. 2017). The measure with added spirituality-related items is distinct from the updated measure that assesses both growth and deprecation. Unfortunately, this measure with added spirituality-related items was created after data collection for this study began. Our qualitative interviews also captured an important aspect of spiritual change that is not measured by the PTG Inventory: that of adopting a more balanced, less zealous approach to spirituality. This type of spiritual change has not been linked earlier to spiritual growth following adversities (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006, Patrick and Henrie 2015). Participants in our study spoke of having had extreme spiritual experiences in the past. It is also acknowledged that intense spiritual practices may sometimes lead to extreme mental states such as psychosis (Kaselionyte and Gumley 2017). Participants' more balanced approach to spirituality may also have been influenced by their treatment team's and loved ones' views of spirituality (as being potentially harmful or not), and its potential to contribute to psychosis-like experiences (Larsen 2004).

The items on the PTG Inventory that were most endorsed by participants were the ones concerned with a greater appreciation for life. This is consistent with some studies investigating positive change following adversities other than psychosis (Feder, Southwick et al. 2008, Sawyer and Ayers 2009). In the interviews, however, participants seldom spoke of becoming more appreciative of their lives. This difference may have arisen because the interviewer did not directly ask participants if they experienced any change in their appreciation for life after FEP. While developing the interview guide, it was felt that this would be a leading question. Participants did however endorse many changes in the qualitative component that may suggest a greater appreciation for life, even if not explicitly framed as such (i.e., semantic differences).

Some studies investigating the factor structure of the PTG Inventory have revealed that individuals experience a changed life philosophy following adversity (Powell, Rosner et al. 2003, Taku, Cann et al. 2008). Participants in our study also reported changed philosophical stances, new knowledge, arriving at important realizations and experiencing profound insights following FEP. Rather than viewing such changes as a distinct theme, we saw these as changes *about* their respective domains. For instance, new spiritual knowledge was seen as part of the theme of greater, more balanced spirituality and religiosity. Our approach is in line with Franz Brentano’s argument that ideas have intentionality and thoughts do not exist on their own, but are directed *towards* something (Brentano 2015). Hence, changed philosophical stances, new knowledge, realizations and insights were not in and of themselves classified as a distinct theme. Nonetheless, changed perspectives and new realizations do appear to significantly underpin positive changes following an FEP.

The qualitative findings identified improved health—in particular, mental health—as an important, oft-described positive change. This finding is consistent with our systematic review

(Jordan, MacDonald et al. 2018). In contrast, the PTG Inventory does not contain items that capture this type of change. This finding may be a reflection of the context of the study: participants may have described developing improved mental health and improved capacities for dealing with challenges because they were receiving care at an early intervention service and interviewed by a student working in the context of this service. The investigators of this study include clinician-scientists, and the first author and interviewer is a graduate student in the Department of Psychiatry at McGill University with a keen interest in mental health. Our positionality may therefore also be reflected in these findings. Participants' responses may have been colored by ongoing improvement or healing from their FEP. Alternatively, our findings on positive change with respect to mental health could reflect the type of adversity participants experienced growth from. This is consistent with other studies reporting improvements in domains of physical health following a physical health problem (Hefferon, Grealy et al. 2009, Heidarzadeh, Rassouli et al. 2017). Our findings are congruent with the idea of an improved way of handling stress being a key aspect of stress-related growth (Schaefer and Moos 1992, Park, Cohen et al. 1996, Schaefer and Moos 1998). Finally, improved mental health is also a key facet of recovery in persons with mental illness (Windell, Norman et al. 2012, McGrath, Peters et al. 2013, Windell, Norman et al. 2014).

The quantitative component revealed a moderate level of endorsement of items measuring the development of a stronger sense of self following FEP. Relatedly, the qualitative component captured changes to participants' personalities, identities, traits and levels of self-awareness. These individual-level areas of growth have been described in other studies that have focused on recovery in the context of FEP (Jordan, MacDonald et al. 2018), and are a common aspect of positive change across many types of adversity (Elderton, Berry et al. 2015). Such changes may reflect a core reaction following adversity (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006).

Similarly, the quantitative findings captured how relationships had improved following FEP, while the qualitative findings revealed how participants learned to manage their relationships better (for instance, by letting go of unhealthy relationships), and how the size and scope of their relationships were enhanced. Such changes are consistent with theoretical claims inherent in the model of posttraumatic growth (Tedeschi and Calhoun 2004). These changes have been described in other studies in FEP (Jordan, MacDonald et al. 2018); and may reflect participants' perceptions that unhealthy relationships contributed to their psychosis, which is an observation echoed in other studies (Taylor 2004).

Our findings revealed that participants changed their lifestyles and developed new goals and expectations for the future following FEP, which is consistent with a theme in our review of other studies describing changes following FEP (Jordan, MacDonald et al. 2018) and other adversities (Taylor 2004, D'Amore, Martin et al. 2018). These findings may reflect participants' realizations that the way they lived their lives earlier was not commensurate with their values; or that their lifestyles precipitated their psychosis.

Finally, a nuance captured only in the qualitative findings is that some participants considered their new, ongoing psychotic experiences as useful additions to their lives. This finding is consistent with one qualitative study reporting posttraumatic growth among persons who had experienced multiple episodes of psychosis (Mapplebeck, Joseph et al. 2015).

A surprising finding from this study was that the majority of participants perceived experiencing at least a moderate amount of positive change following their first episode of psychosis. The distribution of responses on the PTG Inventory was normal. Given the prevailing knowledge about a first episode of psychosis and its aftermath, these results suggest that service users' own evaluation of how they change through their experiences may be more optimistic than what may be expected.

Despite this study's focus on examining aspects of positive change following a first episode of psychosis, it cannot be unequivocally established that the that changes persons experienced fall under the rubric of posttraumatic growth, stress-related growth, or some other form of positive change. From a constructivist standpoint that acknowledges the existence of multiple truths (Guba 1990, Guba and Loncoln 1994, Guba and Lincoln 2005 participants' perceptions of having experienced positive change were veridical, and therefore can be seen as falling under the umbrella of posttraumatic growth or stress-related growth. From a post-positivistic standpoint (Guba 1990, Guba and Loncoln 1994, Guba and Lincoln 2005) however, one can question the veracity and validity of participants' perceptions of positive change. One can also question if such changes reflect posttraumatic growth (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006); stress-related growth (Park, Cohen et al. 1996, Park 2013); illusory (i.e., false) perceptions related to benefit-finding (Tennen and Affleck 2002); or simply a way of coping with psychosis (Taylor 1983, Taylor and Armor 1996, Taylor, Kemeny et al. 2000). Regardless of whether one views the findings from a constructivist or post-positivistic perspective, they contribute to an advancement in our understanding of the ontology of positive change.

Finally, the high endorsement of items on the PTG Inventory may reflect social desirability or the nature of the instrument itself that may have resulted in arguably exaggerated accounts of positive changes. However, prior research has documented that social desirability does not influence scores on the PTG Inventory (Wild and Paivio 2003, Weinrib, Rothrock et al.

2006). Also, the PTG Inventory has been established as an instrument that is sensitive to capturing positive change following adversities, as indicated by its established psychometric properties (Brunet, McDonough et al. 2010, Lee, Luxton et al. 2010) and its widespread use. Even if a proportion of the positive change on the PTG Inventory endorsed by our participants is attributable to response bias or social desirability, our findings are indicative that participants can indeed experience positive changes in multiple domains following the adverse experience of a psychosis.

Similarities and differences between the experience of recovery and positive change following FEP

Descriptions of positive change in the qualitative findings are also similar to some accounts of subjective recovery following FEP (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Braehler and Schwannauer 2012, McGrath, Peters et al. 2013). For instance, the qualitative findings revealed how experiencing improved mental health relative to before the FEP was an area of positive change, which is consistent with subjective accounts of recovery (Windell, Norman et al. 2012, Windell, Norman et al. 2014). Studies have also described growth occurring within the recovery process, including experiences of a stronger sense of self or improved relationships following FEP (Jordan et al., 2015). Such accounts are consistent with theoretical conceptualizations that posit growth as a fundamental part of recovery (Andresen, Oades, et al., 2003).

Subjective recovery may be a broader process or outcome that encompasses a greater breadth of experience than positive change. For instance, Davidson and colleagues (2005) described common elements of recovery, which included “redefining self”, “renewing hope and commitment”, “managing symptoms”, “assuming control”, etc. In experiencing recovery, participants may return to pre-existing levels of functioning; may “seal over” or “integrate” their experiences (McGlashan, Levy et al. 1975); or may be symptom free or still experience symptoms (Davidson 2009). The qualitative findings of this study are consistent with such conceptualizations, in that some participants described recovery as synonymous with positive change; as separate experiences; and, in some cases, a desire to never go back to “normal” or “recover”.

While we did not seek to determine differences between recovery and positive change, findings from this study and the broader literature suggest that positive change may be a facet of recovery; or, it may also be a *way* of recovering. Ultimately, it may be worth deferring to service users’ own descriptions of recovery and positive change to better tease apart differences between both concepts. Irrespective of whether positive change is a distinct process or a sub-component of recovery, our findings suggest that many persons experience such change following psychosis. This possibility is often ignored, despite its potential for inspiring hope among service users and service providers alike.

Implications

Our findings challenge the view of psychosis as exclusively a progressive, degenerative and impairing disease; and provide countering evidence that persons may even change for the better following a first episode of psychosis. Our work has the potential to contribute to paradigm shifts that emphasize hope and possibility following experiences of mental illness. It can also help clinicians and early intervention services to better recognize that positive change is possible following psychosis; and to better implement interventions that foster growth, thereby more closely aligning services with the tenets of the recovery movement.

Finally, although participants perceived experiencing positive change following FEP, our findings should not be taken to imply that efforts to directly prevent FEP should be abandoned; or that the greater economic, political and social forces that increase the risk for mental illnesses be ignored; or that persons with psychosis should be uncared for. Psychosis is often a devastating illness; and like other adverse experiences, persons may be better off without experiencing them and experiencing growth through less traumatic, more positive means. These could include positive life events (Roepke 2013) e.g., going to university, or normative developmental processes (Gottlieb 2007).

Strengths and Limitations

Our study used quantitative and qualitative methods that were employed with a high level of methodological rigour, while respecting the philosophical traditions pertaining to the methods we used. Our reliance on both these methodologies enriched our findings in ways that would not have been possible through a reliance on one method alone. Our study also included a well-characterized sample of service users recruited from a single catchment area.

Given that our sample consisted of a greater proportion of females and persons with higher baseline negative symptoms relative to the overall body of service users at PEPP, it is important to exercise caution before generalizing our quantitative findings to all persons with FEP. We relied on a convenience sample of participants and on cross-sectional data collected at multiple time points over the course of participants’ follow-up. Another limitation is that we relied on service users’ treatment team to identify participants for the qualitative component. This may have resulted in the recruitment of service users who fit the treatment teams’ views of what constitutes positive change.

Finally, we could not recruit enough participants to perform factor analyses of the PTG inventory and the Recovery Assessment Scale. When attempting to determine the factor structure of both measures, our sample size reduced to 75. Due to the reduced sample size and the high number of items (n = 41), the factor structure produced in our analyses was unstable. We therefore elected to discuss potential differences between positive change and recovery at a theoretical level, and making reference to our qualitative findings.

Future Directions

To help establish the reliability and validity of quantitative assessments of positive change following FEP, future studies should examine positive changes prospectively; rely on multiple assessments of positive change measured at specific time points following onset; and determine if positive change is related to improved mental health, well-being and functioning. In order to determine the extent to which our findings only pertain to persons receiving care at early intervention services, future studies should be conducted with persons receiving other forms of care, such as peer support; or with persons who have recovered from FEP without care.

Tables and Figures

Table 1: Baseline demographic and clinical characteristics of study sample relative to those who were eligible but did not participate

Variable	Participants who were interviewed (n = 12) M/SD; *f*/%	All participants who took part in the study (n = 94)[b] M/SD; *f*/%	Eligible but did not participate (n = 110)[c] M/SD; *f*/%	χ^2/F B vs C
Age at assessment	24.27 (2.76)	25.52	N/A	N/A
Age of psychosis onset	22.17 (6.14)	23.27 (5.45)	24.62 (5.15)	2.85
Gender (female)	4 (36.4%)	40 (44.0%)	25 (25.3%)	8.45*
Education (at least high school)	11 (91.7%)	64 (76.2%)	67 (72.8%)	.26
Relationship status (in a relationship)	3 (25%)	9 (10.1%)	9 (9.4%)	.029
Visible Minority (yes)	7 (58.3%)	37 (45.7)	43 (45.7%)	0
Born outside Quebec (yes)	6 (50%)	31 (35.2%)	36 (38.3%)	.18
Socioeconomic Status (middle to upper class)	10 (90.9%)	26 (38.8%)	27 (39.7%)	.01
Income derived from paid employment (yes)	5 (41.7%)	19 (24.1%)	25 (29.1%)	.530
Living with friends, family or independently	12 (100%)	81 (96.4%)	93 (98.9%)	1.3
Schizophrenia-spectrum diagnosis (yes)	7 (58.3%)	55 (63.2%)	61 (67.0%)	.28
Baseline diagnosis of substance abuse/dependence (yes)	4 (33.3%)	27 (34.6%)	39 (46.4%)	2.33
Age of onset of psychosis	22.17 (6.14)	23.26 (5.45)	24.62 (5.15)	2.85
Baseline positive symptoms	14.00 (2.75)	11.84 (3.26)	11.32 (3.02)	1.21
Baseline negative symptoms	9.45 (3.55)	10.39 (3.60)	9.26 (3.89)	4.06*

* = $P \leq .05$

Table 2: Descriptive statistics pertaining to the posttraumatic growth inventory

Posttraumatic Growth Domain	Number of Items	Item Mean	Scale Mean	Standard Deviation	Median	Range	Skewness
Relating to Others	7	2.85	19.66	10.00	21.00	35.00	-0.17
New Possibilities	5	2.82	13.96	6.84	15.00	25.00	-0.17
Personal Strength	4	2.95	11.59	5.48	12.00	20.0	-0.30
Spiritual Change	2	2.70	4.78	3.70	5.00	10.00	0.03
Appreciation of Life	3	3.16	9.40	4.02	9.50	15.00	-0.37
Total	21	2.92	59.40	26.81	58.50	105.00	-0.13

Note. The range represents the difference between the highest and lowest scores reported by participants; it reflects the possible range and the actual minimum and maximum scores of participants

Table 3: Joint display table depicting convergence and divergence between qualitative and quantitative findings addressing the aspects of positive change following a first episode of psychosis

Qualitative Themes Organized by Importance		Domains of the Posttraumatic Growth Inventory Organized by Item Means				
		Appreciation for life	Personal Strength	Relating to others	New possibilities	Spiritual change
Improved health, self and personality	Convergence		Greater strength; maturity			
	Divergence		Health; personality, traits, identity, self-awareness			
Improved, more balanced religiosity and spirituality	Convergence					Greater faith; understanding
	Divergence					New faith; rituals; practices; guidance; approach
Improved relationships with others	Convergence			Closeness; effort; comfort		
	Divergence			Management; size and scope; society		
Improved lifestyles, goals, and expectations for the future	Convergence				Life direction, new activities, goals interests	
	Divergence	Appreciation for life			Improved activities; life satisfaction; appreciation for life	

Figure 1: Proportion of participants endorsing moderate to very great change on each item of the Posttraumatic Growth Inventory (Organized under the scale's five domains)

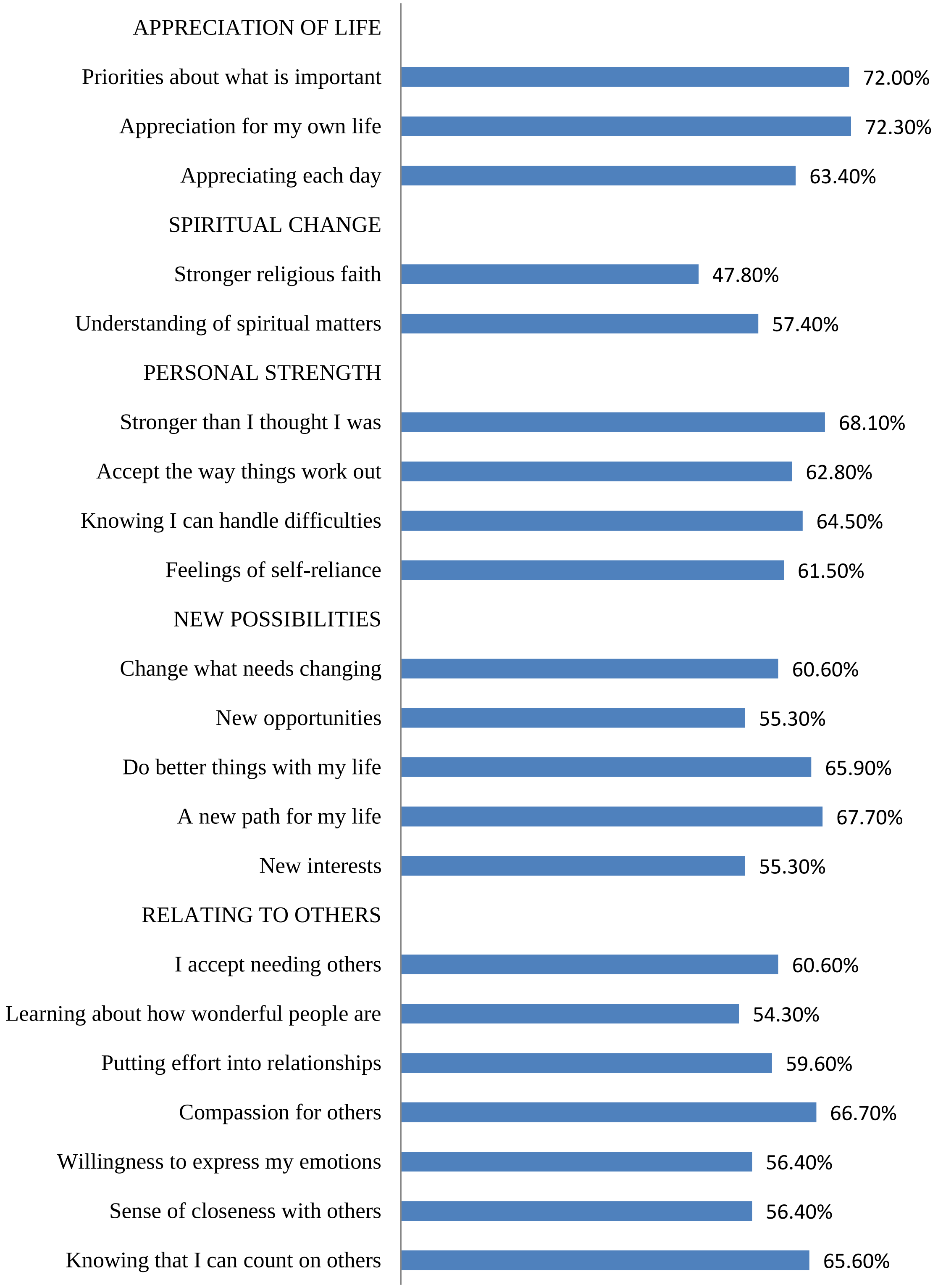
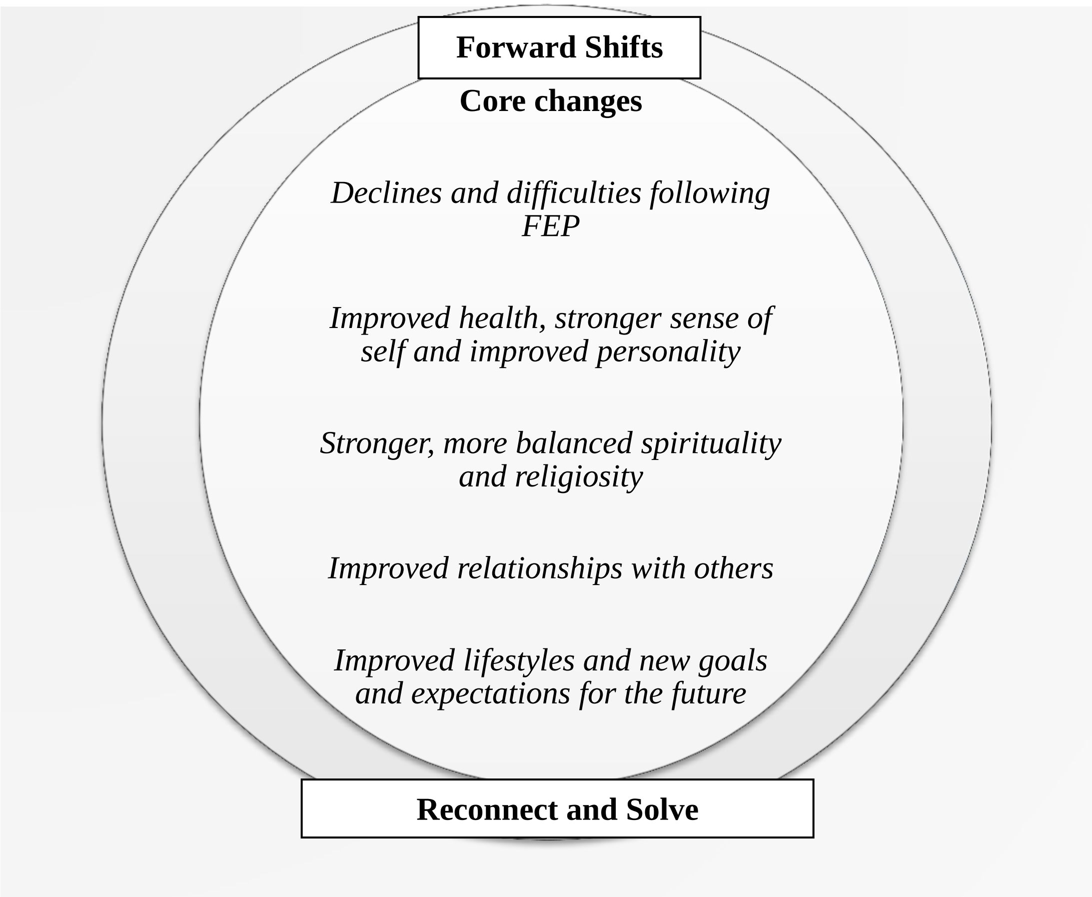


Figure 2: Changes experienced following the first episode of psychosis (FEP)



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Chapter Eight

Title: Predictors and perceived facilitators of positive change following a first episode of psychosis: a mixed methods study using a convergent design

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Introduction

A first episode of psychosis (FEP) is often a traumatic mental illness (Rodrigues and Anderson 2017) that affects young people at a time when they are charting important educational, occupational and social trajectories. The negative sequelae of psychosis are well documented and are important to acknowledge. However, just as positive changes have been documented in the wake of many traumatic “physical” illnesses (e.g., HIV) (Barskova and Oesterreich 2009), the experience of a first episode of psychosis may be associated with positive changes as well. The most well-researched model of positive change is that of Posttraumatic Growth (PTG), which can be defined as positive changes that follow the struggle with adversity. Domains of PTG include a stronger sense of self, improved relationships with others, and a greater appreciation of life following adversity (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006).

In a previously conducted systematic review, we reported that following first episode psychosis (FEP), persons themselves, as well as their families and friends, experienced positive changes at the individual level (e.g., greater self-understanding), the interpersonal level (e.g., spending more time with family) and the spiritual level (e.g., greater involvement with religious institutions) (Jordan, MacDonald et al. 2018.

In a mixed methods study we conducted on this topic, service users receiving treatment at an early intervention service for FEP revealed experiencing improved health; a stronger sense of self and improved personality; greater, more balanced religiosity and spirituality; improved relationships with others; improved lifestyles; and new goals and expectations for the future, along with difficulties following FEP. Quantitative results of this study revealed that a moderate degree of positive change was experienced by service users across all five domains of the PTG

Inventory (relating to others, personal strength, spiritual change, new possibilities, and life appreciation) (Jordan et al., in preparation; Chapter Seven).

While adverse experiences like the experience of psychosis may be the catalyst for positive change, additional factors and processes may facilitate such change. For instance, the degree to which an adverse event or experience impacts a person may influence positive change (Tedeschi and Calhoun 2006, Kleim and Ehlers 2009, Shakespeare-Finch and Lurie-Beck 2014). Studies have shown that the impact of negative experiences has a curvilinear relationship with positive change: negative experiences that have a moderate impact are associated with positive change, while experiences that have a low or high impact are less likely to lead to positive change (Shakespeare-Finch and Lurie-Beck 2014). In addition, coping has been shown to be a key process facilitating positive change. Two coping strategies that have consistently been found to predict positive changes are positive reframing (i.e., seeing good in the bad) and spiritual coping (Prati and Pietrantoni 2009). Both coping strategies may help individuals rebuild their beliefs and outlook on life following adversity (Rajandram, Jenewein et al. 2011). Perceived social support has also been found to be a robust predictor of positive change (Prati and Pietrantoni 2009, Elderton, Berry et al. 2015). Persons who perceive that they have social support may feel that they have opportunities to disclose their experiences to others; and opportunities to receive feedback about their experiences that could highlight the potential for growth following adversity (Tedeschi and Calhoun 2006). Trait resilience (i.e., one’s general ability to bounce back from stress) has also been linked to positive change (Kaye-Tzadok and Davidson-Arad 2016, Garrido-Hernansaiz, Murphy et al. 2017, Yuan, Xu et al. 2018). Other scholars have theorized how resilience comprises resources that persons can draw on in times of stress, and their capacity to obtain those resources (Ungar, Ghazinour et al. 2013), and may thus facilitate positive change. Finally, our systematic review of positive change following FEP included many qualitative studies of recovery following FEP and pinpointed to a possible contribution of the subjective recovery process to recovery (Jordan, MacDonald et al. 2018). While recovery is not often considered a predictor of positive change within the broader literature, recovery may be critically important for positive change following psychosis.

Research examining the degree to which the aforementioned factors and processes predict or facilitate positive change following FEP (Jordan, Pope et al. 2017, Jordan, MacDonald et al. 2018) is non-existent, barring less than a handful of exceptions. Findings from our systematic review identified only one study which investigated *predictors* of positive change following FEP (Pietruch and Jobson 2012). This pioneering quantitative study reported that recovery and self-disclosure predicted positive change following FEP; however, it relied on a small convenience sample that was not recruited from an early intervention service (n = 34), thus limiting the generalizability of the findings, particularly to understanding contributors of positive change following FEP.

The remaining qualitative studies identified by our reviews did not explicitly aim to explore positive change following FEP; rather, they focused on processes such as help-seeking, recovery, illness experiences, etc. (Jordan, MacDonald et al. 2018). Facilitators of positive change, when mentioned in these studies, were described incidentally or as components of recovery or some other process. Based on these descriptions, our synthesis of these studies suggested that personal (e.g., positive reframing), social (e.g., social support) and spiritual (e.g. prayer) factors facilitated positive change. Since the publication of our review, one qualitative study has described processes leading to positive change following FEP (Attard, Larkin et al. 2017). This study showed that positive change was preceded by a process of determining “how psychosis fits into my story", "breaking free from psychosis" and "fighting my way through psychosis".

In sum, there is a paucity of qualitative and quantitative research on predictors and perceived facilitators of positive change following FEP. This knowledge gap is important because persons with lived experience of FEP who desire to grow from their experience may lack the tools to do so. In addition, early intervention services for FEP are increasingly adopting positive, strengths-based approaches and interventions to promote positive change. Yet, there is a lack of knowledge on how to best develop and implement these interventions to promote such change

To address this knowledge gap, we investigated predictors and facilitators of positive change following FEP using a mixed methods convergent design. Two inter-connected research questions were addressed: 1) What factors and processes *predict* positive change following FEP, and 2) What factors and processes are *perceived* to facilitate positive change following FEP? This study was part of a larger mixed methods study investigating aspects and facilitators of positive change following FEP (Jordan, Malla et al. 2016; Jordan et al., in preparation, Chapter Seven).

Methods

Study setting

Participants included service users who received care for FEP at the Prevention and Early Intervention Program for Psychosis (PEPP) between May 2015 and November 2017. This is the only early intervention service for FEP in Southwest Montreal, Canada, and serves approximately 400,000 people. Eligibility criteria for entry into PEPP include being between the ages of 14 and 35; having an IQ of at least 70; experiencing a non-affective or affective psychosis that is not due to an organic brain disorder or exclusively explained by substance use; and not having taken antipsychotic medication for more than 30 days. Treatment offered at PEPP includes recovery-oriented, intensive case management; family interventions; antipsychotic medication; and other interventions (such as Individual Placement and Support and psychotherapy) when indicated (Iyer, Jordan et al. 2015).

Study Eligibility criteria

To participate in the quantitative component of this study, service users had to have been in treatment for at least six months; be fluent in either English or French; be clinically stable as defined by their treatment team (i.e., not currently experiencing a relapse); and be between the ages of 18 and 40. To participate in the qualitative component of this study, service users had to have met these eligibility criteria and to have been identified by their treatment team as having experienced positive change following FEP.

Overall methods and data collection

This study employed a mixed methods convergent design, whereby both qualitative and quantitative components were conducted in parallel and mixed at the level of research questions, data collection, and interpretation (Jordan, Malla et al. 2016). Using a convergent design allowed us to capitalize on the strengths of both qualitative and quantitative methods (Creswell and Plano Clark 2011).

Quantitative methods

The quantitative component of this study employed a cross-sectional survey design. Each participant completed questionnaires assessing positive change and predictors of positive change on one occasion during their follow-up. A power analysis was performed to determine the sample size needed to achieve a moderate effect size with 80% power, and to allow the regression of five independent variables on one dependent variable (Jordan, Malla et al. 2016).

Questionnaires were completed in English (n = 62) or French (n = 32); and online (n = 2) or using pen and paper (n = 92). Validated versions of French questionnaires were used when available. When French versions of questionnaires were unavailable, English questionnaires were translated into French using a well-accepted method (WHO) 2015). Specifically, we translated the Subjective Experiences of Psychosis Scale (Haddock, Wood et al. 2011) and both resilience measures (Liebenberg, Ungar et al. 2013) into French. All questionnaires were pilot tested with service users to ensure their readability.

Qualitative methods

The qualitative component of this study was guided by a constructivist (Guba 1990, Guba and Loncoln 1994, Guba and Lincoln 2005), qualitative descriptive methodology (Sandelowski 2000, Sandelowski 2010). The purpose of qualitative description is to provide a rich account of a phenomenon in a way that is as close to the words of participants as possible. While it is considered one of the least theoretically-driven qualitative methods, qualitative description can be rooted in theory as well as within the naturalistic settings that researchers are situated in (e.g., their clinical experience, knowledge on the subject matter, etc.). Similarly, while qualitative description involves less interpretation compared to other qualitative traditions, some degree of interpretation on the part of researchers comes into play in making sense of study findings.

Data were collected using semi-structured interviews. An interview guide developed by GJ in consultation with multiple stakeholders (i.e., clinicians, researchers, service users, families) was used to probe for the reasons why participants felt they received treatment at PEPP; how participants felt they changed as a result of the reasons that they sought help at PEPP; and what participants felt may have facilitated such changes (Appendix 3). The interview guide also contained probes to elicit perspectives on how participants coped with FEP; the social support participants received; the meaning of recovery and where participants felt they were in the recovery process; as well as participants' connection to culture and community. While an interview guide was used, the interviewer was open to discussing additional areas that participants felt were important to the topic under investigation. Interviews were held in English and lasted up to one hour.

GJ wrote detailed reflections after each interview. He also engaged in extensive reflexive practice to examine how his multiple brought selves (e.g., as a student, a researcher, etc.), which included his role within the PEPP clinic (e.g., as a research assistant who had attended weekly clinical rounds, etc.), may have shaped the study findings (Reinharz 1997, Ferrari 2010).

Ethics

The study was approved by the McGill University Ethics Board. Informed consent was obtained from all participants. Participants were compensated $10.00 for completing questionnaires; and an additional $30 dollars for completing the qualitative interviews.

Measures

Positive change following FEP was measured using the Posttraumatic Growth Inventory, a well-validated, widely used measure of positive change (Tedeschi and Calhoun 1996). The PTG Inventory includes 21 items rated on a numerical 6-point Likert-type scale and measures positive change following adversity across five domains. The domains include appreciation for life (e.g., I have a greater appreciation for the value of my own life), relating to others (e.g., I can more clearly see that I can count on people in times of trouble), spiritual change (e.g., I have a better understanding of spiritual matters), new possibilities (e.g., new opportunities are available which wouldn’t have been otherwise) and personal strength (e.g., I know better that I can handle difficulties). Participants were asked to rate how they changed following their “mental health problem”.

The impact of psychosis was measured using the Impact of Experiences subscale of the Subjective Experiences of Psychosis Scale (Haddock, Wood et al. 2011), a reliable, well-validated measure of participants’ perceptions of their psychotic experiences. The subscale consists of 29 items rated on two dimensions: negative impact and positive impact. Participants were first asked to describe the mental health problem for which they were being treated at PEPP. They were then asked to rate both the positive and negative impact of their mental health problem on various aspects of their lives (e.g., energy, memory, hope for the future, etc.), resulting in a total negative impact score and a total positive impact score. Each item was rated on a 5-point Likert-type scale (not at all to very much). Because the literature suggests that *negative* appraisals of adverse or traumatic experiences are more salient predictors of positive change and growth than positive appraisals, we were primarily interested in how the perceived negative impact of the FEP would be related to positive change. Consequently, we only included the negative impact score derived from the Impact of Experiences subscale in our analyses.

The coping strategies that participants used to deal with FEP were measured using the “situational” version of the Brief COPE scale, which is a widely used measure of various ways of coping with a problem (Carver 1997). Participants were asked to indicate how they coped with their “mental health problem” on a 28-item, 4-point Likert-type scale (with anchors ranging from “I haven’t been doing this at all” to “ I’ve been doing this a lot”). The Brief COPE measures 14 coping strategies; of these, positive reframing (e.g., I've been looking for something good in what is happening) and spiritual coping (e.g., I've been praying or meditating) were included in analyses, based on prior research indicating their contributions to adversarial growth.

Perceived social support was measured using the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem et al. 1988, Zimet, Powell et al. 1990), a valid and reliable measure of perceived social support. The scale includes 12 items rated on a 7-point Likert scale. The scale measures perceived support from family (e.g., my family really tries to help me), friends (e.g., I can count on my friends when things go wrong) and a special person (e.g., there is a special person in my life who cares about my feelings). Items were averaged to produce a total score.

Given the developmental specificity of many valid and reliable measures of resilience, we used the youth and adult versions of one measure developed by the same team using a similar conceptual framework. Participants aged 18 to 23 completed the Brief Child and Youth Resilience Measure, while participants who were 24 years of age or older completed the Brief Adult Resilience Measure (Liebenberg, Ungar et al. 2013). Both measures assess the presence of different aspects of resilience on a 12-item, 3-point scale (with anchors being no, sometimes and yes). Areas measured included education (e.g., I feel I belong at school); personal skills (e.g., I try to finish what I start); peer support (e.g., I think my friends care about me when times are hard); social skills (e.g., I know where to go in my community to get help); caregiver support (e.g., I feel my parents/caregivers know a lot about me); and connection with culture (e.g., I like the way my community celebrates things). Both the youth and adult versions measure the same domains, with slight variations in wording (e.g., I have people I want to be like vs. I have people in my life who I can respect), and in what is included in each domain (e.g., getting an education is important to me vs. getting and improving qualifications and skills is important to me). All items were added to produce a total score.

Recovery was measured using the Recovery Assessment Scale (Giffort, Schmook et al. 1995), a well-validated, widely used measure of the subjective experience of recovery following mental illnesses. The scale contains of 41 items rated on a five-point Likert scale (from strongly disagree to strongly agree) across five domains, including personal confidence and hope (e.g., fear doesn't stop me from living the way I want to), willingness to ask for help (e.g., I know when to ask for help), goal and success orientation (e.g., I have my own plan for how to stay or become well) reliance on others (e.g., even when I don't believe in myself, other people do) and a lack of domination by symptoms (e.g., symptoms interfere less and less with my life). Items were summed to produce a total score.

Covariates

In our protocol, we stated that potential covariates would be controlled for in our main analyses if found to be related to positive change. Originally, we had planned on determining which covariates to include based on their correlations with PTG Inventory scores. However, this method may have resulted in spurious correlations; therefore, covariates were determined based on a review of the literature on predictors of positive change and the availability of data. Accordingly, the covariates we included were age (Ramos and Leal 2013); gender (Vishnevsky, Cann et al. 2010); time elapsed between when participants' were diagnosed with psychosis (Danhauer, Case et al. 2013) and when they completed the study questionnaires; symptoms of psychopathology (i.e., positive and negative symptoms, anxiety, depression, mania/hostility and insight) (Mazor, Gelkopf et al. 2016); medication adherence; and whether participants were hospitalized at the time of entry into treatment for FEP (Anderson, Fuhrer et al. 2013). Age and gender were recorded using a demographic questionnaire created for the purposes of this study. All other data were collected by trained research staff with high inter-rater reliability, as part of PEPP's data collection protocol (Iyer, Jordan et al. 2015).

During the time of this study, symptoms were assessed at PEPP by trained research evaluators at multiple time points during all participants' follow-up (baseline, months 1, 2, 3, 6, 9, 12, 18, and 24, and every 3 months after month 24 for participants who received more than 2 years of follow-up). The symptom assessment closest in time to when study questionnaires were administered was used.

Positive and negative symptoms were measured using the Scale for the Assessment of Positive Symptoms (Andreasen 1984) and the Scale for the Assessment of Negative Symptoms (Andreasen 1983), respectively. Global scores on each domain (i.e., hallucinations, delusions, bizarre behavior, formal thought disorder, affective flattening, alogia, avolition, anhedonia) were used. Depression and anxiety were measured using the Calgary Depression Scale for Schizophrenia (Addington, Addington et al. 1990) and the Hamilton Anxiety Scale (Hamilton 1959), respectively. Total scores from these scales were used. Mania/hostility was measured by summing items 6, 19, 20, 21, 22, and 23 (the items of the scale assessing mania and hostility) of the Brief Psychiatric Rating Scale (Lukoff, Nuechterlein et al., 1986). Medication adherence was derived from clinical notes using a validated method (Cassidy, Rabinovitch et al., 2010). With reference to the month preceding questionnaire administration, participants were categorized either as being adherent (if they took medication 75-100% of the time) or as being non-adherent (if they took medication 0-74% of the time). Insight was measured using the Scale to assess Unawareness of Mental Disorder (Amador, Strauss et al. 1993). Using a previously described method (Lepage, Buchy et al. 2008), scores from the first three items of the scale (awareness of mental illness, awareness of response to medication, and belief in the need for medication and benefit derived from medication) were summed to create a total score.

Clinical notes were reviewed to determine whether service users had been admitted to a hospital immediately prior to their admission to PEPP. Such information is carefully recorded for all PEPP service users in a standardized data reporting system and database since 2003.

Results

Quantitative data analysis

Preliminary Analyses. Descriptive statistics for each variable were computed. Skewed variables were transformed using logarithmic and square root transformations when appropriate. One-way ANOVAs were conducted to determine if responses on English measures differed from responses on French measures and if responses varied according to the administration mode (paper vs. online). In addition, a one-way ANOVA was performed to determine if responses on the youth resilience measure differed from responses on the adult resilience measure. These analyses were performed while correcting for multiple comparisons using a Bonferonni correction.

The presence of multicollinearity among predictor variables in our final model was examined through correlations and VIF statistics. In accordance with previously described rules of thumb, correlations between independent variables that were higher than .90 (Tabachnick and Fidel 2007) and tolerance statistics under .10 (Tabachnick and Fidel 2001) were used as evidence of multicollinearity.

Univariate Analyses. Univariate analyses were conducted to determine if predictors (the negative impact of FEP, positive reframing, spiritual coping, perceived social support, resilience, and recovery) and covariates (age, gender, time since diagnosis, symptoms of psychopathology, and being hospitalized for FEP) were associated with positive change. Specifically, we computed Pearson's correlations between normally distributed variables and total PTG Inventory scores, and Spearman's correlations between non-normally distributed or categorical variables and total PTG Inventory scores. A Bonferroni correction was applied to all univariate analyses.

On average, there was a time difference of 10.95 (SD = 16.32) weeks between when participants completed study questionnaires and when their symptom assessment was conducted. Given this large gap, we conducted univariate analyses between symptom scores and PTG Inventory scores for the entire sample (n = 94), as well as for a subsample of participants whose symptom assessments were conducted within one month of completing questionnaires (n = 42).

A separate analysis was conducted to determine whether Subjective Experiences of Psychosis Scale scores had a curvilinear relationship with Posttraumatic Growth Inventory scores. To do so, we tested if the quadratic term of the Subjective Experiences of Psychosis Scale scores predicted PTG Inventory scores. This entailed squaring the Subjective Experiences of Psychosis Scale scores; entering both the original and squared scores into two separate blocks in a hierarchical regression analysis; and determining if the change between blocks was significant.

Multivariate analysis. Finally, we conducted a multiple regression analysis to determine which of the originally proposed predictors and covariates predicted positive change. To be consistent with our protocol, all *original predictors* were evaluated in this model. Due to power considerations, only the *covariates* that were significantly related to positive change in the univariate analyses were included in the model. Significant covariates were entered into the first block of a hierarchical linear regression, followed by the main predictor variables in a second block.

Qualitative data analysis

Qualitative data were analyzed using thematic analysis (Braun and Clarke 2006). Each transcript was checked against the audio recording for accuracy by GJ and a second researcher. Transcripts were read several times in order to develop a strong, overall understanding of the data. Entire transcripts were subjected to open, line-by-line coding. Initial codes were reviewed and grouped into focused codes, categories and themes, which were checked against the original transcripts. An inductive approach favoring semantic level coding (i.e., reflecting participants' descriptions of experiences) was used early on in the analysis. However, the analysis became informed by theoretical models of positive change [e.g., Tedeschi and Calhoun's model of posttraumatic growth (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006), etc.] and latent constructs (i.e., reflecting the underlying meaning and structure of themes) as the analysis moved forward. The final thematic map was developed by connecting themes, memos and notes with the larger narratives derived from participants' interviews. Detailed analytical memos and reflexive notes kept throughout the process also informed the analysis.

Mixed methods data analysis

Once the qualitative and quantitative data were analyzed independently, both sets of findings were combined in a mixed methods joint display table as per best practices in mixed methods research (Creswell and Plano Clark 2011, Guetterman, Fetters et al. 2015). This joint display table was useful to highlight convergence and divergence between findings (Table 5). Convergence and divergence was then described using a weaving method (Fetters, Curry et al. 2013) in the discussion section as per expert recommendations (Guetterman, Fetters et al. 2015).

Participants

Of the 263 service users who were followed at PEPP during the study period (May 2015 – November 2017), 221 service users were eligible for participation in the *quantitative* component. Of these, 147 were approached, 36 declined, and 111 participated. Data from 16 participants were omitted for different reasons (i.e., they did not return questionnaires, did not complete the questionnaires as per the instructions, or they completed pilot versions of the questionnaires) and one participant withdrew consent after completing the study, yielding a final sample of 94 (Appendix 1). Fourteen service users, who were eligible for participation in the *qualitative* component. were identified by their treatment team as having experienced positive change following FEP and were approached. One service user declined to participate, 13 completed interviews, and one participant withdrew consent after completing the study, yielding a final sample size of 12. Participants who were interviewed also completed the questionnaires or participated in the quantitative component of the study (Appendix 2).

Demographic and clinical characteristics of participants and service users who met the study ‘s eligibility criteria but were not included are shown in Table 1. Compared to those who were eligible but were not included, study participants were more likely to be female χ^2 (1) = 7.37, P = .007 and to have more negative symptoms at baseline $F(1,179) = 4.06$, P = .045.

Quantitative results

Preliminary Results. Descriptive statistics for the study variables are shown in Table 2. All variables were normally distributed except for positive symptoms, alogia, mania/hostility, anxiety, depression, insight, and time since diagnosis; each of which was positively skewed. Following the application of logarithmic transformations, only time since diagnosis (skewness = .30), alogia (skewness = .78), anxiety (skewness = .46) and insight (skewness = .32) became normally distributed.

Analyses showed that average responses on the adult version of the resilience measure (M = 20.05, SD = 3.81) differed significantly from responses on the youth version (M = 18.39, SD = 3.12) [*F*(92) = 4.92, P = .029]. However, PTG scores did not differ significantly between participants who completed the adult version of the resilience measure and those who completed the youth version. Responses on English and French questionnaires were not significantly different and were unrelated to scores on the PTG Inventory.

Univariate analyses of predictors. Spiritual coping, positive reframing, social support, resilience, and recovery were significantly positively correlated with PTG Inventory scores (Table 2). Neither the linear nor the quadratic functions of the negative impact of FEP (as assessed by the Subjective Experiences of Psychosis Scale) were significantly related to PTG Inventory scores.

Univariate analyses of covariates. Age, gender, and time since diagnosis were not related to PTG Inventory scores. Medication adherence was not related to PTG inventory scores. Symptoms were not related to PTG Inventory scores in both the larger sample (n = 94) and the subsample (n = 42). However, being hospitalized prior to or at the time of entry into treatment for FEP was significantly positively related to PTG Inventory scores (Table 2).

Multicollinearity among the predictor variables was not detected. Correlations between all independent variables were below .90 (r =.01 – r = .54) (Table 3); tolerance statistics ranged between .59 and .83.

Multivariate analysis. Our regression model contained hospitalization for FEP in one block and the six hypothesized predictors in a second block (the negative impact of FEP, resilience, perceived social support, spiritual coping, positive reframing, and recovery). The original, linear negative impact of FEP variable was used.

The first block containing hospitalization for FEP ($\beta = .25$, $P = .021$) was significant $F(1,83) = 5.56$, $P = .21$ and associated with a small proportion of variance in PTG Inventory total scores ($R^2_{adj} = .05$). The addition of the main predictors in the second block was associated with a significant change in variance $R^2_{change} = .45$, $P < .001$. This final model was significant $F(7,83) = 11.83$, $P < .001$ and explained 47% of variance in PTG Inventory total scores ($R^2_{adj} = .47$). Variables that attained significance in the final model included spiritual coping ($\beta = .29$, $P = .001$), positive reframing ($\beta = .23$, $P = .01$), recovery ($\beta = .26$, $P = .009$), and being hospitalized for FEP ($\beta = .29$, $P = .001$). The negative impact of FEP approached significance ($\beta = .15$, $P = .08$). Neither resilience nor perceived social support were significant predictors of PTG inventory total scores.

Sensitivity Analyses

Sensitivity Analysis 1. . The authors of the Brief COPE recommend that researchers derive the factor structure for this measure separately for every sample examined (Carver, Scheier et al. 1989, Carver 1997). As such, we sought to determine the factor structure of the Brief COPE and whether these *derived* factors predicted PTG Inventory total scores better than the original factors we included (i.e., positive reframing and spiritual coping). Since no studies have examined the factor structure of the Brief COPE in the context of FEP, we performed a principal components analysis of the Brief COPE using a varimax rotation. We based the factors on eigenvalues greater than one, the curve on the Scree plot derived from the analysis, the internal consistency of the factors, and relevant literature on how persons cope with psychosis. In line with previously established guidelines (Tabachnick and Fidel 2001), a minimum loading of .32 for each item was tolerated.

Once the factors had been derived, a multiple regression was conducted using the derived factors which significantly correlated with PTG Inventory scores, instead of the original two factors from the Brief COPE (positive reframing and spiritual coping). Thus, the first block of this regression model contained being hospitalized for FEP, and the second block contained being hospitalized for FEP, the negative impact of FEP, social support, resilience, recovery, and the derived coping factors.

Results of Sensitivity Analysis 1. The factor analysis originally yielded an eight-factor solution; however, one factor contained only one item (I've been doing something to think about it less, such as going to movies) and was thus dropped from analyses, leaving seven factors which explained 67.28% of variance in the scale. The Kaiser-Meyer-Olkin Measure of Sample Adequacy was .73, and Bartlett's Test of Sphericity was significant; χ^2 (351) = 1098.99. The factors yielded from the analyses comprised emotional and instrumental support (e.g., I've been getting emotional support from others, α = .74); being proactive (e.g., I've been taking action to make the situation better, α = .83); being positive/accepting (e.g., I've been looking for something good in what is happening, α =.78); giving up and self-blame (e.g., I've been giving up trying to deal with it, α =.74); denial and expressing unpleasant emotions (e.g., I've been saying to myself, "this isn't real", α =.62); spiritual coping (e.g., I've been praying or meditating, α =.84) and substance use (e.g., I've been using alcohol or other drugs to make myself feel better, α =.87) (Supplementary Table 1).

Of the seven derived factors, emotional and instrumental support (r = .42, P < .001), being proactive (r = .48, P < .001), being positive/accepting (r = .55, P < .001), and spiritual coping (r = .41, P < .001) were significantly related to PTG Inventory total scores after controlling for multiple comparisons. We did not include the "emotional and instrumental support" factor in the subsequent regression analysis because this coping strategy overlapped conceptually with perceived social support, which we measured using the Multidimensional Scale of Perceived Social Support.

Results of the post-hoc regression analysis generally resembled the results of the original analysis. The first block containing being hospitalized for FEP ($\beta = .25$, $P = .021$) was significant F $(1,83) = 5.56$, $P = .21$ and explained a small proportion of variance in positive change ($R^2_{adj} = .05$). Including the additional variables (hospitalized for FEP, the negative impact of FEP, social support, resilience, recovery, and the coping factors of being proactive, being positive/accepting, and spiritual coping) resulted in a significant overall model $F(8,83) = 11.09$, $P < .001$ that explained 49% of the variance in PTG inventory total scores ($R^2_{adj} = .49$). Spiritual coping ($\beta = .25$, $P = .005$), being positive/accepting ($\beta = .25$, $P = .01$), recovery ($\beta = .22$, $P = .03$), and being hospitalized for FEP ($\beta = .28$, $P = .002$) were significant in this model. Being proactive, resilience, and perceived social support were not significant predictors of PTG.

Rationale for Sensitivity Analysis 2. Since responses on the youth resilience measure differed significantly from responses on the adult resilience measure, a second post-hoc test was conducted to control for this difference. We repeated the main analysis by entering hospitalization for FEP and the resilience measure version (youth vs. adult version) in the first block of a hierarchical regression, followed by the original predictor variables in the second block (i.e., the negative impact of FEP, social support, resilience, recovery, positive reframing, and spiritual coping).

Results of Sensitivity Analysis 2. The first block was not significant F $(2,82) = .27$, $P = .07$ and associated with very little variance in PTG Inventory total scores ($R^2_{adj} = .04$). The addition of the original predictors in the second block resulted in a significant model F $(8, 84) =$

10.22, P < .001 that explained 47% of the variance in PTG Inventory total scores. Spiritual coping (β = .29, P =.001), positive reframing (β = .23, P =.01), recovery (β = .26, P =.01), and being hospitalized for FEP (β = .30, P =.001) were significant in this model, while the negative impact of FEP reached trend levels (β = .15, P =.08).

Qualitative results

In their interviews, participants described a process involving various elements culminating in positive change. Participants perceived that the experience of FEP was an important catalyst for positive change. Aspects of the psychosis itself, receiving mental health services, and drawing on personal and social resources and coping strategies to deal with the psychotic experience, were variously described as directly facilitating positive change or as facilitating recovery, which in turn facilitated positive change. Throughout this process, participants attempted to make sense of their experiences and sought information that they could use to strengthen the positive changes they experienced. Finally, participants described how growing up, maturing and life experiences that had little to do with the FEP also led to positive change (Figure 1).

Theme: Psychosis and its impact. The most important facilitator of the positive changes that participants experienced was the FEP itself. The experience of psychosis was perceived as powerful enough to significantly alter nearly every aspect of participants' lives. Participants described how impacts of FEP such as becoming disorganized, overwhelmed, and confused; having one's "assumptive world" challenged and constantly asking oneself "why me?"; losing sleep, feeling depressed, hopeless, broken down, terrified or traumatized, which made them re-evaluate their lives and chart new directions.

> Respondent: "I think it's the experiences that come with psychosis, the situation I was in because of the psychosis led to all these changes, you know? The uh situations it had caused."

> Respondent: “The experiences I’ve had um with psychosis have um – if I hadn’t had psychosis I don’t think I’d have the same outlook on life.”

In addition, the fear of experiencing a second psychotic episode was seen as an impetus to make important life changes, such as stopping substance use.

> Respondent: “Yeah. I’m scared that I’m just going to get – like I’m just going to take a lot of coke, and I’m just going to be like – there’s going to be voices.”

Theme: Receiving mental health services and treatments. Following the onset of psychosis, participants received mental health services which were described as key facilitators of positive change. For many participants, the first step in receiving mental health services involved a lengthy, emotionally draining, and an occasionally coercive pathway to care. This process resulted in many participants being admitted to the emergency room, or to the inpatient unit at PEPP’s parent institution for up to several months. Many participants described how they did not want to be hospitalized; however, others were thankful for this and appreciated the care that they received. For many participants, hospitalization was an important *turning point* in their lives during which they first realized that they needed to make changes in their lives.

> Respondent: “Because the stress led me to be in the hospital, because I used to stress a lot. So that's what happened - that's how I got my meltdown and how I had a psychosis. So after I went home, back home from the hospital, I was still stressed out, I wasn't myself completely, but I realised that because I stress too much it could come back, so I needed to make some changes in my life, so I needed to let go of certain stuff, so I could feel better and I could be a better person.”

In addition to the hospitalization, participants described how the outpatient care they received at PEPP facilitated positive change. Care favouring a recovery-oriented approach seemed particularly important in facilitating positive change. For instance, an important element of such care included having flexible case managers who treated participants like “normal” people and believed in their potential. In addition, participants described how their treatment team’s efforts to improve their well-being and mental health were important facilitators of positive change. The aspects of treatment that were more closely aligned with therapeutic alliance, such as emotional support particularly in the face of problems, were emphasized as particularly important. Likewise, the willingness and ability of staff to simply listen to participants was highlighted. Other more instrumental aspects of care that participants saw as facilitating positive change included help with finding housing, going back to school or work, achieving broader life goals, and meeting new people through organized group activities offered at PEPP. Participants also highlighted how services helped address the broader economic and social conditions affecting their mental health.

> Respondent: "They listen well and they're right there, like when I was having a really rough time, like my psychiatrist saw me twice a week, like when I was super suicidal, and they were thinking of putting me in the hospital, maybe, but then they trusted like, my family to be able to watch me and to be able to make sure that I didn't like hurt myself, and just being able to recognise and acknowledge the situation that I'm in, in the context that I'm in, they were really, um, flexible."

> Interviewer: "Yeah, so... okay, I'll just ask you a couple more questions. So in what way do you feel like coming to PEPP has a positive impact on your life, in general?
> Respondent: Well, in general, it has reduced my stress.
> Interviewer: Okay.
> Respondent: My ability to cope with stress and unexpected things."

> Respondent: "Because I had psychosis, not only was my mental health out of place but my uhm economic opportunities were out of place, my social status was out of place, my uhm– and those things affect a lot of other things, there was like a domino effect of negative things in my life and this place has helped me recover in all those aspects as well."

An additional important aspect of care that was perceived to facilitate positive change was psychotherapy. Specifically, psychotherapy was perceived to facilitate positive change by helping participants to cope with their problems, for instance, by seeing negative experiences in a positive light, and to better handle their emotions. Just as with case managers, one participant also described how being treated like a "normal" person by their therapist was important.

Respondent: "I'm not really sure how to explain the difference but, like the way I think about myself, and the self-awareness that I have, and the self-awareness I'm continuing to develop, like a lot of it I credit to the help with CBT"

> Respondent: "Like, again, it's CBT that helped me a lot, to think positively ... think positive. I mean, that's the main message I got here [PEPP], and that's the main thing I learned from here, how to turn negative things into positive things."

An important component of treatment offered at PEPP includes antipsychotic medication. Many participants described difficulties with taking medication and dealing with its side effects. However, they also described how medication fostered improved mental health as well as positive change.

Interviewer:	So what do you feel has like helped you to get to where you are now?
Respondent:	My medication that they threw me on. Yeah because if I didn't take the medication I'd probably still be the same person I was."

In contrast, one participant felt that taking medication was only useful in laying the foundation for her mental and emotional stability; but that taking too much medication may have prevented her from experiencing positive change.

Respondent:	"I took medication twice in the hospital, I'm not going to take anymore, because I'm just, I just feel like I have to face – and that if I just take medication I deny the deeper meaning of what's going on and what's happening and why.
Interviewer:	And the deeper meaning was like I guess bringing you into your authentic self and then challenging how you were before?
Respondent:	Exactly. Exactly. Challenging how I was before, exactly."

Theme: Drawing on personal and social resources and strategies. In addition to experiencing positive change through receiving mental health services, participants drew on additional resources and strategies. Some of these were available to participants prior to the onset of their psychosis (e.g., having always been strong, independent and self-reliant), while others were more recently developed (e.g., beginning to attend church after onset and being supported by fellow church members).

The most important resource that participants drew on to facilitate positive change was social support. In addition to feeling supported by their treatment team, most participants received support from family and friends, peers with lived experience of FEP, and romantic partners. In addition, some described being supported by voices or visions of loved ones, such as deceased relatives.

> Interviewer: Okay, so like how do you ... like, what do you think has helped you get to the point where you're at now? Like, what would you identify as things that have helped you get here?
> Respondent: Support.
> Interviewer: From who?
> Respondent: From my family, from my friends, from PEPP.

Participants highlighted several actions that their loved ones carried out which facilitated positive change, such as simply “being there”; treating them like “normal” rather than sick people; engaging with them in regular, everyday activities; listening to them and providing opportunities to express their feelings; and providing instrumental support (e.g., providing financial support).

> Respondent: “They - they listened to me, they encouraged me to just - they always told me that it's a temporary thing - I'm going to get through it - it's not permanent. They would take me out just to like - they were really patient with me and they will really encourage me to do better and not to feel like I'm stuck in this, because I felt stuck. I felt like I was never going to - going to be 100%. Yeah.

> Respondent: “She (mother) kicked me in the ass. Yeah. Because if it wasn’t for her I’d probably still be doing the stuff I was doing.”

Spirituality and religion were also seen as important resources that facilitated positive change. Illustratively, one participant felt that she had become kinder to others following FEP:

> Respondent: “I do believe in God - I believe there's a bigger - a higher spirit or a - I don't know how to call it - just God…And I just feel like to be kind in life, doing good for others, doing good for yourself, is a good way to live life.”

Others described how engaging in spiritual or religious practices (e.g., meditation or prayer), attending religious institutions (e.g., church), or feeling loved by God facilitated recovery and, by extension, positive changes. In the example below, one participant describes how attending church had helped her let go of what could not be controlled in life:

> Interviewer: Has the church and that kind of spiritual stuff you do now, does that also help you?
> Respondent: Yes, a lot. [quick response]
> Interviewer: In what way?
> Respondent: To be calm and every day to…to do what I have to do, but to, to leave some stuff to God, that I cannot control everything.

Some participants described how their positive changes were facilitated by ongoing spiritual experiences. For instance, some described having new knowledge revealed to them by the voice of God. Perceptions that ongoing spiritual experiences facilitated positive change appeared to depend on participants' belief in the veracity of such experiences.

> Respondent: I put all my entourage in what I read and it makes so much sense. So sometimes, sometimes it even tells me like what's going to happen tomorrow, and it really happens. So that's how it changed really – my perspective about life is that the word of God is so important in life. And you never know what the word can tell you because the word has so many secrets, even things that didn't even happen yet. But the word, in the word of God there's almost everything you need in life.

In addition to drawing on social support and spirituality, participants described how they relied on their agency and self-determination to facilitate positive change. For some, this involved taking the risks needed to improve their lives. Others described the importance of having the strength and willpower needed to make positive changes; believing in themselves and being true to their feelings; and making conscious decisions to change for the better. Some participants also described how being authentic to their values and passions (which in itself also constituted an aspect of positive change) helped them live more "congruent" lives

> Respondent: "I know that it [psychosis] makes me a lot more aware, it makes me a lot more stronger. Like I feel like I'm stronger now just because I. . . I had to fight to stay alive. Right? I had to fight my depression in order to not commit suicide. Which I've attempted. I had to, um…I had to convince myself that I don't deserve to be inflicted, to inflict pain on myself. I have to really, really love what I'm doing with every second of my, of my life because if I don't, then I'm wasting my time."

In addition, some participants described how being open to change and willing to learn from challenges led to experiencing self-improvement.

> Respondent: "I've always had that desire to improve myself and I'll always been very open to criticism, that uh positive criticism, you know, anything that could help me be a better person, I'll always take it"

Participants also reported having used coping strategies to deal with FEP and its aftermath, which in turn facilitated positive change. Key coping strategies included finding ways to disengage from stressful situations; relinquishing behaviors or activities that were seen post-psychosis as harmful; or learning to "get a grip" on "life's curveballs".

Interviewer:	What role do you feel like stopping drugs played in getting to where you are now?
Respondent:	A big role because if I didn't stop drugs I would probably still be on the path I was on. Yeah."

Theme: Healing and recovery. Drawing on formal mental health services as well as personal and social resources and strategies helped participants heal and recover from the FEP. For some, experiencing recovery (and not the experience of psychosis) was seen as the *main* facilitator of positive change.

> Respondent: “All of my positive changes came from not those things, but getting out of those things. That is something I will absolutely make clear is that none of the positive effects that I have in my life right now came from these awful, crappy, terrible diseases”

Participants felt that they were at varying points in the recovery process. Some felt like they were still healing while others described feeling fully recovered. Participants’ definitions of recovery sometimes reflected a return to normality; being able to engage in meaningful activities once again; and being symptom-free or back at school. One participant described how it was up to her doctor to decide if she was in recovery or not. For others, recovery was synonymous with positive change and a new way of being.

> Respondent: “I don't know what it means anymore, because there's no ... like someone said like, there's a new normal, kind of, like there's no going back to normal cause like there's no way back. It's just moving forward and finding the new way that I am and accepting the new way that I am.”

One participant saw recovery adversely, as it referred to a return to how things were prior to the onset of psychosis and said:

> “Yeah, I'm not really going to recover, and I don't really want to go back to where I was before, at all, cause like it didn't work out very well for me, where I was headed”

Theme: Making meaning and gaining knowledge. Participants described how they engaged in a meaning-making process that facilitated positive change. This process began when participants first became unwell and assigned causal attributions to their illness experience. These attributions included seeing psychosis as a positive, useful, therapeutic or spiritual experience; as well as viewing psychosis as medical problem that could be explained by science. Some also described how the illness experience provided meaningful information that contributed to self-improvement and change.

> Respondent: “It's [psychosis] information. I feel like I'm in a stage where I'm able to receive information about what's really going on with me and then like now I'm out of that state, right, so now I have to take that information that I was receiving and try to apply it to reality”

In addition to making causal attributions, participants appraised and reflected on aspects about themselves and their lives in the aftermath of psychosis. A key facet of this process involved experiencing important realizations about the various aspects that participants felt needed changing. Such realizations were described as fundamental to many of the positive changes that participants experienced.

> Respondent: “I let go of that because I realised like I can't control what they're doing, what, or what they do, or what mistakes they make because I can't fix it for them. The only thing I can fix is myself. So I let go of that, so. That in a way I'm better because I don't stress about those things anymore.”

A second important meaning-making process involved consciously searching for ways that positive change could follow FEP or other life experiences (i.e., engaging in “positive reframing”). For some participants, this process was fostered through psychotherapy.

> Respondent: “Like, I used to see, you know, okay, this was bad, but how can I find the good in it and . . . But it's like now that I look back, it's [psychosis] just all inherently positive, because it gives me so much each time.”

In addition to these meaning making processes, some participants drew on cultural frameworks describing growth following adversity. These frameworks helped participants understand the nature of psychosis, why it happened, and how they changed following their psychosis. Such frameworks included life mottos; religious or spiritual norms; descriptions about spiritual emergencies in the Diagnostic and Statistical Manual for Mental Disorders-IV (in which spiritual growth and awakening follow a spiritual crisis); and even the lives of pop culture figures.

> Respondent: “Well, it’s kind of like the quote that says, like when you fall, you fall, but when you rise, you become stronger, you know? So you kind of like – it’s kind of like my motto to my life.”

> Respondent: “Yeah. I heard there's like, a category in the psychiatrist's manual that's like, spiritual or religious problem, and like I feel like that helps me make sense of my experience. I'm like, that's probably what I had, something about, along those lines, except I wouldn't really call it a problem. It was more like, an experience.”

Several participants searched for information about and gained new knowledge related to the domains in which they experienced positive change. For instance, one participant who gained spiritual knowledge following FEP engaged in extensive reading of religious texts to further strengthen and develop this new knowledge. Another participant who felt that his psychosis had made him an activist spent time reading and learning about social justice issues to further reinforce his legitimacy as an activist:

> Respondent: "I'm in a lot of spoken word scenes, and, and I, I must spend hours and hours every couple days just…reading and going through, different activist's art and understanding it. Like, I mean, I'm not saying that psychosis is the only reason for me to be an activist, I just feel like without it I wouldn't have the experiences that I do"

Theme: Growing up, experiencing life, and moving on. Some participants described how additional, important life events that were unrelated to psychosis facilitated positive change. Such experiences included being far away from home and needing to survive; having a loving romantic partner who motivated change; and making and learning from mistakes and life choices.

> Respondent: "Uhm… When you travel 30 hours in a different country, and you're all by yourself, and you got to survive, yeah, it kind of changes you a bit."

> Respondent: "Yeah, like my boyfriend – I've – because he's the type of person that – he's very honest, he's very open. Well, I'm more open that he is, but he's very honest, he's very straightforward, he's very vulnerable, he's more vulnerable than I am. He'll say what he feels, he's not afraid of saying what he feels, he's not afraid of – not looking weak, but like just being vulnerable. He's not afraid of that, you know? So he's taught me a lot in that, because, before that, like I would just… somebody hurt me, like I wouldn't tell them that they hurt me, you know? I would just keep it inside, and bury it, just like okay, whatever, like it's fine. But now it's not fine. And then, I just, yeah, just sort of being more…even honest with myself, you know?"

In addition to life experiences, many described how their positive changes arose from growing up. Some—especially those whose mental health problems emerged at a young age—described how their positive changes were facilitated by completing a life phase or attaining a milestone; by simply becoming more mature; or through a desire to become more mature. To some extent, these participants had some difficulty unraveling whether their positive changes were due to FEP or to growing up.

> Respondent: “Well, I feel like who I am as a person has changed because of psychosis, but I feel like because of my psychosis hit while I was in my prime… years of high school, that, it's hard to figure out what part of me changed just because I was a teenager growing up and what part of me changed because of psychosis, because they were happening at the same time, right? So as I was going through this between the ages of 13 and 18, that's—I wonder what changed what, I don't know!”

Discussion

Summary of results and findings

The purpose of this study was to investigate predictors and perceived facilitators of positive change following FEP using a mixed methods convergent design. The quantitative results revealed that being hospitalized for FEP, spiritual coping, positive reframing, and subjective recovery were robust predictors of positive change. Social support and resilience were related to positive change in the univariate analyses, but not in the multivariate analyses. Age, gender, time since diagnosis, and symptoms were unrelated to positive change.

The qualitative findings revealed that positive change unfolded through a process. The FEP was perceived to directly facilitate positive change, but also led participants to draw on formal mental health services and treatments (i.e., early intervention services, psychotherapy, and medication) as well as personal and social resources (i.e., self-determination and agency, spirituality, coping and social support). Drawing on mental health services as well as personal and social resources were perceived to facilitate positive change directly. Both were also perceived to lead to recovery and in turn positive change. Participants also described how they engaged in a meaning-making and knowledge-gaining process that facilitated positive change; and some attributed their positive changes to normative developmental processes.

Convergence between quantitative results and quantitative findings

Spirituality/Religion. The qualitative findings converged with the quantitative findings in several ways. Both sets of findings reveal how positive change was facilitated through spiritual coping, which is consistent with other studies of PTG (Shaw, Joseph et al. 2005, Tallman, Shaw et al. 2010, Rajandram, Jenewein et al. 2011). These findings highlight the potential role that spirituality and religion play in buffering persons with mental illness from (Koenig 2009), and support theoretical claims that spirituality or religion "can provide a unifying philosophy of life" (Emmons 2005; p. 738) that can help persons grow from adversity (Park 2013). Other studies have shown that "positive" spiritual or religious coping (e.g., seeking spiritual support) is a stronger predictor of positive change than "negative" spiritual or religious coping (e.g., experiencing religious struggles)(Park, Smith et al. 2017). While we could not determine the degree to which spiritual coping was "positive" in the quantitative component, spiritual coping often fell under such a "positive" definition in the qualitative findings.

Positive reframing. Both sets of findings demonstrated that positive reframing was an important facilitator of positive change, which is consistent with our systematic review's earlier finding (Jordan, MacDonald et al. 2018) and with studies of growth following other adversities (Prati and Pietrantoni 2009, Rajandram, Jenewein et al. 2011, Shand, Cowlishaw et al. 2015). Our findings support claims that positive reframing is an important mechanism through which persons ascribe a constructive meaning to the aftermath of adversity (Park 2010). Yet, it has been argued that some of the positive change (Zoellner and Maercker 2006, Hobfoll, Hall et al. 2007, Zoellner, Rabe et al. 2008) or all of it (Taylor 1983, Taylor and Armor 1996, Taylor, Kemeny et al. 2000) is illusory and reflects a way of coping with adversity that is akin to positive reframing. However, studies have shown that positive reframing predicts positive change longitudinally at later time points, albeit less so than in cross sectional studies (Prati and Pietrantoni 2009), suggesting that the constructs of positive reframing and positive change may indeed be disparate. While we could not test if positive reframing predicted positive change longitudinally in our quantitative component, participants themselves pointed to how positive reframing facilitated positive change.

Hospitalization. The qualitative and quantitative findings also converged in revealing that being hospitalized for FEP facilitated positive change. Only one other study examining broader experiences of help-seeking in the context of FEP has described how experiences around hospitalization or help-seeking led to positive change (Anderson, Fuhrer et al. 2013). To our knowledge, this finding has not been observed following other adversities. Our qualitative findings also revealed that being hospitalized was both distressing and an important turning point in participants' lives. This is noteworthy because experiences being seen as distressing and important have been conceptualized to be key facilitators of positive change in general (Pals and McAdams 2004, Shakespeare-Finch and Lurie-Beck 2014).

Recovery. The quantitative and qualitative findings also reveal that experiencing subjective recovery is a key facilitator of positive change. This finding is consistent with other studies (Lam, Pearson et al. 2010, Romano, McCay et al. 2010, Pietruch and Jobson 2012, Connell, Schweitzer et al. 2014, Connell, Schweitzer et al. 2015) and suggests that experiencing broader areas of improvement are needed to grow following FEP. Efforts made to promote, maintain and sustain recovery may therefore be key to experiences of positive change among persons with FEP. Relatedly, some participants who were at different phases of the recovery process also described how they viewed their "psychotic" experiences as a source of strength, which in turn facilitated positive change. This finding is consistent with studies reporting how some perceive the voices that they heard to be useful or to serve a purpose (Miller, O'Connor et al. 1993, Beavan and Read 2010). Conversely, the quantitative results did not reveal a relationship between symptom levels and positive change, which is at odds with one study examining PTG among persons who had experienced multiple episodes of psychosis (Mazor, Gelkopf et al. 2016). An effect may not have been found because the symptom scales we included measured the pathological—rather than the potentially benevolent, useful or supportive—attributes of psychotic experiences.

Gender, age and time since diagnosis and medication adherence. Our study found no evidence that gender predicted positive change. These findings are in contrast with other studies (Vishnevsky, Cann et al. 2010), and may be due to similarities in how both males and females in our sample coped with FEP; or because our sample included a greater number of females. In our study, age was unrelated to positive change, which is dissimilar with findings from other studies (Linley and Joseph 2004, Ramos and Leal 2013, Husson, Zebrack et al. 2017). While study participants varied with respect to their ages, participants were generally young. Had we included much older participants in our study, we may have observed a relationship between age and positive change. Furthermore, the time since diagnosis did not predict positive change. This finding is inconsistent with some studies that have investigated positive change following adversities other than mental illness (Danhauer, Case et al. 2013), and may reflect our choice to recruit service users who had completed at least six months of treatment. Alternatively, the time since the onset of psychosis may be related to positive change after much time has elapsed.

Divergence between quantitative results and qualitative findings.

Resilience and social support. While we found evidence of convergence between the quantitative results and qualitative findings, we found greater evidence of divergence. Perhaps the most striking divergence was observed when examining findings on resilience and social support. In the quantitative component, resilience and social support were measured as independent constructs and were significantly related to positive change in univariate, but not the multivariate analyses. In the qualitative component, participants spoke of how drawing on personal and social resources (which fall under the concept of resilience) facilitated positive change. Further, social support was seen as a key social resource which facilitated positive change.

There may be several reasons for this divergence. Since the resilience measure we employed in the quantitative component assessed social support (Liebenberg, Ungar et al. 2013), this divergence may reflect multicollinearity between both variables. However, we found no evidence of multicollinearity in the quantitative component of this study. Conversely, certain areas of resilience that were measured were found to be unrelated to positive change, such as education and participants' connection to their culture. These areas were not found to facilitate positive change in the qualitative component and may therefore be less relevant in the FEP context. Similarly, the measure of perceived social support that we employed (Zimet, Dahlem et al. 1988, Zimet, Powell et al. 1990) only captured perceptions of *who* offered support, and not the myriad *ways* that social support could be offered (which was described in the qualitative findings). The ways that social support was offered may have been a stronger predictor of positive change

Our findings on resilience are therefore partially consistent with other studies that have found that resilience as a trait is an important predictor of positive change (Kaye-Tzadok and Davidson-Arad 2016, Garrido-Hernansaiz, Murphy et al. 2017). However, since no other study has reported how ecological forms of resilience relate to positive change, our findings cannot be directly compared to results of other studies.

Our findings on social support are also only partially consistent with other studies (Prati and Pietrantoni 2009, Elderton, Berry et al. 2015). Our findings on social support add some strength to Tedeschi and Calhoun's claim that such support fosters positive change (Tedeschi and Calhoun 1995, Tedeschi and Calhoun 2004, Tedeschi and Calhoun 2006).

The negative impact of FEP. Additional divergence was noted with respect to the findings on the negative impact of FEP. While FEP was seen as facilitating positive change in the qualitative findings, the negative impact of FEP did not predict positive change in the quantitative results. This divergence may reflect the measure we used to assess the negative impact of psychosis (Haddock, Wood et al. 2011). Many studies that report a relationship between the impact of an adversity on positive change include measures of the emotional intensity of an adversity, or the posttraumatic stress symptoms arising from an adversity (Shakespeare-Finch and Lurie-Beck 2014). Conversely, the measure we used assessed the negative impact of FEP in multiple domains (which included but were not limited to distress). Thus, our measure may not have been sensitive enough to assess the type of impact that may facilitate positive change.

Mental health services and treatments. The qualitative findings described how receiving mental health services and treatments facilitated positive change, a process which was not measured in the quantitative component. Our finding that early intervention services were perceived to facilitate positive change is consistent with findings from our systematic review (Jordan, MacDonald et al. 2018). Specifically, our review reported that such services facilitated positive change when they emphasized self-efficacy, recovery, hope, and self-acceptance; were not-diagnostically driven; and helped service users deal with stress. Such approaches to care are consistent with established guidelines for recovery-oriented care for mental illnesses (Mental Health Commission of Canada, 2015). The finding that psychotherapy facilitated positive change is also consistent with previous work (Roepke 2015), and points to the capacity of psychotherapists to foster positive change among service users (Tedeschi, Calhoun et al. 2015). Medication was seen as facilitating healing and recovery and positive change in the qualitative, but not the quantitative, results. Our earlier review of studies on FEP also suggested that medication can facilitate positive change following psychosis (Jordan, MacDonald et al. 2018). This has also been reported in a few studies of other illnesses where receiving treatment contributed to positive change (Sherr, Nagra et al. 2011).

Meaning-making and gaining knowledge. The qualitative findings diverged from the quantitative results in revealing how participants engaged in a meaning-making process that facilitated positive change. This process entailed finding meaning in their illness experience and its aftermath; experiencing powerful insights and realizations; and drawing on cultural frameworks of growth following adversity. Overall, these findings are consistent with other studies (Wang, Gan et al. 2016, Zeligman, Varney et al. 2018) and provide theoretical support to models that depicting the search for meaning as a key facilitator of positive change (Park 2010, Park 2013). The finding that experiencing realizations and insights was a fundamental facilitator of positive change is consistent with prior work (Jordan, MacDonald et al. 2018) and Hobfall`s (2007) claim that cognitions about positive change can sometimes translate into action. Similarly, the finding that cultural frameworks facilitated positive change is consistent with Tedeschi and Calhoun’s (2006) claims that cultural frameworks describing growth following adversity can serve as examples for people to follow during hardships. In a similar vein, our qualitative findings revealed that some positive changes were facilitated through gaining knowledge about the domains within which positive change was experienced. Prior work has also demonstrated the value of seeking information; learning and receiving educational instruction in contributing to transformational experiences and positive change (Kitchenham 2008).

Normative developmental processes. Our qualitative findings revealed that some participants saw positive change as resulting from normative developmental processes, a nuance which was not captured in the quantitative results. This finding is seldom described within the context of positive change stemming from adversity (Tedeschhi and Calhoun, 2006), and supports claims that developmental and adversity-related trajectories can share similar outcomes, and that there are multiple paths to positive change (Aldwin, Levenson et al. 2009). Our finding may also be attributable in part to the young age of our sample.

Similarities and differences between predictors of recovery and positive change following FEP

The predictors and perceived facilitators of positive change described in this study are similar to predictors of subjective recovery. For instance, a recent systematic review identified social support, personal agency and hope, environmental resources, and high-quality care from services as facilitating subjective recovery (Wood and Alsawy 2017). Studies describing positive change following FEP have also described such change as occurring within the broader recovery process (Jordan, Pope et al. 2017, Jordan, MacDonald et al. 2018). These similarities may imply that recovery and positive change are analogous phenomena.

However, there are also differences between predictors of positive change and recovery, which suggests that recovery and positive change are at least partially discrete experiences. In the present study, recovery was seen as an important facilitator of positive change. The extant literature also describes predictors of positive change that are different from the known predictors of recovery. For instance, systematic reviews and meta-analyses have revealed that positive change is robustly predicted by positive reframing (Prati and Pietrantoni 2009) and the level of distress associated with an adversity (Shakespeare-Finch and Lurie-Beck 2014), whereas these factors have not been linked to recovery to the same extent.

Theoretical work has also described positive change as the result of a meaning-making process (Park 2010, Park 2013) or as a recognition that old possibilities and ways of viewing the world may no longer be tenable (Tedeschi and Calhoun 2006). Some have even claimed that positive change may result from a process of illusory self-deception (Taylor 1983, Taylor and Armor 1996, Taylor, Kemeny et al. 2000, Zoellner and Maercker 2006, Zoellner, Rabe et al. 2008). These cognitive processes have not been seen as similarly linked with recovery.

Together, these findings suggest that recovery may be a broader, salutogenic process, and that positive change may be one form or type of recovery.

Methodological Considerations

The figure (Figure 1) depicting our qualitative findings related to the facilitators of positive change may suggest that participants experienced such change through a linear process. Our diagram was designed this way to enhance the interpretability of the qualitative findings. However, this process was not always linear, as participants moved between different phases. For instance, some described being in recovery at one point, but later felt that they needed additional support from PEPP. Our diagram should therefore be interpreted in light of the nonlinear processes through which positive change generally seemed to unfold.

In the qualitative component of our study, we asked participants what they felt facilitated the “changes” that they had experienced. We avoided using the words “positive changes” during the interviews because we felt that this would be a leading term. Still, it was easy to determine from conducting interviews, analyzing the data, and reviewing relevant literature that participants seemed to describe facilitators of positive changes in their lives.

Some participants who were included in this study lived with ongoing psychotic experiences, such as hearing voices. All participants were deemed clinically stable and well enough to partake in the study by participants' treatment teams. Some may argue that the inclusion of such participants may diminish the validity of our findings. We contend that including such participants may have instead added depth to our findings.

Implications

Until now, few studies have examined positive changes following FEP (Jordan, Pope et al. 2017, Jordan, MacDonald et al. 2018). This is the first empirical investigation of predictors or perceived facilitators of positive change following FEP to employ mixed methods. This study has implications for persons who have experienced FEP; services designed to support them, including early intervention services; and a broad range of clinicians working with them. Our work can support efforts to experience positive change among persons who would like to grow following their experience of psychosis. Specifically, our findings suggest that such persons who desire to grow following a first episode of psychosis may benefit from attempting to adopt a positive mindset about the aftermath of their experiences; or from drawing on narratives describing ways that persons grow following adversity. Our findings also suggest that services can facilitate positive change by adopting a recovery orientation to care; and helping service users understand, adapt and grow from their experiences in a way that is in line with service users' wishes to grow. Service providers can help facilitate positive change by helping service users to find meaning in and positively reframe their experiences; by informing them of cultural and/or research perspectives on growth following adversity; by helping service users reconnect with and strengthen their relationships with their loved ones; and by helping service users foster a positive spiritual or religious side, if they so desire.

Finally, although being hospitalized for FEP was a robust facilitator of positive change, our findings should not be construed as romanticizing the hospitalization experience. Although it can be a significant turning point, being hospitalized is often a traumatic experience (Paksarian, Mojtabai et al. 2014) and efforts must always be taken to minimize the need for hospitalization.

Moreover, our study highlights that other routes to positive change are possible. Progressing through normative developmental processes that are not traumatic is one such route that was identified in our study. Also, persons can grow and develop by learning about areas that interest them. While highlighting the possibility of positive change following an FEP and the factors that facilitate it (including the experience of psychosis itself and its accompaniments such as hospitalization), our results also point to the value of fostering people's normative potential for growth.

Strengths and Limitations

We conducted this study with a high level of methodological rigour while respecting and giving equal weight to the philosophical paradigms guiding the study. Our findings were able to capitalize on the strengths of both quantitative and qualitative methods, yielding a more complete understanding of the topic than would have been possible if we had used only one method. The study findings build on prior knowledge, and were congruent with established theories of positive change following adversity. Participants were a well-characterized sample of service users with FEP recruited from a single catchment area.

Limitations of this study include its cross-sectional nature. Due to the study design, it was impossible to establish if the independent variables had a causal relationship to positive change.

Another limitation was that there was conceptual overlap, and some degree of measurement overlap between the independent variables used in this study. Our quantitative sample contained a higher proportion of females, and participants with greater baseline negative symptoms, relative to the larger body of service users in our program.

Future Directions

Future studies should aim to determine differences and similarities between positive change and recovery, and to disentangle differences in their predictors. Further, future qualitative studies should explore positive change following FEP using a grounded theory approach that can better describe the relationships between potential facilitators and aspects of positive change. Future quantitative studies should explore predictors of positive change longitudinally, over several different time points, to help establish causal relationships between predictor variables and positive change.

Tables & Figures

Table 1: Baseline demographic and clinical characteristics of study sample relative to those who were eligible but did not participate

Variable	Participants who were interviewed (n = 12)	All participants who took part in the study (n = 94)[b]	Eligible but did not participate (n = 110)[c]	χ^2/F B vs C
Age at assessment	24.27 (2.76)	25.52	N/A	N/A
Age of psychosis onset	22.17 (6.14)	23.27 (5.45)	24.62 (5.15)	2.85
Gender (female)	4 (36.4%)	40 (43.5%)	25 (25.3%)	8.45*
Education (at least high school)	11 (91.7%)	64 (76.2%)	67 (72.8%)	.26
Relationship status (in a relationship)	3 (25%)	9 (10.1%)	9 (9.4%)	.029
Visible Minority (yes)	7 (58.3%)	37 (45.7)	43 (45.7%)	0
Born outside Quebec (yes)	6 (50%)	31 (35.2%)	36 (38.3%)	.18
Socioeconomic Status (middle to upper class)	10 (90.9%)	26 (38.8%)	27 (39.7%)	.01
Income derived from paid employment (yes)	5 (41.7%)	19 (24.1%)	25 (29.1%)	.530
Living with friends, family or independently	12 (100%)	81 (96.4%)	93 (98.9%)	1.3
Schizophrenia-spectrum diagnosis (yes)	7 (58.3%)	55 (63.2%)	61 (67.0%)	.28
Baseline substance abuse (yes)	4 (33.3%)	27 (34.6%)	39 (46.4%)	2.33
Age of onset of psychosis	22.17 (6.14)	23.26 (5.45)	24.62 (5.15)	2.85
Baseline positive symptoms	14.00 (2.75)	11.84 (3.26)	11.32 (3.02)	1.21
Baseline negative symptoms	9.45 (3.55)	10.39 (3.60)	9.26 (3.89)	4.06

* = $P \leq .05$

Table 2: Descriptive statistics for predictor variables and their correlations with total scores of the PTGI

Items	M/SD; n/%	Min – Max Possible Score	Min – Max Participants' Responses	Skewness	Correlation with Total Posttraumatic Growth
Original Predictors					
Negative impact of psychosis	41.42 (30.18)	0 - 116	0 - 116	.64	.03
Spiritual coping	2.25 (2.04)	0 – 6	0 - 6	.45	.52**
Positive reframing	3.24 (1.80)	0 - 6	0 - 6	-.04	.51**
Perceived Social support	5.45 (1.32)	1 - 7	1 - 7	-.62	.45**
Resilience	19.38 (3.62)	0 - 24	10 - 24	-.59	.42**
Recovery	164.98 (23.60)	1 - 205	97 - 205	-.33	.51**
Additional Predictors					
Age	25.35 (4.89)	-	18 - 37	.64	0.13
Gender (female)	38 (41.3%)	-	-	-	0.10
Time since diagnosis (months)	20.1 (13.59)	-	6 - 75	1.87	-.03
Hallucinations	.45 (1.09)	0 – 5	0 - 5	2.85	-.08
Delusions	.57 (.90)	0 – 5	0 - 3	1.39	-.10
Bizarre behavior	.57 (.10)	0 – 5	0 - 4	1.72	.04
Positive formal thought disorder	.18 (.49)	0 - 5	0 - 2	2.80	-.02
Affective flattening	1.07 (1.22)	0 – 5	0 - 5	1.00	-.10
Alogia	.65 (.92)	0 – 5	0 - 4	1.53	.17
Avolition – apathy	1.86 (1.39)	0 – 5	0 - 5	-.02	.002
Anhedonia - asociality	1.67 (1.36)	0 - 5	0 - 5	.33	-.09
Anxiety	2.97 (4.16)	0 - 56	0 – 19	2.37	-.06
Depression	1.7 (3.17)	0 - 27	0 - 14	2.47	-.17
Mania/hostility	7.16 (1.80)	0 - 42	6 – 13	1.67	-.08
Insight	6.00 (2.66)	0 - 15	3 - 15	1.74	.009
Hospitalization for psychosis (yes)	55 (58.5%)	-	-		.23*

Note. *= P ≤ .05; ** = P ≤ .001; PTGI = Posttraumatic Growth Inventory

Table 3: Correlations among main independent variables

	1	**2**	**3**	**4**	**5**	**6**	**7**
1. Hospitalization	-	-.37**	-.01	-.16	.13	.06	.15
2. Negative impact of FEP	-.37**	-	.03	.07	-.14	-.08	-.14
3. Positive Reframing	-.01	.03	-	.32**	.35**	.37**	.27**
4. Spiritual Coping	-.16	.07	.32**	-	.22*	.23*	.20
5. Social Support	.13	-.14	.35**	.22*	-	.47**	.52**
6. Recovery	.06	-.08	.37**	.23*	.47**	-	.51**
7. Resilience	.15	-.14	.27**	.20	.52**	.51**	-

Note. * = P $\leq$ .05; ** = P $\leq$ .001

Table 4: Results of main quantitative analysis examining predictors of positive change

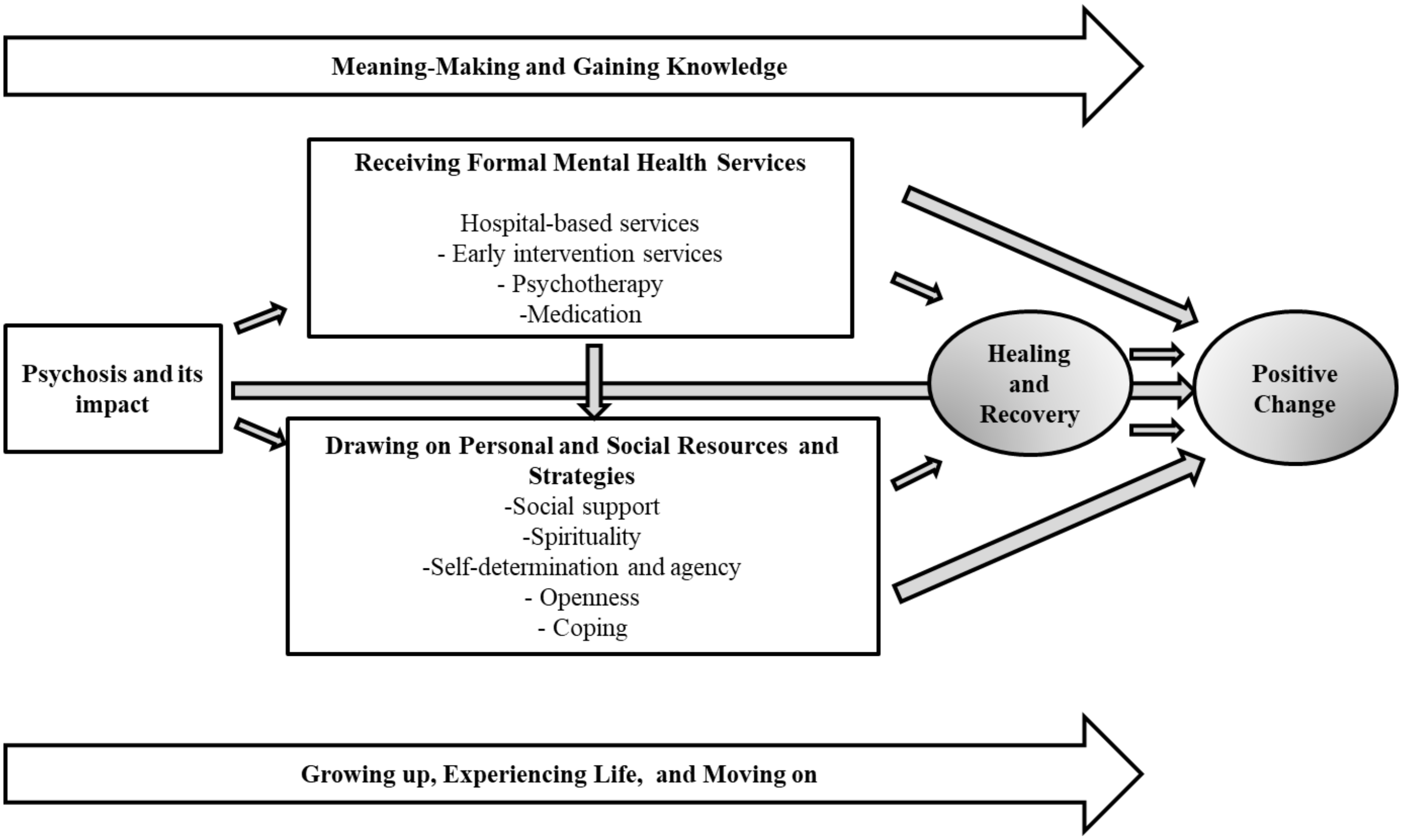
Variable	β	SE β	Standard β	P	-95%CI	+95%CI
Planned analysis						
Block 1						
Hospitalization for FEP	13.52	5.73	.25	.021	2.12	24.93
R² change = .06						
Block 2						
Hospitalized for FEP	16.15	4.73	.29	.001	6.73	25.57
Negative impact of FEP	.14	.08	.15	.08	-.02	.29
Resilience	.74	.72	.10	.30	-.69	2.17
Social support	1.88	1.99	.09	.35	-2.09	5.86
Spiritual coping	3.78	1.11	.29	.001	1.56	6.00
Positive reframing	3.46	1.31	.23	.01	.854	6.06
Recovery	.29	.11	.26	.009	.07	.50
R² change = .45						
Post-hoc analysis using the coping domains derived from the factor analysis						
Block 1						
Hospitalization for FEP	13.52	5.73	.25	.021	2.12	24.93
R² change = .06						
Block 2						
Hospitalized for FEP	14.95	4.75	.28	.002	5.48	24.12
Negative impact of FEP	.13	.07	.15	.08	-.02	.28
Resilience	.86	.71	.12	.23	-.55	2.27
Social support	1.13	2.00	.05	.57	-2.87	5.13
Being proactive	.65	.74	.09	.38	-.82	2.12
Spiritual coping	3.29	1.13	.25	.005	1.04	5.53
Being positive/accepting	1.73	.70	.25	.015	.34	3.13
Recovery	.25	.11	.22	.03	.02	.47
R² change = .49						
Post-hoc analysis controlling for type of resilience measure						
Block 1						
Hospitalization for FEP	13.39	5.81	.25	.024	1.82	24.95
Resilience measure version	1.06	5.81	.02	.86	-10.51	12.62
R² change = .06						
Block 2						
Hospitalized for FEP	16.15	4.79	.30	.001	6.62	25.69
Resilience measure version	-.03	4.62	.0	1.00	-9.22	9.17
Negative impact of FEP	.14	.08	.15	.08	-.02	.29
Resilience	.74	.76	.10	.33	-.76	2.25
Social support	1.88	2.01	.09	.35	-2.12	5.89
Spiritual coping	3.78	1.13	.29	.001	1.53	6.03
Positive reframing	3.46	1.33	.23	.01	.81	6.12
Recovery	.29	.11	.26	.01	.07	.51
R² change = .45						

Table 5: Joint display table depicting themes related to positive change and the degree to which corresponding variables predicted positive change

Themes describing facilitators of positive change ordered by importance	**Closely matching quantitative variable(s) and their standardized β weights**
FEP and its impact The FEP itself; the negative impact FEP had on one's emotions, assumptions, as well as social and life domains.	Negative experience of psychosis (β = .15, P = .08)
Drawing on formal mental health services Being hospitalized for FEP; the care received at PEPP; psychotherapy; medication.	Hospitalization for FEP (β = .29, P = .001)
Making meaning and gaining knowledge Finding meaning in experiences; experiencing insights and realizations; drawing on cultural frameworks describing growth from adversity; seeking knowledge to strengthen domains of growth.	Positive Reframing (β = .23, P = .01)
Drawing on personal and social resources and strategies Social support; spirituality; agency; openness about emotions, thoughts, experiences and challenges; coping with FEP and its aftermath.	Spiritual coping (β = .29, P = .001); Social support (β = .09, P = .35); Resilience (β = .10, P = .30)
Recovery and healing Recovering from FEP.	Personal recovery (β = .26, P = .009)
Growing up, experiencing life, and moving on Life experiences; growing up; maturing; completing milestones in life.	None

Note. FEP = first episode psychosis; PEPP = Prevention and Early Intervention Program for Psychosis

Figure 1: Qualitative results showing facilitators of positive change



Supplementary Table 1: Factor loadings of the Brief COPE scale

Item	1	2	3	4	5	6	7
1. I've been turning to work or other activities to take my mind off things.		.61					
2. I've been concentrating my efforts on doing something about the situation I'm in.		.74					
3. I've been saying to myself "this isn't real."					.76		
4. I've been using alcohol or other drugs to make myself feel better.							.89
5. I've been getting emotional support from others.	.78						
6. I've been giving up trying to deal with it.				.73			
7. I've been taking action to try to make the situation better.		.67					
8. I've been refusing to believe that it has happened.					.46		
9. I've been saying things to let my unpleasant feelings escape.					.63		
10. I've been getting help and advice from other people.	.79						
11. I've been using alcohol or other drugs to help me get through it.							.90
12. I've been trying to see it in a different light, to make it seem more positive.			.54				
13. I've been criticizing myself.				.75			
14. I've been trying to come up with a strategy about what to do.		.68					
15. I've been getting comfort and understanding from someone.	.77						
16. I've been giving up the attempt to cope.				.74			
17. I've been looking for something good in what is happening.			.57				
18. I've been making jokes about it.			.54				
20. I've been accepting the reality of the fact that it has happened.			.82				
21. I've been expressing my negative feelings.	.53						
22. I've been trying to find comfort in my religion or spiritual beliefs.						.86	
23. I've been trying to get advice or help from other people about what to do.	.75						
24. I've been learning to live with it.			.67				
25. I've been thinking hard about what steps to take.		.66					
26. I've been blaming myself for things that happened.				.74			
27. I've been praying or meditating.						.88	
28. I've been making fun of the situation.					.48		

Note. 1 = Emotional and instrumental social support; 2 = Being proactive/productive; 3 = Being positive/accepting; 4 = Giving up and self-blame; 5 = Denial and negative self-expression; 6 = Spirituality; 7 = Substance use

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Chapter Nine: Overall Conclusion

This dissertation sought to answer two research questions: 1) what are the positive changes that follow a first episode of psychosis? and 2) what factors and processes predict or are perceived to facilitate such changes? These research questions were addressed in scoping (Chapter Two) and mixed studies systematic reviews (Chapter Three) as well as in two empirical mixed methods studies (Chapters Seven and Eight). Findings addressing our research questions were remarkably similar across these studies, and revealed that following a first episode of psychosis, persons often experienced positive change. Specifically, participants across these studies described experiencing positive changes at the individual level (e.g., developing a stronger sense of self, improved mental health, etc.), the interpersonal level (e.g., improving relationships with others) and the spiritual/religious level (e.g., experiencing greater spirituality). They also reported improved lives and new goals for the future. I also found that such changes were facilitated by factors and processes at the personal level (e.g., coping, experiencing personal recovery, engaging in spirituality, etc.), the relational or social level (e.g., through receiving social support, etc.) and the contextual level (e.g., through receiving mental health services, having cultural frameworks to draw on, etc.). Of these facilitators, receiving mental health services was perhaps the most salient. Notably, positive changes were also facilitated by processes unrelated to FEP (e.g., normative developmental experiences).

Our finding that improved mental health was seen as an aspect of positive change, and that mental health services were identified as important facilitators of positive change, reflects both the profile of the sample (i.e., persons affected by FEP) and the context of our study (i.e., an early intervention service for FEP). Hence, while there are aspects and facilitators of positive change that are common across types of adversity, there are also important differences.

Aspects of positive change described in this dissertation were mostly consistent with the domains of posttraumatic growth identified by Tedeschi and Calhoun in their model of Posttraumatic Growth (1995, 2004, 2006). Our study extends this model by revealing how positive changes can represent new shifts forward; attempts to reconnect with forgotten aspects of oneself; and efforts to solve one's current problems. Novel to this study was also our finding of improved mental health as a dimension of positive change. Similarly, the predictors and facilitators of positive change described in our studies have been depicted as important in the model of Posttraumatic Growth. For instance, our findings are consistent with Tedeschi and Calhoun's (2006) framework wherein growth follows an intense, emotional struggle with an adverse experience, and facilitators of growth include coping strategies and social support. Our findings support Tedeschi and Calhoun's (2006) idea that identifying the meaning of an adverse experience can facilitate positive change, and that certain cultural frameworks can inspire people to grow following adversity. While Tedeschi and Calhoun (2006) acknowledged the importance, but not primacy, of psychotherapy in facilitating growth, our findings suggest that, in the context of FEP, mental health services and treatments are highly important facilitators of positive change. This finding is noteworthy since most studies on positive change following adversity tend to focus on individual-level facilitators and ignore the systemic contexts (e.g., a growth-oriented treatment program) that can facilitate positive change.

Reflections on the scientific study of positive change

In carrying out this doctoral work, it became evident that the conceptual foundations of the field of positive change bear refinement. There is a multitude of theories or models describing how positive change can follow adversity dating back at least 120 years, with new theoretical frameworks being proposed every few years (Park 2004, Joseph and Linley 2006, Park 2009). The field is therefore both emerging, yet very loosely tied to its conceptual past. Until recently, there was confusion about how terms like posttraumatic growth, stress-related growth and benefit-finding are distinct (Park 2009). Similarly, the measures used to assess positive change have been called into question. For instance, it cannot be conclusively established whether the Posttraumatic Growth Inventory actually measures posttraumatic growth, perceptions of growth, stress-related growth, or the illusion that growth has occurred (Frazier, Tennen et al. 2009). Until these issues are resolved and researchers agree on a single conceptual framework, our understanding of positive change following adversity will be limited. On the other hand, one could argue that adhering to a single conceptual framework would not be desirable, especially from a constructivist perspective that accepts the possibility of multiple “truths” being valid.

Furthermore, theoretical and empirical work describing how concepts such as resilience (Lepore and Revenson 2006) and recovery (Tedeschi and Calhoun 2008) are related to positive change have relied on narrow and sometimes outdated ways of conceptualizing these constructs. This limits their applicability to a study of positive change following severe mental illnesses. For instance, rather than acknowledging how resilience is derived from personal resources and resources external to oneself, research on positive change has narrowly defined resilience as a trait (i.e., an individual’s capacity to bounce back from stress) (Garrido-Hernansaiz, Murphy et al. 2017). Others have described resilience as the absence of mental illness (Levine, Laufer et al. 2009), which is puzzling since persons with mental illnesses have been shown to possess resilience (Morton, Fairhurst et al. 2010). Researchers investigating positive change have also described positive change as a state beyond recovery; yet, most research on subjective recovery from mental illness has highlighted how positive changes can occur during and following the recovery process, and even in the course of illness.

In carrying out this work, it became apparent that the distinction between aspects and facilitators of positive change are difficult to tease apart and may not be distinct phenomena. It is possible that one area of positive change (e.g., improved ways of relating to others) can strengthen other areas of a person's life (e.g., stronger relationships) and in turn further facilitate positive change (e.g., pursuing passions because of encouragement from a close other). In the systematic review presented in this thesis (Chapter 3), we described this process as a "virtuous circle" (Jordan, MacDonald et al. 2018). Part of the difficulty in separating aspects from facilitators of positive change in this dissertation stems from the cross-sectional nature of the study. Longitudinal studies could help distinguish the differences between aspects and facilitators of positive change.

Finally, one could argue that few traits, aspects, beliefs or behaviors are inherently good, bad, positive or negative. Simply because participants described their changes as though they were positive does not mean that such changes are *necessarily* positive under *all* circumstances. Any characteristic or behavior could be evaluated according to how well it fits within the context in which it is expressed. This is a point that only a few researchers have reflected upon. For instance, Hobfoll, Hall et al. (2007) found that persons who reported higher levels of posttraumatic growth following a terrorist incident were more likely to endorse extreme right-wing policies against Palestinians living in the Gaza Strip. Whether this is "good" or "bad" may also reflect one's positionality, political beliefs, values, etc. Hence, while positive changes may be associated with improved health (Taylor, Kemeny et al. 2000), positive changes may have additional consequences that require more attention.

Reflections on positive change and recovery

The scientific study of positive change following the emergence of serious mental illnesses like psychosis is still in its infancy. As such, there remains much work to be done to determine how positive change (and the concepts covered by this umbrella term) and recovery are both similar and different. The work contained in this dissertation may provide a preliminary understanding on the similarities and differences between these concepts.

The traditions of the study of recovery and positive change have varying origins. The recovery model has its roots first in consumer/survivor activism and, later, in longitudinal data that brought to light the possibility of recovery following serious mental illness (Davidson 2016). Clinician-defined recovery has been established to capture recovery rates as objectively as possible (yet these definitions often exclude important elements of personal recovery) (Jaaskelainen, Juola et al. 2013). The field of positive change has a nebulous, complicated history, as outlined in the introductory chapter of this dissertation. Its origins are in religion, existential philosophy and psychology; and the model of posttraumatic growth that was developed primarily through Tedeschi and Calhoun's clinical work with persons who experienced trauma (Tedeschi and Calhoun, 2006).

Furthermore, conceptualizations of subjective recovery have emphasized agency, self-determination, and individual rights to define, own and shape, and decide where they are in the recovery process. In contrast, posttraumatic growth, and indeed many other models of positive change, has been conceptualized differently. Specifically, these models have been developed without explicit input from persons who have experienced adversity, and there is little flexibility within such models as to how persons can define their own positive changes and how such changes came to be. By extension, subjective recovery has been best understood qualitatively, whereas positive change has been mainly investigated quantitatively.

In terms of definitions, subjective recovery refers to an individualized process that encompasses several domains. These domains may include “connectedness, hope and optimism about the future, identity, meaning in life, and empowerment” (Leamy Bird et al., 2011). Others have described common elements of recovery to include “renewing hope and commitment, redefining self, incorporating illness, being involved in meaningful activities, overcoming stigma, assuming control, becoming empowered and exercising citizenship, managing symptoms, and “being supported by others” (Davidson, O’Connell et al., 2005). Scholars have noted that recovery is a personal experience, that many subjective definitions exist, and that perceptions of a person’s own recovery may shift over time (Slade, Amering et al., 2014). Clinician-defined recovery has been conceptualized in the literature as mild to absent symptoms combined with good functioning, and may be a somewhat distinct experience from personal recovery inasmuch as the latter can be experienced while persons with mental illness are symptomatic. Positive change may be experienced as posttraumatic growth, stress-related growth, benefit finding, or the myriad other ways that such change occurs. Posstraumatic growth, which is the dominant model conceptualizing positive change, typically occurs across five domains (i.e., a greater appreciation for life; closer, more intimate relationships with others; increased personal strength; new possibilities and paths in life; and greater spiritual or existential growth). Of these, experiencing greater personal strength may be most similar to areas of recovery commonly experienced; although persons may also recover in ways that encompass additional areas of positive change. Hence, the experience of subjective recovery may be broader than the experience of positive change; albeit, there are also diverse areas within which positive change may be experienced.

That said, there also appears to be some confusion and a lack of consensus on what subjective recovery represents. As described in the previous section, there is a similar lack of consensus on conceptualizations of positive change. Until confusion and disagreements in the fields of recovery and positive change are resolved, any understanding of both similarities and differences between these concepts should be viewed as tentative. On the other hand, one could also question the utility and feasibility of even seeking such distinctions, given the inherent nature of these concepts.

Significance of the findings

The findings of this dissertation may help shift notions of what is possible following FEP, and may help challenge the prevailing medical paradigm by reframing psychosis as an experience that can lead to positive change. By shifting the dominant narrative from one of suffering, decline, and deterioration to one of hope and growth, this project may have a looping effect (Hacking 2000) on the ontology of psychosis and transform the way multiple stakeholders (e.g., clinicians, researchers, persons who have experienced psychosis and their families and friends) think about psychosis.

Our findings may help positively alter the lives of service users and the aspirations of their families and service providers. Our findings validate people’s experiences of positive change following FEP. For service users who have *not* experienced positive change, our findings can provide an opportunity to reflect on the possibility of positive change and how to become equipped for it. Knowing that one’s future may include growth, flourishing, and thriving can provide hope when it is arguably most needed. With the benefit of this knowledge, families, clinicians and other stakeholders could better support service users in their transformative journey towards greater authenticity and connectedness. Our findings can also help clinicians develop and apply strengths-based treatment approaches that would more closely align early intervention services for psychosis with the recovery movement.

Implications

Despite the limitations of the field of positive change following adversity, my doctoral work has important implications. It highlights that in addition to there being a negative aftermath to FEP, persons themselves, their friends and families may also experience positive sequelae. The findings also point to steps that persons with psychosis can take to facilitate growth; and underline the critical role that mental health services can play in this regard. While not the focus of this study, it is important to reflect on how governments and policy-makers can promote enabling contexts that can foster normative developmental positive changes and make positive changes more likely to follow adversity.

Strengths and Limitations

Our scoping and systematic reviews are the first to ever be conducted on the topic of positive changes experienced following an FEP. Furthermore, this dissertation made rigorous, reflexive use of quantitative and qualitative methods to answer the research questions. The use of quantitative methods helped establish the frequency with which service users endorse positive changes following an FEP and the predictors of these changes. Meanwhile, our use of qualitative methods permitted us to explore service users’ experiences of FEP and positive change in greater depth, revealing the contexts and processes that give rise to positive change.

While our studies yielded important and novel findings, the work contained in this thesis have some limitations. The scoping and systematic reviews presented in Chapter two and three would have benefitted from forward citation searches. The use of a sequential mixed-methods design in which our systematic review would have preceded the later empirical quantitative and qualitative studies may have been optimal. Findings from the systematic review could have pointed to areas to probe during qualitative interviews and informed the choice of measures in the study's quantitative component. Nevertheless, the convergence between the findings of our systematic review and our quantitative, and qualitative components suggests that our study effectively captured aspects and facilitators of positive change.

Future Directions

There is growing recognition that early intervention services for psychosis need to incorporate recovery-, resilience-, and strengths-based approaches to foster the empowerment and agency of service users and affirm their potential. Improving awareness among persons with lived experience of FEP, their families, and clinicians of the potential for and capacity to facilitate positive change could better address this need. This is of particular importance given the young age of onset for most persons experiencing psychosis. While positive change should not be seen as an expectation or requirement for recovery, such change can be seen as a desirable possibility that can be attained. Yet, service users, their families, and the clinicians who support them may lack awareness of the transformative potential of FEP and of their capacity to facilitate it. In light of this, a future direction of this study is to share the knowledge contained in this dissertation with persons with lived experience of FEP, their families and clinicians using meaningful, accessible and effective knowledge translation strategies.

While disseminating this knowledge can be helpful, its potential impact may be influenced by various contextual factors that need to be acknowledged. Although the availability of early intervention services for psychosis is increasing, many persons with a psychosis may lack access to these services (Wang, Berglund et al. 2005). In jurisdictions without government support for prescription drugs, the costs of medications used to treat psychosis may place a large financial burden on individuals with FEP, even if they are covered through private insurance (Mental Health Commission of Canada, 2012). Psychotherapy is rarely publicly funded and is costly for many young people (Cohen and Peachey 2014). Stigma and social structures which isolate persons who have psychosis FEP may limit the availability of social support (Gerlinger, Hauser et al. 2013). Persons who consider their greater spirituality post-FEP to be a positive change may face dismissal by service providers (Larsen 2004) Thus, to be mobilized, our study findings require governments, policy makers, and members of society to also address the broader conditions affecting the experience and expression of positive change.

As alluded to earlier, future studies should attempt to unpack both the similarities and differences between recovery and positive change. Systematic and narrative reviews can be conducted to help disentangle these constructs on a conceptual level. A factor analysis of measures of recovery and positive change (e.g., the Posttraumatic Growth Inventory, Stress-Related Growth Inventory, etc.) can further help distinguish these concepts. Empirical quantitative studies comparing predictors of personal and clinical recovery as well as positive change (e.g., posttraumatic growth) should also be conducted.

Several studies have reported how positive changes following other adversities predict both poorer and better outcomes. Some have argued that poor outcomes linked to positive change are associated with illusions that growth has occurred (Zoellner and Maercker 2006, Zoellner, Rabe et al. 2008). Thus, future studies should examine the issue of how positive changes impact broader life domains in psychosis and outcomes later in the illness course, using quantitative and qualitative methods. Another fruitful approach would be to involve service users themselves in focus or narrative groups to co-create knowledge on how positive change was experienced and what facilitated it. At a more fundamental level, we need to explore and understand if and how positive change is related to shifts in identity following a psychosis; namely, from that of a victim to a survivor.

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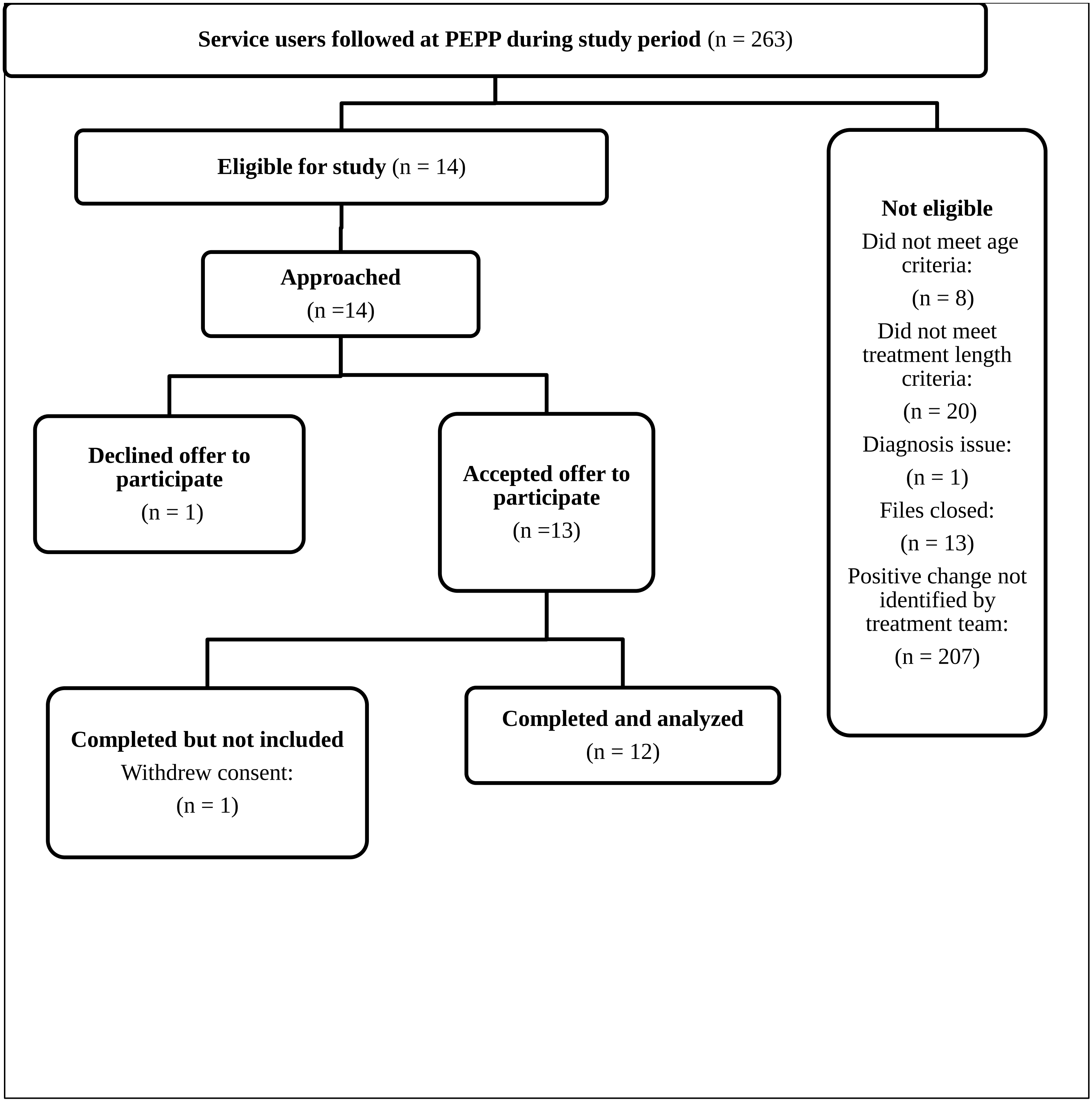
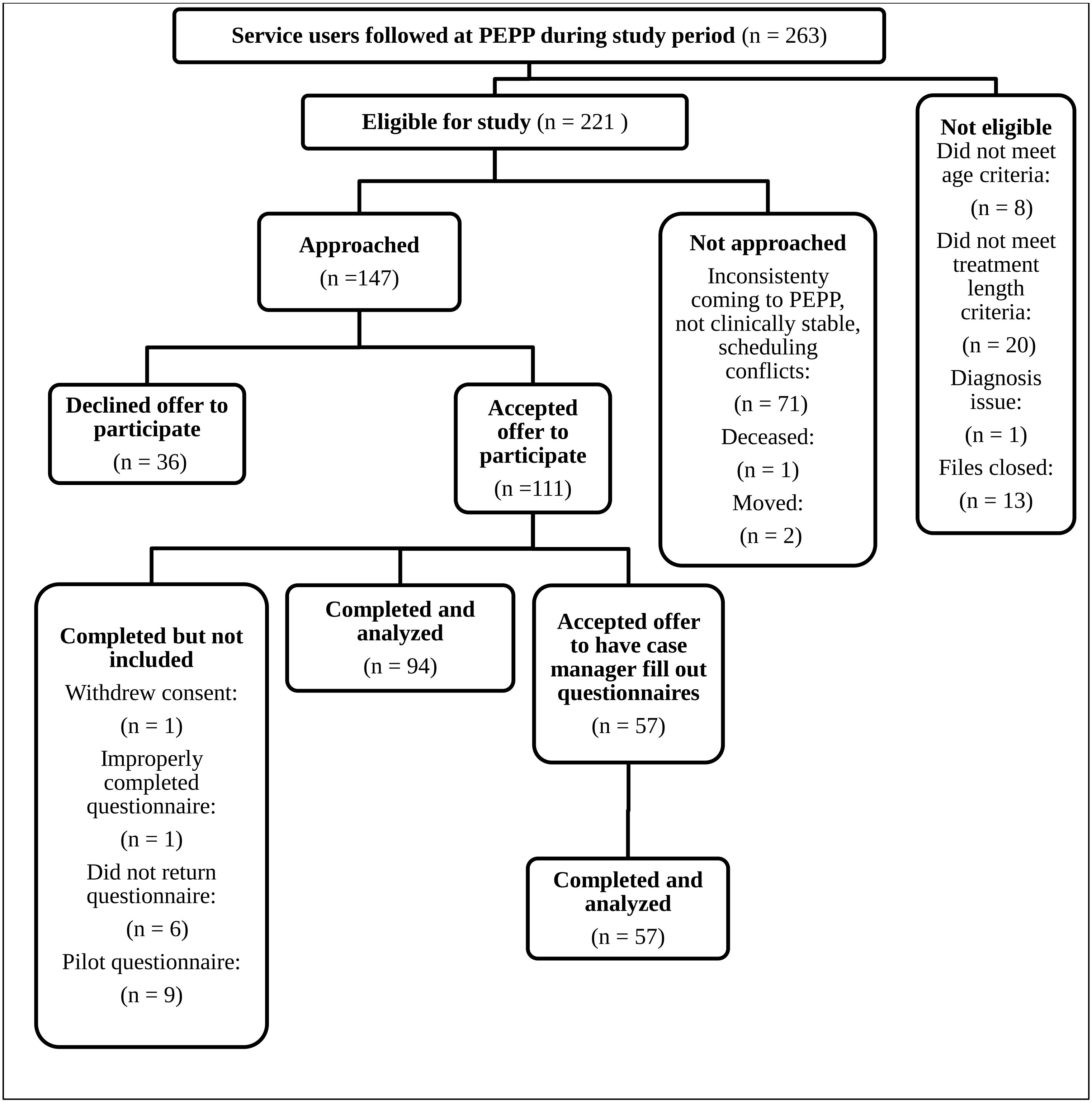
Appendix 2: Participant breakdown of the quantitative component of the study



Appendix 1: Participant breakdown of the quantitative component of the study



Engage in small talk, explain study, explain note-taking, obtain consent.

Hello, the purpose of this interview is to talk about the changes in your life you've experienced as a result of the mental health problem for which you sought help at PEPP.

First, I would like to talk about why you sought services at PEPP.

1. Briefly, could you tell me why you sought help for at PEPP?

Next, I would like to ask you about the changes you have experienced in your life as a result of the reasons you sought help at PEPP.

1. How do you feel like you have changed as a person because of your experience with _________?

2. Overall, do you think you are better off or worse off now, after your experience with _________, compared to how you were before?

3. Has your experience with ________ affected your relationships with other people? (for instance, friends, family members, significant others, coworkers) How?

4. Has has your experience with _________ changed the way you think about your future and new things that might happen in your life? How?

5. Has your experience with __________ changed your daily routine, or things you feel are important in day-to-day life? For instance, your involvement with any activities or hobbies? How?

6. Has has your relationship with religion or spirituality changed because of your experience with________? How?

7. Has your experience with _________ changed your perspective on life? How?

8. How has your experience with ___________ changed other aspects of your life? How?

Next, I would like to talk about what factors may have led to the changes you've experienced.

1. Overall, what do you think has led to the changes you've felt since your experience with ____________?

2. How did you cope with your experience of ___________?

3. Did you have a person or people in your life to support you while you experienced _____________?

4. Where are you in terms of your recovery process?

5. Do you feel you had other resources in your environment or community to help you through your experience with____________? These may include cultural events, opportunities to apply your abilities, knowing where to go when you need help, and having opportunities to improve your qualifications.

End.

1. Is there anything else you would like to add?

CONSENT FORM– PATIENT QUESTIONNAIRE (ENGLISH)

PROJECT TITLE: Positive and negative change in persons receiving services in a first episode psychosis program: A mixed methods study using a convergent design

STUDENT INVESTIGATOR: Gerald Jordan; Student in PhD Program, Department of Psychiatry, McGill University; (514-761-6131 extension 6129); Prevention and Early Intervention Program for Psychosis (PEPP-Montreal); Douglas Mental Health University Institute

SUPERVISORS: Ashok Malla, M.D., FRCPC, Director, Prevention and Early Intervention Program for Psychoses (PEPP-Montréal), Douglas Mental Health University Institute, Professor, Department of Psychiatry, McGill University, Canada Research Chair in Early Psychosis (514-761-6131, extension 2391)

Srividya Iyer, PhD, Program Coordinator, Prevention and Early Intervention Program for Psychoses (PEPP- Montréal), Douglas Mental Health University Institute, Assistant Professor, Department of Psychiatry, McGill University (514-761-6131, extension 3377)

INSTITUTIONS: The Douglas Mental Health University Institute

INTRODUCTION

You have been invited to participate in this study because you are receiving services through at the Douglas Mental Health University Institute. To participate in this study you must also be fluent in either English or French and be between the ages of 18 and 40. The purpose of this study is to better understand how people change (e.g., grow or improve or experience declines) through their experience of psychosis.

RIGHTS AS A PARTICIPANT

Your participation in this research study is voluntary. You can refuse to participate or stop participating at any time without stating a reason. You are encouraged to ask questions before making a decision or at any time during the study. Feel free to discuss study participation with our doctor, or your family members before making a decision.

STUDY PROCEDURES

Your participation in this study will involve completing questionnaires assessing 1) the impact psychosis has had on your life 2) how your life has or has not changed following your experience with psychosis 3) how you usually cope with day-to-day situations and 4) the support you receive from family, friends, and spouses or partners and 5) your experience of recovery following psychosis. If you are between the ages of 18 and 25, you will be asked you about the aspects about you and your environment that influence your life. The questionnaires can be completed at one point in time, and will take about 25 minutes to complete. In addition, the relationship between responses on these questionnaires and other measures that you complete at the Douglas Hospital will be examined, including demographic information (e.g., the age when your psychosis occurred, gender, socioeconomic status, marital status, ethnicity, and amount of time you have been receiving treatment for psychosis) your experience of recovery, symptoms, functioning, and how often you take medication.

As part of this study, someone who you feel knows you very well (like a family member, friend or spouse) may be consulted about how they think you've changed as a result of your experience of psychosis. To do this, they will each complete one questionnaire where they will be asked to rate how they think *you* have changed as a result of your experience.

If you agree, the contact information of a person who you feel knows you very well may be provided at the end of this form.

Please note that you may complete this questionnaire online if this is more convenient for you. To do so, please provide your email address below so an online version of the questionnaire will be forwarded to you

RISKS

We are not aware of any risks associated with participating in this study. There is a small possibility that participating in this study may cause some discomfort, such as stress, anxiety or sadness. To reduce these risks, you can choose to respond to questions you feel most comfortable answering. At any time you can discontinue from completing the questionnaires. In case of any discomfort, we will help you to contact your primary mental health care provider at the Douglas Hospital. Your personal information will be kept strictly confidential.

BENEFITS

You might not receive any direct benefits from participating in this study. However, your participation can help generate new knowledge that may benefit patients in the future.

WITHDRAWL

You have the right to withdraw from the study at any time. Withdrawing from the study will not affect your access to services or care in any way, and will not affect your honorarium. To withdraw from the study, please let the student investigator know your wishes. Upon withdrawing from the study, the student investigator will destroy all information related to you as part of this study, including answers to questions you have answered or that others have answered regarding you, as well as audio recordings with you.

COMPENSATION

As a token of appreciation for your contribution and to make up for the costs associated with transportation or inconvenience, you will receive a $10.00 honorarium at the beginning of the survey.

PRESENTATION OF RESULTS

The results of the study will be presented to participants, their families and to clinicians. The results may also be published in journal articles, presented at national and international conferences, and discussed during knowledge sharing meetings. Results will be presented in scientific journal articles, posters or at conferences. Findings will be presented in such a way that they will never be traced to you.

CONFIDENTIALITY

If you participate in the survey, you will be identified by a code number and your responses to the survey will be completely untraceable to your code number. When results of the study are presented they will be presented in a way that will not be linked to you in any way. No other information that could identify you will be included in the research reports. All identifying information from the study will be kept strictly confidential. Data will be kept in a locked filing cabinet at the Douglas Mental Health University Institute for a period of five years following publication of the results, and digital files will be password protected. Only the student investigator (Gerald Jordan) and his supervisors (Ashok Malla and Srividya Iyer) will have access to your responses. The McGill Institutional Review Board may access the study files to ensure the ethical conduct of the study.

FURTHER QUESTIONS

You can always contact the student investigator (Gerald Jordan, 514 761 6131 extension 6129), his primary supervisor (514-761-6131, extension 2391) or his secondary supervisor (514-761-6131, extension 3377)

If you have any questions concerning your rights as a patient in research, you can contact your affiliate hospital ombudsman or patient representative.

- Douglas Hospital: 514-761-6131, ext. 3287

PROJECT TITLE: Positive and negative change in persons receiving services in a first episode psychosis program: A mixed methods study using a convergent design

CONSENT

I have read this consent form, or had the consent form read to me. I have been informed of the purpose of this study, and I am aware of the study procedures, and the risks and benefits of taking part. I have asked any questions I had, and my questions were answered to my satisfaction. I have been informed that participation in this study is voluntary, and that I can withdraw from this study at any time without giving a reason. I agree to take part in this research study. I will receive a signed and dated copy of this consent form. I do not give up any of my legal rights by signing this consent form. Your signature below indicates that you agree to participate in this study and that you have received a copy of this consent form for your own records.

Name (Print): ____

Signature: ____

Date: ____

Person who obtained consent: ______________________________________

Signature: ____

Date: ____

Your signature below indicates that you agree to provide the student investigator with the name of a person he may contact to take part in this study, so that they will complete a questionnaire assessing how you have changed through psychosis, and that you have received a copy of this consent form for your own records.

Name (Print): ____

Signature: ____

Date: ____

Person who obtained consent: ______________________________________

Signature: ____

Date: ____

Your signature below indicates that you agree to allow the student investigator to ask your case manager to complete a questionnaire assessing how you have changed through psychosis, and that you have received a copy of this consent form for your own records.

Name (Print): ____

Signature: ____

Date: ____

Person who obtained consent: ____

Signature: ____

Date: ____

If you have given consent to contact someone who you feel knows you best (above), please fill out contact information for someone who knows you well below

Contact Name (Print): ____

Contact telephone number: ______________________________

Contact email address: ___________________________________

If you consent to providing me with an email address to which I can email you a link to an online version of the questionnaires, please fill out this section.

Name (Print): ____

Signature: ____

Date: ____

Person who obtained consent: ____

Signature: ____

Date: ____

Email Address: ___________________________________

FORMULAIRE DE CONSENTEMENT –QUESTIONNAIRES DU PATIENT (FRANÇAIS)

TITRE DU PROJET: Changements positifs et négatifs chez les personnes recevant un service dans un programme pour les premiers épisodes psychotiques : Une étude aux méthodes mixtes utilisant un design convergent

CHERCHEUR PRINCIPAL: Gerald Jordan; Étudiant au programme de Ph.D., Département de psychiatrie, Université McGill; (514-761-6131, poste 6129); Programme de prévention et d'intervention précoce pour la psychose (PEPP-Montréal); Institut universitaire en santé mentale Douglas

SUPERVISEUR PRINCIPAL : Ashok Malla, M.D., FRCPC, Directeur, Programme de prévention et d'intervention précoce pour la psychose (PEPP-Montréal), Institut universitaire en santé mentale Douglas, Professeur, Département de psychiatrie, Université McGill, Chaire de recherche du Canada sur l'étude des premier stades de la psychose (514-761-6131, poste 2391)

Srividya Iyer, Ph.D., Coordinatrice de programme, Programme de prévention et d'intervention précoce pour la psychose (PEPP-Montréal); Institut universitaire en santé mentale Douglas, Professeur assistant, Département de psychiatrie, Université McGill (514-761-6131, poste 3377)

INSTITUTIONS : L'Institut universitaire en santé mentale Douglas.

INTRODUCTION

Vous avez été invité à participer à cette étude parce que vous recevez des services à l'Institut universitaire en santé mentale Douglas. Afin de participer à cette étude, vos devez être à l'aise en français ou en anglais et être âgé entre 18 et 40 ans. Le but principal de cette étude est de mieux comprendre comment les personnes changent (i.e. croissent ou s'améliorent ou un déclin de l'expérience) à travers une expérience d'un premier épisode psychotique.

PROCÉDURES DE L'ÉTUDE

Votre participation à cette étude implique de compléter quatre questionnaires évaluant 1) l'impact que la psychose peut avoir dans votre vie, 2) à quel point votre vie à pu changer ou pas suivant votre expérience de la psychose, 3) comment vous faites face aux situations quotidiennes, 4) le support que vous recevez de la part de la famille, amis et conjoints ou partenaire amoureux et 5)le degré avec lequel vous avez récupéré de votre expérience de la psychose. Si vous êtes âgé entre 18 et 25 ans, on vous demandera également des questions à propos des aspects de vous et votre environnement qui influencent votre vie. Les questionnaires peuvent être complétés à un moment donné durant le suivi, et prendront environ 25 minutes à compléter. De plus, je pourrais examiner les liens entre vos réponses sur ces quatre questionnaires et d'autres informations provenant des évaluations que vous auriez pu compléter services à l'Institut universitaire en santé mentale Douglas (et pour lesquels vous avez donné votre consentement séparément), incluant des information démographique (par exemple, l'âge auquel votre psychose est survenue, le genre, le statut socio-économique, le statut marital, l'ethnie et la durée de votre suivi pour le traitement de la psychose), les symptômes, le niveau de fonctionnement et la fréquence de prise de médication.

Dans cette étude, on est aussi intéressé à demander à quelqu'un que vous considérez qui vous connait très bien (membre de la famille, amis, copine/copain ou conjoint), ainsi qu'à votre gestionnaire de cas services à l'Institut universitaire en santé mentale Douglas, à quel point ils pensent que vous avez changé suite à votre expérience de la psychose. Pour ce faire, on leur remettra un questionnaire (qui mesurera la manière dont ils pensent que vous avez changé ou pas à travers la psychose) et on leur demandera d'évaluer comment ils pensent que vous avez changé suite à votre expérience. Si vous acceptez, on aimerait entrer en contact avec une personne que vous considérez qui vous connait très bien. Vous pourrez fournir ces informations dans une section séparée à la fin de ce formulaire de consentement.

Vous n'avez pas à fournir ces informations si vous choisissez de ne pas le faire. Si tel est le cas, vous pouvez toujours participer à l'étude et on collectera uniquement vos réponses. On approchera jamais quelqu'un en pensant qu'il vous connaissant bien sans votre consentement.

S'il vous plait notez que vous pouvez compléter ces questionnaires en ligne si c'est plus facile pour vous. Pour ce faire, on aura besoin de recevoir votre adresse courriel et vous transférer une version en ligne du questionnaire. Si cela vous intéresse, s'il vous plait laissez votre adresse courriel à la fin de ce formulaire de consentement.

RISQUES ET BÉNÉFICES

Nous ne sommes pas conscients d'aucuns risques associés avec votre participation à cette étude. Il y a une faible possibilité que le fait de participer à cette étude vous cause un inconfort. Afin de réduire ces risques, vous pouvez choisir de répondre aux questions auxquelles vous vous sentez le plus à l'aise de répondre. À n'importe quel moment, vous pouvez exiger que des parties de l'entrevue ne soient pas utilisée dans cette étude. En cas de quelconque malaise, nous vous aiderons à contacter votre fournisseur de soins de santé mentale primaires services à l'Institut universitaire en santé mentale Douglas.

Vous pourriez ne recevoir aucun bénéfice direct au fait de participer à cette étude. Toutefois, votre participation peut aider à générer de nouvelles connaissances qui pourraient s'avérer bénéfiques pour les futurs patients.

COMPENSATION

Comme un signe d’appréciation pour votre contribution et pour pallier aux coûts associés aux transports ou aux inconvénients, vous recevrez des honoraires de 10$ au début du sondage.

DROITS EN TANT QUE PARTICIPANT

En tant que participant, vous avez plusieurs droits :

1) Vous avez le droit de poser des questions à tout moment.
2) Avant toute activité en lien avec cette étude, on vous demandera de signer ce formulaire de consentement. Votre participation à cette étude est volontaire, et vous avez le droit de refuser ou de cesser votre participation à cette étude sans pénalité ou perte de bénéfices auxquels vous auriez normalement droit.
3) Vous pouvez retirer votre consentement à n’importe quel moment sans subir de préjudice en tout temps. Vous pouvez aussi poser des questions additionnelles à tout moment pour clarifier votre participation dans cette étude.

PRÉSENTATION DES RÉSULTATS

Les résultats de l’étude seront présentés aux participants, leurs famille et aux cliniciens. Les résultats peuvent aussi être publiés dans des articles de journaux, présentés à des conférences nationales et internationales, et discutés durant la Journée du partage des connaissances services à l’Institut universitaire en santé mentale Douglas. Les résultats seront présentés dans des articles de journaux scientifiques, des poster ou à des conférences. Les trouvailles seront présentées de manière à ce que vous ne soyez jamais retracé.

CONFIDENTIALITÉ

Si vous participez à l’étude, vous serez identifié par un code numérique et toutes vos réponses ne seront pas rétractables à votre code numérique. Quand les résultats de l’étude seront présentés ils seront présentés de manière a ce qu’ils ne soient pas liés à vous d’une quelconque manière. Aucune autre information d’identification ne sera inclue dans les rapports de recherche. Toutes les informations d’identification dans l’étude seront considérées strictement confidentielles. Les données seront conservées dans un classeur verrouillé services à l’Institut universitaire en santé mentale Douglas pendant une période de cinq ans suivant la publication des résultats, et les dossiers digitaux seront protégés à l’aide d’un mot de passe. Seuls le chercheur principal (Gerald Jordan) et ses superviseurs (Ashok Malla et Srividya Iyer) auront accès à vos réponses. Le comité d'éthique de la recherche de McGill pourrait accéder aux dossiers de l’étude afin d’assurer la conduite éthique de l’étude.

QUESTIONS ADDITIONNELLES

Vous pouvez contacter le chercher principal (Gerald Jordan, 514-761-6131, poste 6129) ou ses superviseurs (Ashok Malla, 514-761-6131, poste 2391 et Srividya Iyer, 514-761-6131, poste 3377) si vous avez des questions supplémentaires.

Si vous avez des questions quelconques concernant vos droits en tant patient que participant dans la recherche, vous pouvez contacter l’ombudsman ou le représentant des patients de l’hôpital auquel vous êtes affilié.

- Hôpital Douglas : 514-761-6131, poste 3287

TITRE DU PROJET: Changements positifs et négatifs chez les personnes recevant un service dans un programme pour les premiers épisodes psychotiques : Une étude aux méthodes mixtes utilisant un design convergent

CONSENTEMENT

Les buts et procédures de cette investigation à laquelle on m'a demandé de prendre part m'ont été expliqués par : ______________________________. Je comprends que ma participation dans cette recherche est volontaire, et que mes soins ne seront pas affectés si je choisi de ne pas participer. Avant de signer, s'il vous plait cocher les cases suivantes qui s'appliquent :

- ☐ **J'ai lu et compris ces informations et le formulaire de consentement.**
- ☐ **J'ai eu suffisamment de temps pour prendre les informations fournies en considération.**
- ☐ **J'ai eu l'opportunité de poser des questions et j'ai obtenus des réponses satisfaisantes à mes questions.**
- ☐ **Je comprends que toute l'information collectée par le chercheur sera gardée confidentielle et que les résultats seront uniquement utilisés dans un but clinique et scientifique.**
- ☐ **J'ai lu ce formulaire et je consens de manière libre de participer à cette étude.**
- ☐ **Je ne renonce à aucun de mes droits légaux en signant ce formulaire de consentement.**

Votre signature ci-dessous indique que vous acceptez de participer à cette étude et que vous avez reçu une copie de ce formulaire de consentement pour vos dossiers.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: ____

Signature: ____

Date: ____

Votre signature ci-dessous indique que vous acceptez que le chercheur principal demande à votre gestionnaire de cas de compléter un questionnaire évaluant à quel point vous avez changé durant la psychose et que vous avez reçu une copie de ce formulaire de consentement pour vos dossiers.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: _____________________________________

Signature: ____

Date: ____

Votre signature ci-dessous indique que vous acceptez de fournir au chercheur principal le nom d'une personne qu'il pourra contacter pour prendre part à cette étude afin qu'il complète un questionnaire évaluant à quel point vous avez changé durant la psychose et que vous avez reçu une copie de ce formulaire de consentement pour vos dossiers.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: _____________________________________

Signature: ____

Date: ____

Si vous avez donné votre consentement afin que l’on contacte quelqu’un que vous considérez qui vous connait très bien (voir plus haut), s’il vous plait écrire les coordonnées de cette personne ci-dessous.

Nom de la personne contact: ____

Lien avec vous : ___________________________________ (ex. : mère)

Numéro de téléphone de la personne contact: _____________________________

Adresse courriel de la personne contact: __________________________________

Si vous acceptez de fournir votre adresse courriel afin que l’on vous envoie le lien menant à la version en ligne des questionnaires, s’il vous plait remplir cette section.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: ____

Signature: ____

Date: ____

Adresse courriel: __________________________________

CONSENT FORM– PATIENT INTERVIEWS AND QUESTIONNAIRES (ENGLISH)

PROJECT TITLE: Positive and negative change in persons receiving services in a first episode psychosis program: A mixed methods study using a convergent design

STUDENT INVESTIGATOR: Gerald Jordan; Student in PhD Program, Department of Psychiatry, McGill University; (514-761-6131 extension 6129); Prevention and Early Intervention Program for Psychosis (PEPP-Montreal); Douglas Mental Health University Institute

SUPERVISORS: Ashok Malla, M.D., FRCPC, Director, Prevention and Early Intervention Program for Psychoses (PEPP-Montréal), Douglas Mental Health University Institute, Professor, Department of Psychiatry, McGill University, Canada Research Chair in Early Psychosis (514-761-6131, extension 2391)

Srividya Iyer, PhD, Program Coordinator, Prevention and Early Intervention Program for Psychoses (PEPP- Montréal), Douglas Mental Health University Institute, Assistant Professor, Department of Psychiatry, McGill University (514-761-6131, extension 3377)

INSTITUTIONS: The Douglas Mental Health University Institute

INTRODUCTION

You have been invited to participate in this study because you are receiving services at the Douglas Mental Health University Institute. To participate in this study, you must be fluent in either English or French and be between the ages of 18 and 40. The purpose of this study is to better understand how people change (e.g., grow or improve or experience declines) through their experience of psychosis.

RIGHTS AS A PARTICIPANT

Your participation in this research study is voluntary. You can refuse to participate or stop participating at any time without stating a reason. You are encouraged to ask questions before making a decision or at any time during the study. Feel free to discuss study participation with our doctor, or your family members before making a decision.

STUDY PROCEDURES

Your participation in this study will involve taking part in two audiotaped interviews with the student researcher. The second interview will be scheduled one year after the first interview. You are free to either accept or decline an invitation for the second interview and your decision will not affect your treatment at the Douglas Hospital or disqualify you from receiving an honorarium for the study. Both interviews will last up to one hour.

During the first interview, you will be asked questions about how your experience with psychosis has affected your life; how you have changed, or grown from the experience, and how you have not changed after the experience; and what you think has led you to change or not. During the second interview, you will be asked to draw a timeline, showing how much you think you have changed or not changed through the experience of psychosis once again, and you will be asked what you think has helped you change (or not).

In addition to completing interviews, you will be asked to complete a set of questionnaires.

The questionnaires will determine 1) the impact psychosis may have had on your life 2) how your life may or may not have changed following your experience with psychosis 3) how you usually cope with day-to-day situations 4) support you receive from family, friends, and spouses or partners and 5) the degree to which you have recovered from your experience with psychosis. If you are between the ages of 18 and 25, you will also be asked about the aspects about you and your environment that influence your life.

In addition, the relationship between your responses on these four questionnaires and other information from assessments that you may complete at the Douglas Hospital may be examined, (and for which you have separately consented), including demographic information (e.g., the age when your psychosis occurred, gender, socioeconomic status, marital status, ethnicity, and amount of time you have been receiving treatment for psychosis), symptoms, functioning, and how often you take medication.

The questionnaires can be completed at one point in time, and will take about 25 minutes to complete. You are currently being asked to complete these questionnaires at two time points: today and one year after today.

As part of this study, a person you feel knows you very well, (like a family member, friend, or spouse), as well as a treatment provider at the Douglas Hospital, may be consulted regarding how they think you have changed as a result of your experience of psychosis. To do this, they would each complete one questionnaire which measures how they think *you* have changed as a result of your experience.

If you agree, the contact information of a person who you feel knows you very well will be asked for.

Permission from you to provide your case manager with this questionnaire will also be asked. Please note that you may complete this questionnaire online if this is more convenient for you. To do so, please provide your email address below so an online version of the questionnaire will be forwarded to you.

RISKS

To the best of our knowledge, there are no moderate or major risks associated with participating in this study. There is a small possibility that participating in this study may cause some discomfort, such as stress, anxiety or sadness. To reduce these risks, you can choose to speak only about topics you feel comfortable talking about. At any time you can request that parts of the interview not be used in the study. In case of any discomfort, we will help you to contact your primary mental health care provider at PEPP.

BENEFITS

You might not receive any direct benefits from participating in this study. However, your participation can help generate new knowledge that may benefit persons with psychosis in the future.

WITHDRAWL

You have the right to withdraw from the study at any time. Withdrawing from the study will not affect your access to services or care in any way, and will not affect your honorarium. To withdraw from the study, please let the student investigator know your wishes. Upon withdrawing from the study, the student investigator will destroy all information related to you as part of this study, including answers to questions you have answered or that others have answered regarding you, as well as audio recordings with you.

COMPENSATION

As a token of appreciation for your contribution and to make up for the costs or inconvenience associated with transportation, you will receive a $30.00 honorarium at the beginning of the first interview and $40.00 at the beginning of the second interview.

PRESENTATION OF RESULTS

The results of the study will be presented to participants, their families and to clinicians. The results may also be published in journal articles, presented at national and international conferences, and discussed during knowledge sharing seminars. Results will be presented in scientific journal articles, posters or at conferences. Findings will be presented in such a way that they will never be traced to you. If quotations from interviews are presented, your name, or any identifying information about you, will be presented with them.

CONFIDENTIALITY

If you participate in an interview, with your permission, we will audio-record the discussion. This audio recording will then be transcribed and will help us to summarize the topics discussed. The audio files will be destroyed once they have been transcribed. Your name will not be transcribed and will not appear in any reports. Instead, you will be identified by a code number in all notes and transcripts related to the survey. No other information that could identify you will be included in the research reports.

If you participate in the survey, you will be identified by a code number in a database and your responses to the survey will be completely untraceable to your code number. When results of the study are presented they will be presented in a way that will not be linked to you in any way. No other information that could identify you will be included in the research reports. All identifying information from the study will be kept strictly confidential.

All identifying information from the study will be kept strictly confidential. Data will be kept in a locked filing cabinet at PEPP Montreal located at the Douglas Mental Health University Institute for a period of five years following publication of the results, and digital files will be password protected. The McGill Institutional Review Board may access the study files to ensure the ethical conduct of the study. The student investigator, (Gerald Jordan), another research staff who will help with analyzing findings and his supervisors (Ashok Malla and Srividya Iyer) will have access to your responses. The McGill Institutional Review Board may access the study files to ensure the ethical conduct of the study.

FURTHER QUESTIONS

You can contact the student investigator (Gerald Jordan, 514 761 6131 extension 6129) or his s supervisors (Ashok Malla, 514-761-6131, extension 2391and Srividya Iyer, 514-761-6131, extension 3377) if you have any further questions.

If you have any questions concerning your rights as a patient in research, you can contact the ombudsman or patient representative in the hospital you receive care in.

- Douglas Hospital: 514-761-6131, ext. 3287

PROJECT TITLE: Positive and negative change in persons receiving services in a first episode psychosis program: A mixed methods study using a convergent design

CONSENT

> I have read this consent form, or had the consent form read to me. I have been informed of the purpose of this study, and I am aware of the study procedures, and the risks and benefits of taking part. I have asked any questions I had, and my questions were answered to my satisfaction. I have been informed that participation in this study is voluntary, and that I can withdraw from this study at any time without giving a reason. I agree to take part in this research study. I will receive a signed and dated copy of this consent form. I do not give up any of my legal rights by signing this consent form.

Your signature below indicates that you agree to participate in this study and that you have received a copy of this consent form for your own records.

Name (Print): ____

Signature: ____

Date: ____

Contact Information: ___________________________________

Person who obtained consent: ______________________________________

Signature: ____

Date: ____

Your signature below indicates that you agree to allow the student investigator to ask your case manager to complete a questionnaire assessing how you may have changed through psychosis, and that you have received a copy of this consent form for your own records.

Name (Print): ____

Signature: ____

Date: ____

Person who obtained consent: ____

Signature: ____

Date: ____

Your signature below indicates that you agree to provide the student investigator the name of a person he may contact to take part in this study, so that they will complete a questionnaire assessing how you may have changed through psychosis, and that you have received a copy of this consent form for your own records.

Name(Print): ____

Signature: ____

Date: ____

Person who obtained consent: ____

Signature: ____

Date: ____

If you have given consent to contact someone who you feel knows you best (above), please fill out contact information for someone who knows you well below

Contact Name (Print): ____

Relationship to you: ___________________________________ (e.g., Mother)

Contact telephone number: _____________________________

Contact email address: __________________________________

If you consent to providing me with an email address to which I can email you a link to an online version of the questionnaires, please fill out this section.

Name (Print): ____

Signature: ____

Date: ____

Person who obtained consent: ____

Signature: ____

Date: ____

Email Address: __________________________________

FORMULAIRE DE CONSENTEMENT – ENTREVUES ET QUESTIONNAIRES DU PATIENT (FRANÇAIS)

TITRE DU PROJET: Changements positifs et négatifs chez les personnes recevant un service dans un programme pour les premiers épisodes psychotiques : Une étude aux méthodes mixtes utilisant un design convergent

CHERCHEUR PRINCIPAL: Gerald Jordan; Étudiant au programme de Ph.D., Département de psychiatrie, Université McGill; (514-761-6131, poste 6129); Programme de prévention et d'intervention précoce pour la psychose (PEPP-Montréal); Institut universitaire en santé mentale Douglas

SUPERVISEUR PRINCIPAL : Ashok Malla, M.D., FRCPC, Directeur, Programme de prévention et d'intervention précoce pour la psychose (PEPP-Montréal), Institut universitaire en santé mentale Douglas, Professeur, Département de psychiatrie, Université McGill, Chaire de recherche du Canada sur l'étude des premier stades de la psychose (514-761-6131, poste 2391)

Srividya Iyer, Ph.D., Coordinatrice de programme, Programme de prévention et d'intervention précoce pour la psychose (PEPP-Montréal); Institut universitaire en santé mentale Douglas, Professeur assistant, Département de psychiatrie, Université McGill (514-761-6131, poste 3377)

INSTITUTIONS : L'Institut universitaire en santé mentale Douglas.

INTRODUCTION

Vous avez été invité à participer à cette étude parce que vous recevez des services à l'Institut universitaire en santé mentale Douglas. Afin de participer à cette étude, vos devez être à l'aise en français ou en anglais et être âgé entre 18 et 40 ans. Le but principal de cette étude est de mieux comprendre comment les personnes changent (i.e. croissent ou s'améliorent ou un déclin de l'expérience) à travers une expérience d'un premier épisode psychotique.

PROCÉDURES DE L'ÉTUDE

Votre participation dans cette étude implique que vous ayez deux entrevues avec le chercheur principal, à un an d'écart l'une de l'autre. Les deux entrevues dureront jusqu'à une heure et seront enregistrées. De plus, on vous demandera de compléter une série de questionnaires après chaque entrevue.

Durant la première entrevue, on vous questionnera sur la manière dont votre expérience de la psychose a affectée votre vie; à quel point vous avez changé, grandi à partir de cette expérience, à quel point vous n'avez pas changé et ce que vous pensez qui vous a mené à ce changement ou à cette absence de changement.

Durant la deuxième entrevue, on vous demandera de dessiner une ligne du temps, démontrant à quel point vous pensez avoir changé ou pas, à travers l'expérience de la psychose et on vous demandera ce que vous pensez qui a aidé ce changement (ou pas).

Si vous participez à la première entrevue, vous n'avez pas à participer à la seconde entrevue. Vous serez invité à venir participer à la seconde entrevue un an après la première entrevue, et vous serez libre d'accepter ou décliner l'invitation. Le fait de décliner l'invitation n'aura aucune influence sur votre traitement à l'Institut universitaire en santé mentale Douglas ou ne vous disqualifiera pas pour recevoir les honoraires de cette étude.

Répondre au questionnaires implique de répondre aux questions reliées à 1) l'impact que la psychose peut avoir dans votre vie, 2) à quel point votre vie à pu changer ou pas suivant votre expérience de la psychose, 3) comment vous faites face aux situations quotidiennes, 4) le support que vous recevez de la part de la famille, amis et conjoints ou partenaire amoureux et 5) le degré avec lequel vous avez récupéré de votre expérience de la psychose. Si vous êtes âgé entre 18 et 25 ans, on vous demandera également des questions à propos des aspects de vous et votre environnement qui influencent votre vie. Les questionnaires peuvent être complétés à un moment donné durant le suivi, et prendront environ 25 minutes à compléter. On vous demandera de compléter ces questionnaires à deux moments soient, aujourd'hui et dans un an.

De plus, je pourrais examiner les liens entre vos réponses sur ces quatre questionnaires et d'autres informations provenant des évaluations que vous auriez pu compléter à l'Institut universitaire en santé mentale Douglas (et pour lesquels vous avez donné votre consentement séparément), incluant des information démographique (par exemple, l'âge auquel votre psychose est survenue, le genre, le statut socio-économique, le statut marital, l'ethnie et la durée de votre suivi pour le traitement de la psychose), les symptômes, le niveau de fonctionnement et la fréquence de prise de médication.

Dans cette étude, on est aussi intéressé à demander à quelqu'un que vous considérez qui vous connait très bien (membre de la famille, amis, copine/copain ou conjoint), ainsi qu'à votre gestionnaire de cas à l'Institut universitaire en santé mentale Douglas, à quel point ils pensent que vous avez changé suite à votre expérience de la psychose. Pour ce faire, on leur remettra un questionnaire (qui mesurera la manière dont ils pensent que vous avez changé ou pas à travers la psychose) et on leur demandera d'évaluer comment ils pensent que vous avez changé suite à votre expérience.

Si vous acceptez, on aimerait entrer en contact avec une personne que vous considérez qui vous connait très bien. Vous pourrez fournir ces informations dans une section séparée à la fin de ce formulaire de consentement.

On aimerait également avoir votre permission pour fournir un questionnaire à voter gestionnaire de cas.
S'il vous plait notez que vous pouvez compléter ces questionnaires en ligne si c'est plus facile pour vous. Pour ce faire, on aura besoin de recevoir votre adresse courriel et vous transférer une version en ligne du questionnaire. Si cela vous intéresse, s'il vous plait laissez votre adresse courriel à la fin de ce formulaire de consentement.

RISQUES ET BÉNÉFICES

Nous ne sommes pas conscients d'aucuns risques associés avec votre participation à cette étude. Il y a une faible possibilité que le fait de participer à cette étude vous cause un inconfort. Afin de réduire ces risques, vous pouvez choisir de répondre aux questions auxquelles vous vous sentez le plus à l'aise de répondre. À n'importe quel moment, vous pouvez exiger que des parties de l'entrevue ne soient pas utilisée dans cette étude. En cas de quelconque malaise, nous vous aiderons à contacter votre fournisseur de soins de santé mentale primaires à l'Institut universitaire en santé mentale Douglas.

Vous pourriez ne recevoir aucun bénéfice direct au fait de participer à cette étude. Toutefois, votre participation peut aider à générer de nouvelles connaissances qui pourraient s'avérer bénéfiques pour les futurs patients.

COMPENSATION

Comme un signe d'appréciation pour votre contribution et pour pallier aux coûts associés aux transports ou aux inconvénients, vous recevrez des honoraires de 30$ au début de la première entrevue et 40$ au début de la seconde entrevue.

DROITS EN TANT QUE PARTICIPANT

En tant que participant, vous avez plusieurs droits :

1) Vous avez le droit de poser des questions à tout moment.
2) Avant toute activité en lien avec cette étude, on vous demandera de signer ce formulaire de consentement. Votre participation à cette étude est volontaire, et vous avez le droit de refuser ou de cesser votre participation à cette étude sans pénalité ou perte de bénéfices auxquels vous auriez normalement droit.
3) Vous pouvez retirer votre consentement à n'importe quel moment sans subir de préjudice en tout temps. Vous pouvez aussi poser des questions additionnelles à tout moment pour clarifier votre participation dans cette étude.

CONFIDENTIALITÉ

Si vous participez à une entrevue, avec votre permission, nous ferons un enregistrement audio de la discussion. Cet enregistrement audio sera transcrit et nous aidera à résumer les sujets discutés. Les dossiers audio seront détruits une fois qu'ils seront retranscrits. Votre nom ne sera pas retranscrit et n'apparaîtra dans aucun rapport. Vous serez identifié par un code numérique dans toutes les notes et retranscriptions liées à ce sondage. Aucune autre information pouvant vous identifier ne sera inclus dans les rapports de recherche.

Si vous participez au sondage, vous serez identifié par un code numérique dans une base de données et les réponses au sondage seront complètement introuvables à votre code numérique. Quand les résultats de l'étude seront présentés, ils seront présentés comme des moyennes de groupe et non en tant que scores individuels. Aucune autre information pouvant servir à vous identifier ne sera inclue dans les rapports de recherche. Toutes les informations d'identification dans l'étude seront considérées strictement confidentielles. Les données seront conservées dans un classeur verrouillé à l'Institut universitaire en santé mentale Douglas pendant une période de cinq ans suivant la publication des résultats, et les dossiers digitaux seront protégés à l'aide d'un mot de passe.

Toutes les informations d'identification de l'étude seront conservées de manière strictement confidentielle. Les données seront conservées dans un classeur verrouillé à l'Institut universitaire en santé mentale Douglas pendant une période de cinq ans suivant la publication des résultats, et les dossiers digitaux seront protégés à l'aide d'un mot de passe. Le Comité d'éthique de la recherche de McGill pourrait accéder aux dossiers de l'étude afin d'assurer la conduite éthique de l'étude. Le chercheur principal (Gerald Jordan), un autre employé en recherche qui aidera à l'analyse des résultats et ses superviseurs (Ashok Malla et Srividya Iyer) auront accès à vos réponses. Le Comité d'éthique de la recherche de McGill pourrait accéder aux dossiers de l'étude afin d'assurer la conduite éthique de l'étude.

PRÉSENTATION DES RÉSULTATS

Les résultats de l'étude seront présentés aux participants, leurs famille et aux cliniciens. Les résultats peuvent aussi être publiés dans des articles de journaux, présentés à des conférences nationales et internationales, et discutés durant la Journée du partage des connaissances à l'Institut universitaire en santé mentale Douglas. Les résultats seront présentés dans des articles de journaux scientifiques, des poster ou à des conférences. Les trouvailles seront présentées de manière à ce que vous ne soyez jamais retracé. Si des citations des entrevues dont présentes, votre nom, ou toute autre information d'identification à votre sujet ne seront pas présentés avec elles.

QUESTIONS ADDITIONNELLES

Vous pouvez contacter le chercher principal (Gerald Jordan, 514-761-6131, poste 6129) ou ses superviseurs (Ashok Malla, 514-761-6131, poste 2391 et Srividya Iyer, 514-761-6131, poste 3377) si vous avez des questions supplémentaires.

Si vous avez des questions quelconques concernant vos droits en tant patient que participant dans la recherche, vous pouvez contacter l'ombudsman ou le représentant des patients de l'hôpital auquel vous êtes affilié.

- Hôpital Douglas : 514-761-6131, poste 3287

TITRE DU PROJET: Changements positifs et négatifs chez les personnes recevant un service dans un programme pour les premiers épisodes psychotiques : Une étude aux méthodes mixtes utilisant un design convergent

CONSENTEMENT

Les buts et procédures de cette investigation à laquelle on m'a demandé de prendre part m'ont été expliqués par : ______________________________. Je comprends que ma participation dans cette recherche est volontaire, et que mes soins ne seront pas affectés si je choisi de ne pas participer. Avant de signer, s'il vous plait cocher les cases suivantes qui s'appliquent :

- ☐ **J'ai lu et compris ces informations et le formulaire de consentement.**
- ☐ **J'ai eu suffisamment de temps pour prendre les informations fournies en considération.**
- ☐ **J'ai eu l'opportunité de poser des questions et j'ai obtenus des réponses satisfaisantes à mes questions.**
- ☐ **Je comprends que toute l'information collectée par le chercheur sera gardée confidentielle et que les résultats seront uniquement utilisés dans un but clinique et scientifique.**
- ☐ **J'ai lu ce formulaire et je consens de manière libre de participer à cette étude.**
- ☐ **Je ne renonce à aucun de mes droits légaux en signant ce formulaire de consentement.**
- ☐ **Je consens à fournir mes coordonnées au chercher principal afin qu'il puisse me contacter pour une seconde entrevue.**

Votre signature ci-dessous indique que vous acceptez de participer à cette étude et que vous avez reçu une copie de ce formulaire de consentement pour vos dossiers.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: ____

Signature: ____

Date: ____

Votre signature ci-dessous indique que vous acceptez que le chercheur principal demande à votre gestionnaire de cas de compléter un questionnaire évaluant à quel point vous avez changé durant la psychose et que vous avez reçu une copie de ce formulaire de consentement pour vos dossiers.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: ____

Signature: ____

Date: ____

Votre signature ci-dessous indique que vous acceptez de fournir au chercheur principal le nom d'une personne qu'il pourra contacter pour prendre part à cette étude afin qu'il complète un questionnaire évaluant à quel point vous avez changé durant la psychose et que vous avez reçu une copie de ce formulaire de consentement pour vos dossiers.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: ____

Signature: ____

Date: ____

Si vous avez donné votre consentement afin que l’on contacte quelqu’un que vous considérez qui vous connait très bien (voir plus haut), s’il vous plait écrire les coordonnées de cette personne ci-dessous.

Nom de la personne contact: ____

Lien avec vous : ____________________________________ (ex. : mère)

Numéro de téléphone de la personne contact: ______________________________

Adresse courriel de la personne contact: ___________________________________

Si vous acceptez de fournir votre adresse courriel afin que l’on vous envoie le lien menant à la version en ligne des questionnaires, s’il vous plait remplir cette section.

Nom: ____

Signature: ____

Date: ____

Nom du témoin: ____

Signature: ____

Date: ____

Adresse courriel: ___________________________________

Please take a few minutes to provide us with some information about yourself.

1) What is your gender? Male ☐ Female ☐ Other ☐

2) What is your age? ______________________

3) Please indicate your highest level of education received:

☐ Less than high school
☐ High school
☐ College/vocational degree or diploma
☐ Bachelor's degree
☐ Master's degree
☐ Doctoral Degree

4) What is your yearly household income?

☐ Less than $20,000
☐ $20,000 to $39,999
☐ $40,000 to $59,999
☐ $60,000 to $79,999
☐ $80,000 to $99,000
☐ $100,000 or more
☐ Cannot answer

5) What is the primary source of your income?

☐ Employment/salary
☐ Welfare
☐ Allowance from parent/guardian
☐ Disability pension
☐ Other: ____

6) Were you born in:

☐ Canada
☐ Outside Canada

7) Was your mother born in:
☐ Canada
☐ Outside Canada
☐ Don't know

8) Was your father born in:
☐ Canada
☐ Outside Canada
☐ Don't know

9) Which of these categories best describes you? *(Tick more than one if applicable)*

☐ Arab
☐ Black
☐ Chinese
☐ Filipino
☐ Japanese
☐ Korean
☐ Latin American
☐ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
☐ Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, etc.)
☐ West Asian (e.g., Iranian, Afghan, etc.)
☐ White
☐ Other; please specify: ___________________________

10) Are you currently *(tick all that apply)***:**

☐ In school part-time
☐ In school full-time
☐ Working part-time
☐ Working full-time
☐ Working as a volunteer
☐ Caregiving for a child/children and/or a dependent adult
☐ Neither in school nor working nor caregiving

11) What is your current living situation?

☐ Live alone
☐ Live with partner
☐ Live with friend/roommate
☐ Live in residence/group home
☐ Homeless
☐ Live with family (please specify who: ____)

12) Are you:

☐ Single
☐ In a relationship
☐ Legally married (or common-law)
☐ Separated or divorced
☐ Widowed

SVP veuillez prendre quelques minutes pour nous fournir les renseignements personnels suivants.

1) Quelle âge avez-vous? _________________________

2) Quelle est votre sexe? Homme ☐ Femme ☐ Autre ☐

3) SVP indiquez le plus haut niveau d'éducation que vous avez complété:

☐ Moins que l'école secondaire
☐ École secondaire
☐ CEGEP/diplôme technique ou professionnel
☐ Baccalauréat
☐ Maîtrise
☐ Doctorat

4) Quelle est votre revenu annuel de ménage?

☐ Moins de $20,000
☐ $20,000 à $39,999
☐ $40,000 à $59,999
☐ $60,000 à $79,999
☐ $80,000 à $99,000
☐ $100,000 ou plus
☐ Je ne peux pas répondre

5) Quelle est la source principale de votre revenu?

☐ Emploi/salaire
☐ Assistance sociale
☐ Allocation d'un parent/tuteur légal
☐ Pension d'invalidité
☐ Autre: ____

6) Êtes-vous né au:

☐ Canada
☐ À l'extérieur du Canada

7) Votre mère est-elle née au :

☐ Canada
☐ À l'extérieur du Canada
☐ Je ne le sais pas

8) Votre père est-il né au :

☐ Canada
☐ À l'extérieur du Canada
☐ Je ne le sais pas

9) Laquelle de ces catégories vous décrit le mieux?
(Cochez toutes les cases qui s'appliquent)

☐ Arabe
☐ Noir(e)
☐ Chinois(e)
☐ Philippin(e)
☐ Japonais(e)
☐ Coréen(e)
☐ Latino-Américain(e)
☐ Asiatique du Sud (ex., Indien(ne) de l'Est, Pakistanais(e), Sri Lankais(e), etc.)
☐ Asiatique du Sud-Est (ex., Vietnamien(ne), Cambodgien(ne), Malaisien(ne), etc.)
☐ Asiatique de l'Ouest (ex., Iranien(ne), Afghan(e), etc.)
☐ Blanc(he)
☐ Autre; spécifiez s.v.p.: __________________________

10) Actuellement, je ___________ *(cochez toutes les cases qui s'appliquent)***:**

☐ Suis à l'école à temps partiel
☐ Suis à l'école à temps plein
☐ Travaille à temps partiel
☐ Travaille à temps plein
☐ Travaille comme bénévole
☐ Suis responsable d'un enfant/d'enfants et/ou d'un adulte à charge
☐ Ne vais pas à l'école, ne travaille pas, et n'ai pas la charge d'un enfant ou d'un adulte à charge

11) Quelle est votre situation de vie actuelle?

☐ J'habite seul(e)
☐ J'habite avec un(e) conjoint(e)
☐ J'habite avec un ami/colocataire
☐ J'habite dans une résidence/ foyer de groupe
☐ Je suis sans-abri
☐ J'habite avec ma famille (SVP précisez qui : ____)

12) Êtes-vous:

☐ Célibataire
☐ En relation
☐ Marié(e) (ou conjoint de fait)
☐ Séparé(e) ou divorcé(e)
☐ Veuf/Veuve

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your mental health problem, using the following scale.

0= **I did not experience this change** as a result of my mental health problem.
1= I experienced this change to **a very small degree** as a result of my mental health problem.
2= I experienced this change to **a small degree** as a result of my mental health problem.
3= I experienced this change to **a moderate degree** as a result of my mental health problem.
4= I experienced this change to **a great degree** as a result of my mental health problem.
5= I experienced this change to **a very great degree** as a result of my mental health problem.

	0	**1**	**2**	**3**	**4**	**5**
I changed my priorities about what is important in life.						
I have a greater appreciation for the value of my own life.						
I developed new interests.						
I have a greater feeling of self-reliance.						
I have a better understanding of spiritual matters.						
I more clearly see that I can count on people in times of trouble.						
I established a new path for my life.						
I have a greater sense of closeness with others.						
I am more willing to express my emotions.						
I know better that I can handle difficulties.						
I am able to do better things with my life.						
I am better able to accept the way things work out.						
I can better appreciate each day.						
New opportunities are available which wouldn't have been otherwise.						
I have more compassion for others.						
I put more effort into my relationships.						
I am more likely to try to change things which need changing.						
I have a stronger religious faith.						
I discovered that I'm stronger than I thought I was.						
I learned a great deal about how wonderful people are.						
I better accept needing others.						

Indiquez pour chacun des énoncés ci-dessous, dans quelle mesure ce changement est apparu dans votre vie suite à votre expérience de problèmes de santé mentale, en utilisant l'échelle suivante

0= Je **n'ai pas vécu ce changement** suite à ma problème de santé mentale.
1= J'ai vécu ce changement **à un très faible degré** suite à ma problème de santé mentale.
2= J'ai vécu ce changement **à un faible degré** suite à ma problème de santé mentale.
3= J'ai vécu ce changement **à un degré modéré** suite à ma problème de santé mentale.
4= J'ai vécu ce changement **à un degré important** suite à ma problème de santé mentale.
5= J'ai vécu ce changement **à un degré très important** suite à ma problème de santé mentale.

	0	**1**	**2**	**3**	**4**	**5**
J'ai changé mes priorités à propos de ce qui est important dans la vie.						
J'ai une meilleure appréciation de la valeur de ma propre vie.						
J'ai développé de nouveaux intérêts.						
J'ai un meilleur sens de l'autonomie.						
J'ai une meilleure compréhension des sujets spirituels.						
Je vois mieux que je peux compter sur les gens durant les moments difficiles						
J'ai donné une nouvelle direction à ma vie.						
J'e me sens plus proche des autres.						
Je suis plus ouvert(e) à exprimer mes émotions.						
Je sais davantage que je peux faire face aux difficultés.						
Je suis capable de faire quelque chose de mieux de ma vie.						
Je suis davantage capable d'accepter la manière dont les choses fonctionnent.						
Je suis davantage capable d'apprécier chaque jour.						
Des nouvelles opportunités sont disponibles, ce qui n'était pas le cas avant.						
J'ai davantage de compassion pour les autres.						
Je mets plus d'efforts dans mes relations.						
Je suis plus enclin à essayer de changer les choses qui nécessitent de changer.						
J'ai une foi religieuse plus forte.						
J'ai découvert que j'étais plus fort(e) que je le pensais						
J'ai appris à quel point les gens sont merveilleux.						
J'accepte mieux le fait d'avoir besoin des autres.						

Participant No.

Date

The Service User Experiences of Psychosis Scale

Service users and clinicians have developed this scale. It aims to explore people's personal experience of psychosis. Psychosis can include things such as voices that others don't hear, seeing things others don't see, paranoia and unusual beliefs that others don't share. Sometimes these are called psychotic experiences or symptoms. The questions ask about different ways that these can change or affect people's lives. Some of these may apply to you and some may not. Everyone's experiences are different. The scale can be completed alone, with a friend, carer or mental health worker.

Instructions

1. Think about what you call your experiences (e.g. symptoms, psychosis, voices, illness, paranoia etc). You may want to write this in the space below. Please insert this name in the space at the top of each question page.

My experiences are……………………..………………..
………………………………………………………………………………………

2. Spend time looking at each question and rate how your experiences have affected you OVERALL. For each question, consider how your experiences have had a positive and negative effect on you. There is an example on the next page that shows you how to do this.

Participant No.

Date

An example of how to fill out the questionnaire:

Case Study

John has been hearing voices for some time. They vary in how much they bother him. Sometimes he feels glad that that the voices are there as they can be helpful and supportive. This gives him confidence to get out and meet people. At other times they say horrible things about him. This sometimes makes him feel anxious and he avoids his friends. So, for John, the experiences he has sometimes have a positive effect on his ability to socialise as well as a negative effect. This scale is designed to let you rate both the good aspects of your experiences as well as the bad aspects. An example of how John might fill out an item is shown below:

Overall, how have your 'Voices'** affected your…**

		Not at all	A little	Moderately	Quite a lot	Very Much
1. Ability to socialise?	In a **positive** way	☐	☐	☒	☐	☐
	In a **negative** way	☐	☒	☐	☐	☐

As John only has voices, he has used this term to describe his experiences in the sentence above.

He has identified that his voices have had a moderately positive effect on his ability to socialise, and a little negative effect.

Participant No. ☐☐☐☐☐☐☐☐☐

Date ☐☐☐☐☐☐

Section 1 – Overall, how has your __________________ affected your…

		Not at all	A little	Mode rately	Quite a lot	Very Much
1. Ability to socialize?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
2. Ability to trust others?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
3. Relationships with friends and loved ones?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
4. Levels of anxiety and stress?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
5. Levels of energy?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
6. Ability to look after yourself?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
7. Hope for the future?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
8. Personality/character?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
9. Motivation to change any experiences you may have?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
10. Amount and/or quality of sleep?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐

Participant No. ☐☐☐☐☐☐☐☐☐

Date ☐☐☐☐☐☐

Section 1 – Overall, how has your __________________ affected your…

		Not at all	A little	Mode rately	Quite a lot	Very Much
11. Ability to enjoy hobbies and/or activities?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
12. Feelings of isolation?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
13. Concerns about becoming unwell?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
14. Concentration?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
15. Levels of depression?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
16. Feelings of empowerment?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
17. Ability to find work (e.g. paid/voluntary)?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
18. Worries over your financial situation?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
19. Ability to control your own thoughts?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐

Participant No. ☐☐☐☐☐☐

Date ☐☐☐☐☐☐

Section 1 – Overall, how has your _________________ affected your…

		Not at all	A little	Moderately	Quite a lot	Very Much
20. Ability to cope with everyday life?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
21. Memory?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
22. Your feelings of control over any experiences you may have?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
23. Levels of embarrassment?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
24. Feelings about your freedom and personal rights?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
25. Feelings of discrimination or being judged	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
26. Ability to feel emotion?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
27. Feelings of vulnerability?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
28. Sense of personal identity?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐
29. Amount of anger and frustration?	In a **positive** way	☐	☐	☐	☐	☐
	In a **negative** way	☐	☐	☐	☐	☐

No. Participant

Date

ÉCHELLE D’EXPÉRIENCE DE LA PSYCHOSE DE L’UTILISATEUR DE SERVICE

Des utilisateurs de services et des cliniciens ont développé cette échelle. Elle a pour but d’explorer les expériences personnelles de la psychose. La psychose peut inclure le fait d’entendre des voix que les autres ne peuvent pas entendre, de voir des choses que les autres ne voient pas, de la paranoïa et des croyances inhabituelles que les autres ne partagent pas. Parfois, nous appelons cela des expériences ou des symptômes psychotiques. Les questions de ce questionnaire concernent les différentes façons que ces expériences peuvent changer ou affecter la vie des gens. Certaines d’entre elles peuvent s’appliquer à votre situation et d’autres pas. Les expériences de chacun et chacune sont différentes. L’échelle peut être complétée seul(e), avec un(e) ami(e), un(e) soignant(e) ou un(e) professionnel(le) en santé mentale.

Instructions

1. Pensez à ce que vous appelez «vos expériences » (par exemple : symptômes, psychoses, voix, maladie, paranoïa, etc.) Vous pourriez vouloir écrire ceci dans l’espace ci-dessous. S’il vous plaît, utilisez cette appellation dans l’espace situé en haut de chaque page de question

   .

   Mes expériences sont ……………………………………………………………………..

   ……………………………………………………………………………………………..

2. Prenez votre temps avec chaque question et indiquez comment vos expériences vous ont affecté GLOBALEMENT. Pour chaque question, pensez à comment vos expériences ont eu des impacts positifs et négatifs sur vous. Vous trouverez un exemple à la page suivante.

No. Participant

	[redacted]		[redacted]		[redacted]			

Date

Un exemple de la façon de remplir le questionnaire :

Étude de cas

John entend des voix depuis un certain temps. Elles varient dans la manière dont elles le dérangent. Parfois, il est content que les voix soient présentes parce qu’elles l’aident et le réconfortent. Elles lui donnent la confiance nécessaire dont il a besoin pour sortir et rencontrer des gens. D’autres fois, elles disent des choses horribles à son sujet. Elles lui font parfois ressentir de l’anxiété, ce qui lui fait s’éloigner de ses amis, donc il évite de les rencontrer. Alors, pour John, ses expériences ont parfois un effet positif ou négatif sur ses capacités à socialiser. Cette échelle a été conçue pour vous permettre d’évaluer les bons et les mauvais aspects de vos expériences. Voici comment John répondrait à une question du questionnaire :

Globalement, comment vos « voix » ont affecté votre ...

		Pas du tout	Un peu	Modérément	Plutôt	Beaucoup
1. Capacité à socialiser ?	**Positivement**	☐	☐	☒	☐	☐
	Négativement	☐	☒	☐	☐	☐

Puisque John n’entend que des voix, il a utilisé ce terme pour décrire ses expériences dans la première phrase.

Il a identifié que ses voix avait un effet modérément positif et un faible effet négatif sur sa capacité à socialiser.

No. Participant ☐■☐■☐■☐☐☐

Date ☐☐☐☐☐☐

Section 1 – Globalement, comment vos ______________________ ont affecté votre...

		Pas du tout	Un peu	Modérément	Plutôt	Beaucoup
1. Capacité à socialiser ?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
2. Capacité à faire confiance aux autres?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
3. Relation avec vos amis et vos proches?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
4. Niveau d’anxiété et de stress?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
5. Niveau d’énergie?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
6. Capacité à prendre soin de vous?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
7. Espoir pour le futur?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
8. Personnalité/caractère?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
9. Motivation à changer toute expérience que vous pourriez avoir?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
10. Quantité et/ou qualité du sommeil?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐

No. Participant

Date

Section 1 – Globalement, comment vos ______________________ ont affecté votre...

		Pas du tout	Un peu	Modérément	Plutôt	Beaucoup
11. Capacité à apprécier les loisirs et/ou activités?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
12. Sentiment d'isolement?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
13. Préoccupation à propos de tomber malade?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
14. Concentration?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
15. Niveau de dépression?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
16. Sentiment d'autonomisation?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
17. à trouver du travail (ex. rémunéré/bénévole)?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
18. Inquiétude à propos de votre situation financière?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
19. Capacité à contrôler vos propres pensées?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐

No. Participant

Date

Section 1 – Globalement, comment vos ________________ ont affecté votre...

		Pas du tout	Un peu	Modérément	Plutôt	Beaucoup
20. Capacité à faire face à la vie quotidienne?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
21. Mémoire?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
22. Sentiment de contrôle sur les expériences que vous pourriez avoir?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
23. Niveau d'embarras/gêne?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
24. Sentiment à propos de votre liberté et de vos droits personnels?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
25. Sentiments de discrimination ou d'avoir été jugé?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
26. Capacité à ressentir des émotions?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
27. Sentiment d'être vulnérable?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
28. Sens de l'identité personnelle?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐
29. Niveau de colère et de frustration?	**Positivement**	☐	☐	☐	☐	☐
	Négativement	☐	☐	☐	☐	☐

These items deal with ways you've been coping with the stress in your life since you started experiencing the mental health problem which led you to receive care at PEPP. There are many ways to try to deal with problems. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your mental health problem. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

I haven't been doing this at all
I've been doing this a little bit
I've been doing this a medium amount
I've been doing this a lot

	I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I've been doing this a lot**
1. I've been turning to work or other activities to take my mind off things.				
2. I've been concentrating my efforts on doing something about the situation I'm in.				
3. I've been saying to myself "this isn't real.".				
4. I've been using alcohol or other drugs to make myself feel better.				
5. I've been getting emotional support from others.				
6. I've been giving up trying to deal with it.				
7. I've been taking action to try to make the situation better.				
8. I've been refusing to believe that it has happened.				
9. I've been saying things to let my unpleasant feelings escape.				
10. I've been getting help and advice from other people.				
11. I've been using alcohol or other drugs to help me get through it.				
12. I've been trying to see it in a different light, to make it seem more positive.				
13. I've been criticizing myself.				
14. I've been trying to come up with a strategy about what to do.				

	I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I've been doing this a lot**
15. I've been getting comfort and understanding from someone.				
16. I've been giving up the attempt to cope.				
17. I've been looking for something good in what is happening.				
18. I've been making jokes about it.				
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
20. I've been accepting the reality of the fact that it has happened.				
21. I've been expressing my negative feelings.				
22. I've been trying to find comfort in my religion or spiritual beliefs.				
23. I’ve been trying to get advice or help from other people about what to do.				
24. I've been learning to live with it.				
25. I've been thinking hard about what steps to take.				
26. I’ve been blaming myself for things that happened.				
27. I've been praying or meditating.				
28. I've been making fun of the situation.				

Ces items concernent les façons dont vous gérez le stress dans votre vie depuis que vous éprouvez le problème de santé mentale qui vous a amené à être suivi au PEPP. Évidemment différentes personnes gèrent ces situations de manières différentes, mais je suis intéressé par la façon dont vous avez essayé de régler votre problème de santé mentale. Chaque élément exprime quelque chose à propos d'une façon particulière de gérer. Je veux savoir à quel point vous faites ce que chaque item dit. Comment, et à quelle fréquence. Ne répondez pas selon si ça semble fonctionner ou pas--seulement si vous le faites ou non. Utilisez les choix de réponses. Essayez d'évaluer chaque élément séparément dans votre esprit. Répondez par des choix aussi vrai POUR VOUS que vous pouvez.

Pas du tout
Un petit peu
Modérément
Beaucoup

	Pas du tout	**Un petit peu**	**Modéré ment**	**Beaucoup**
1. Je me tourne vers le travail ou d’autres activités pour me changer les idées.				
2. Je mets beaucoup d’effort pour améliorer ma situation.				
3. Je me dis : ‘cela n’est pas réel’.				
4. Je consomme de l’alcool ou d’autres substances pour me sentir mieux.				
5. Je recherche un soutien émotionnel de la part des autres.				
6. Je renonce à essayer de résoudre la situation.				
7. Je concentre mes efforts pour améliorer la situation.				
8. Je refuse de croire que ça m’est arrivé.				
9. J’évacue mes sentiments déplaisants en en parlant.				
10. Je recherche l’aide et le conseil d’autres personnes.				
11. Je consomme de l’alcool ou d’autres substances pour m’aider à passer à travers la situation.				
12. J’essaie de voir la situation plus positivement.				
13. Je me critique.				
14. J’essaie d’élaborer une stratégie à propos de ce qui pourrait être fait.				
15. Je recherche le soutien et la compréhension de quelqu’un.				
16. J’ai abandonné l’idée d’être capable de gérer la situation				

	Pas du tout	**Un petit peu**	**Modérément**	**Beaucoup**
17. Je recherche les aspects positifs dans ce qu’il m’arrive.				
18. Je prends la situation avec humour.				
19. Je fais quelque chose pour moins y penser (comme aller au cinéma, regarder la TV, lire, rêver tout éveillé, dormir ou magasiner).				
20. J’accepte que ce qui m’est arrivé s’est réellement passé.				
21. J’exprime mes sentiments négatifs.				
22. J’essaie de trouver du réconfort dans ma religion ou dans des croyances spirituelles.				
23. J’essaie d’avoir des conseils ou de l’aide d’autres personnes à propos de ce qu’il faut faire.				
24. J’apprends à vivre avec ma nouvelle situation.				
25. Je pense aux prochaines étapes à suivre.				
26. Je me reproche les choses qui me sont arrivées.				
27. Je prie ou médite.				
28. Je me suis moqué de la situation.				

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you **Very Strongly Disagree**
Circle the “2” if you **Strongly Disagree**
Circle the “3” if you **Mildly Disagree**
Circle the “4” if you are **Neutral**
Circle the “5” if you **Mildly Agree**
Circle the “6” if you **Strongly Agree**
Circle the “7” if you **Very Strongly Agree**

1. There is a special person who is around when I am in need. 1 2 3 4 5 6 7

2. There is a special person with whom I can share my joys and sorrows. 1 2 3 4 5 6 7

3. My family really tries to help me. 1 2 3 4 5 6 7

4. I get the emotional help and support I need from my family. 1 2 3 4 5 6 7

5. I have a special person who is a real source of comfort to me. 1 2 3 4 5 6 7

6. My friends really try to help me. 1 2 3 4 5 6 7

7. I can count on my friends when things go wrong. 1 2 3 4 5 6 7

8. I can talk about my problems with my family. 1 2 3 4 5 6 7

9. I have friends with whom I can share my joys and sorrows. 1 2 3 4 5 6 7

10. There is a special person in my life who cares about my feelings. 1 2 3 4 5 6 7

11. My family is willing to help me make decisions. 1 2 3 4 5 6 7

12. I can talk about my problems with my friends. 1 2 3 4 5 6 7

Instructions: Nous sommes intéressés à savoir comment vous vous sentez par rapport aux énoncés suivants. Veuillez lire attentivement les énoncés suivants et indiquez comment vous vous sentez par rapport à chacun d`eux.

Encerclez le "1" si vous êtes **Très Fortement en Désaccord**.
Encerclez le "2" si vous êtes **Fortement en désaccord**.
Encerclez le "3" si vous êtes **Un peu en désaccord**.
Encerclez le "4" si vous êtes **Neutre**.
Encerclez le "5" si vous êtes **Un peu en accord**.
Encerclez le "6" si vous êtes **Fortement en accord**.
Encerclez le "7" si vous **Très fortement en accord**.

1. Il y a une personne importante autour de moi lorsque j`en ai de besoin.	1	2	3	4	5	6	7
2. Il y a une personne importante avec qui je peux partager mes joies et mes peines.	1	2	3	4	5	6	7
3. Ma famille essaie vraiment de m`aider.	1	2	3	4	5	6	7
4. Je reçois l`aide et le support émotif dont j`ai besoin de ma famille.	1	2	3	4	5	6	7
5. Je connais une personne importante qui est une vraie source de confort pour moi.	1	2	3	4	5	6	7
6. Mes amis essaient vraiment de m`aider.	1	2	3	4	5	6	7
7. Je peux compter sur mes amis lorsque les choses vont mals.	1	2	3	4	5	6	7
8. Je peux parler de mes problèmes avec ma famille.	1	2	3	4	5	6	7
9. J`ai des amis avec qui je peux partager mes joies et mes peines.	1	2	3	4	5	6	7
10. Il y a une personne importante dans ma vie qui se soucie de mes sentiments.	1	2	3	4	5	6	7
11. Ma famille est prête à m`aider pour prendre des décisions	1	2	3	4	5	6	7
12. Je peux parler de mes problèmes à mes amis.	1	2	3	4	5	6	7

INSTRUCTIONS: Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and check the box to the right that best describes the extent to which you agree or disagree with the statement. Check only one box for each statement and do not skip any items.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
1. I have a desire to succeed.	☐	☐	☐	☐	☐
2. I have my own plan for how to stay or become well.	☐	☐	☐	☐	☐
3. I have goals in life that I want to reach.	☐	☐	☐	☐	☐
4. I believe I can meet my current personal goals.	☐	☐	☐	☐	☐
5. I have a purpose in life.	☐	☐	☐	☐	☐
6. Even when I don’t care about myself, other people do.	☐	☐	☐	☐	☐
7. I understand how to control the symptoms of my mental illness.	☐	☐	☐	☐	☐
8. I can handle it if I get sick again.	☐	☐	☐	☐	☐
9. I can identify what triggers the symptoms of my mental illness.	☐	☐	☐	☐	☐
10. I can help myself become better.	☐	☐	☐	☐	☐
11. Fear doesn’t stop me from living the way I want to.	☐	☐	☐	☐	☐
12. I know that there are mental health services that do help me.	☐	☐	☐	☐	☐
13. There are things that I can do that help me deal with unwanted symptoms.	☐	☐	☐	☐	☐
14. I can handle what happens in my life.	☐	☐	☐	☐	☐
15. I like myself.	☐	☐	☐	☐	☐
16. If people really knew me, they would like me.	☐	☐	☐	☐	☐
17. I am a better person than before my experience with mental illness.	☐	☐	☐	☐	☐
18. Although my symptoms may get worse, I know I can handle it.	☐	☐	☐	☐	☐
19. If I keep trying, I will continue to get better.	☐	☐	☐	☐	☐
20. I have an idea of who I want to become.	☐	☐	☐	☐	☐

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
21. Things happen for a reason.	☐	☐	☐	☐	☐
22. Something good will eventually happen.	☐	☐	☐	☐	☐
23. I am the person most responsible for my own improvement.	☐	☐	☐	☐	☐
24. I'm hopeful about the future.	☐	☐	☐	☐	☐
25. I continue to have new interests.	☐	☐	☐	☐	☐
26. It is important to have fun.	☐	☐	☐	☐	☐
27. Coping with my mental illness is no longer the main focus of my life.	☐	☐	☐	☐	☐
28. My symptoms interfere less and less with my life.	☐	☐	☐	☐	☐
29. My symptoms seem to be a problem for shorter periods of time each time they occur.	☐	☐	☐	☐	☐
30. I know when to ask for help.	☐	☐	☐	☐	☐
31. I am willing to ask for help.	☐	☐	☐	☐	☐
32. I ask for help when I need it.	☐	☐	☐	☐	☐
33. Being able to work is important to me.	☐	☐	☐	☐	☐
34. I know what helps me get better.	☐	☐	☐	☐	☐
35. I can learn from my mistakes.	☐	☐	☐	☐	☐
36. I can handle stress.	☐	☐	☐	☐	☐
37. I have people I can count on.	☐	☐	☐	☐	☐
38. I can identify the early warning signs of becoming sick.	☐	☐	☐	☐	☐
39. Even when I don't believe in myself, other people do.	☐	☐	☐	☐	☐
40. It is important to have a variety of friends.	☐	☐	☐	☐	☐
41. It is important to have healthy habits.	☐	☐	☐	☐	☐

DIRECTIVES: La liste d'énoncés qui suit décrit comment les gens peuvent parfois se sentir par rapport à eux-mêmes ou leur vie. Veuillez s'il vous plait lire chaque énoncé attentivement et cocher la case qui correspond le mieux à votre niveau d'accord avec l'énoncé. Cochez seulement une case par énoncé et n'en sautez pas.

	Fortement en désaccord	En désaccord	Indécis	D'accord	Fortement d'accord
1. J'ai le désir de réussir.	☐	☐	☐	☐	☐
2. J'ai mon propre plan sur la façon de rester ou devenir bien.	☐	☐	☐	☐	☐
3. J'ai des objectifs dans la vie que je veux atteindre.	☐	☐	☐	☐	☐
4. Je crois que je peux atteindre mes objectifs personnels actuels	☐	☐	☐	☐	☐
5. J'ai une raison d'être.	☐	☐	☐	☐	☐
6. Même quand je ne me soucis pas de moi-même, il y a d'autres personnes qui se soucient de moi.	☐	☐	☐	☐	☐
7. Je comprends comment contrôler les symptômes de ma maladie mentale.	☐	☐	☐	☐	☐
8. Si je tombe malade de nouveau, je pourrai le gérer.	☐	☐	☐	☐	☐
9. Je suis en mesure d'identifier les éléments qui peuvent déclencher ma maladie mentale.	☐	☐	☐	☐	☐
10. Je peux contribuer moi-même à mon rétablissement.	☐	☐	☐	☐	☐
11. La peur ne m'empêche pas de vivre de la façon que je veux.	☐	☐	☐	☐	☐
12. Je sais qu'il y a des services de santé mentale qui m'aident.	☐	☐	☐	☐	☐
13. Il y a des choses que je peux faire qui m'aident à gérer des symptômes indésirables.	☐	☐	☐	☐	☐
14. Je peux gérer ce qui arrive dans ma vie.	☐	☐	☐	☐	☐
15. Je m'apprécie.	☐	☐	☐	☐	☐
16. Si les gens me connaissaient vraiment, ils m'aimeraient.	☐	☐	☐	☐	☐
17. Je suis une meilleure personne qu'avant mon expérience avec la maladie mentale.	☐	☐	☐	☐	☐
18. Même si mes symptômes s'aggravent, je sais que je suis capable de le gérer.	☐	☐	☐	☐	☐
19. Si je continue mes efforts, je vais me sentir de mieux en mieux.	☐	☐	☐	☐	☐
20. J'ai une idée de qui j'aimerais devenir.	☐	☐	☐	☐	☐

	Fortement en désaccord	En désaccord	Indécis	D’accord	Fortement d’accord
21. Les choses n’arrivent jamais sans raison.	☐	☐	☐	☐	☐
22. Quelque chose de bien arrivera éventuellement.	☐	☐	☐	☐	☐
23. Je suis la personne la plus responsable de mon progrès.	☐	☐	☐	☐	☐
24. J’ai de l’espoir envers l’avenir.	☐	☐	☐	☐	☐
25. Je continue d’avoir des nouveaux intérêts.	☐	☐	☐	☐	☐
26. C’est important de s’amuser.	☐	☐	☐	☐	☐
27. Faire face et gérer ma maladie mentale n’est plus le la préoccupation principale de ma vie.	☐	☐	☐	☐	☐
28. Mes symptômes interfèrent de moins en moins avec ma vie.	☐	☐	☐	☐	☐
29. Les périodes où apparaissent mes symptômes semblent durer de moins en moins longtemps.	☐	☐	☐	☐	☐
30. Je sais quand demander de l’aide.	☐	☐	☐	☐	☐
31. Je suis prêt à demander de l’aide.	☐	☐	☐	☐	☐
32. Je demande de l’aide quand j’en ai besoin.	☐	☐	☐	☐	☐
33. Être capable de travailler est important pour moi.	☐	☐	☐	☐	☐
34. Je sais ce qui m’aide à me rétablir.	☐	☐	☐	☐	☐
35. Je peux apprendre de mes erreurs.	☐	☐	☐	☐	☐
36. Je suis capable de gérer le stress.	☐	☐	☐	☐	☐
37. J’ai des gens sur lesquels je peux compter.	☐	☐	☐	☐	☐
38. Je suis capable d’identifier les signes précurseurs de ma maladie.	☐	☐	☐	☐	☐
39. Même quand je ne crois pas en moi, il y a des gens qui croient en moi.	☐	☐	☐	☐	☐
40. C’est important d’avoir une variété d’amis.	☐	☐	☐	☐	☐
41. C’est important d’avoir des habitudes saines.	☐	☐	☐	☐	☐

To what extent do the sentences below describe you? Circle one answer for each statement.

	No	**Sometimes**	**Yes**
I. I have people I want to be like	No	Sometimes	Yes
2. Getting an education is important to me	No	Sometimes	Yes
3. I feel that my parent(s)/ caregiver(s) know a lot about me (for example, who my friends are, what I like to do)	No	Sometimes	Yes
4. I try to finish activities that I start	No	Sometimes	Yes
5. When things don't go my way, I can fix it without hurting myself or other people (for example hitting others or saying nasty things)	No	Sometimes	Yes
6. I know where to go to get help	No	Sometimes	Yes
7. I feel that I belong at my school	No	Sometimes	Yes
8. I think my family cares about me when times are hard (for example if I am sick or have done something wrong)	No	Sometimes	Yes
9. I think my friends care about me when times are hard (for example if I am sick or have done something wrong)	No	Sometimes	Yes
10. I am treated fairly	No	Sometimes	Yes
11. I have chances to learn things that will be useful when I am older (like cooking, working, and helping others)	No	Sometimes	Yes
12. I like the way my community celebrates things (like holidays, festivals)	No	Sometimes	Yes

À quel point les phrases ci-dessous vous décrivent-elles? Encerclez une réponse pour chaque affirmation.

	Non	**Parfois**	**Oui**
1. Il y a des personnes à qui j'aimerais ressembler	Non	Parfois	Oui
2. Avoir une éducation est important pour moi	Non	Parfois	Oui
3. Je sens que mes parents/ceux qui prennent soin de moi, en savent beaucoup sur moi (par exemple, qui sont mes amis , ce que je envie de faire)	Non	Parfois	Oui
4. J'essaie de finir les activités que je commence	Non	Parfois	Oui
5. Quand les choses ne se passent pas comme je le souhaite, je peux les régler sans faire du mal à moi-même ou aux autres (par exemple frapper les autres ou de dire des choses désagréables)	Non	Parfois	Oui
6. Je sais où aller pour obtenir de l'aide	Non	Parfois	Oui
7. Quand je suis à l'école, je me sens à ma place	Non	Parfois	Oui
8. Je pense que ma famille se préoccupe de mon bien-être quand les temps sont durs (par exemple, quand je suis malade ou dans le trouble)	Non	Parfois	Oui
9. Je pense que mes amis se préoccupent de mon bien-être quand les temps sont durs (par exemple, quand je suis malade ou dans le trouble)	Non	Parfois	Oui
10. Je suis traité(e) de manière juste	Non	Parfois	Oui
11. J'ai la chance d'apprendre des choses qui me seront utiles plus tard dans la vie compétences (comme utiliser mes habiletés, avoir un emploi ou prendre soin d'autrui)	Non	Parfois	Oui
12. J'apprécie les traditions de ma communauté (ex. : les fêtes ou les festivals)	Non	Parfois	Oui

To what extent do the sentences below describe you? Circle one answer for each statement.

	No	**Sometimes**	**Yes**
I. I have people in my life who I can respect	No	Sometimes	Yes
2. Getting and improving qualifications and skills is important to me	No	Sometimes	Yes
3. My family knows a lot about me (for example, who my friends are, what I like to do)	No	Sometimes	Yes
4. I try to finish activities what I start	No	Sometimes	Yes
5. When things don't go my way, I usually fix it without hurting myself or other people (e.g., without using drugs or being violent)	No	Sometimes	Yes
6. I know where to go if I need help	No	Sometimes	Yes
7. I feel that I belong in my community	No	Sometimes	Yes
8. My family cares about me when times are hard (for example, when I am ill or in trouble)		Sometimes	Yes
9. My friends care about me when times are hard (for example, when I am ill or in trouble)	No	Sometimes	Yes
10. I am treated fairly	No	Sometimes	Yes
11. I have opportunities to apply my abilities in life (like using skills, working at a job, or caring for others)	No	Sometimes	Yes
12. I like my community's culture and the way my community celebrates things (e.g., holidays or festivals)	No	Sometimes	Yes

À quel point les phrases ci-dessous vous décrivent-elles? Encerclez une réponse pour chaque affirmation.

	Non	**Parfois**	**Oui**
1. Il y a des personnes dans ma vie que je peux respecter	Non	Parfois	Oui
2. Développer et améliorer des qualifications et des habiletés est important pour moi	Non	Parfois	Oui
3. Ma famille en sait beaucoup sur moi (par exemple, ils connaissent mes amis, ce que j'aime faire)	Non	Parfois	Oui
4. J'essaie de finir les activités que je commence	Non	Parfois	Oui
5. Quand les choses ne se passent pas comme je le souhaite, je peux les régler sans me faire du mal à moi-même ou aux autres (ex. : sans utiliser de drogues ou sans être violent(e))	Non	Parfois	Oui
6. Je sais où aller pour obtenir de l'aide	Non	Parfois	Oui
7. Je sens que je suis à ma place au sein de ma communauté	Non	Parfois	Oui
8. Ma famille se préoccupe de mon bien-être quand les temps sont durs (par exemple, quand je suis malade ou dans le trouble)	Non	Parfois	Oui
9. Mes amis se préoccupent de mon bien-être quand les temps sont durs (par exemple, quand je suis malade ou dans le trouble)	Non	Parfois	Oui
10. Je suis traité(e) de manière juste	Non	Parfois	Oui
11. Dans la vie, j'ai des opportunités de mettre en pratique mes compétences (comme utiliser mes habiletés, avoir un emploi ou prendre soin d'autrui)	Non	Parfois	Oui
12. J'aime la culture de ma communauté et la façon dont ma communauté célèbre les choses (ex. les fêtes ou les festivals)	Non	Parfois	Oui