Relapse Risk Assessment in Early Phase Psychosis: Development of a Reliable and Valid Tool Informed by Patient and Caregiver Perspectives

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Introduction

Rates of relapse in young people diagnosed with a first episode of psychosis (FEP) are alarmingly high. Up to 83% will have a relapse of symptoms within the first 5 years of illness[1], and even when patients are treated in specialized early intervention programs, rates of relapse are a substantial barrier to recovery[2, 3].

There is no available tool for assessing the risk of relapse during the first five years following the index episode of psychosis. Evidence is also limited on intervention strategies that effectively target relapse prevention in this population[4].

Our team is in the early stages of building an assessment tool for risk of relapse during the critical period following onset of psychosis. The tool will incorporate all currently established risk factors, knowledge on behaviours and processes of relapse derived from literature, and historical accounts and perspectives from patients and caregivers.

Objectives

The objective of this study is to better understand relapse from the perspectives of patients and caregivers. An in-depth understanding of patient and caregiver views of relapse, in terms of its process, reasons for why relapse occurs, and early warning signs of relapse, can help to inform the development of relapse assessments and interventions for prevention.

Methods

This is a qualitative study using focus group methods. Patients and caregivers were recruited from three early intervention programs for psychosis in Canada. Six focus groups with patients and caregivers were conducted separately ranging from 4-8 participants in each group.

Patients had to (a) be diagnosed with a psychotic disorder (affective or non-affective); (b) be within the first 2 to 5 years of treatment; (c) be symptomatically stable and capable of participating in the discussion; (d) have experience with relapse (broadly defined) or be willing to participate in a discussion about it; and (e) be 18 years or older. Caregivers had to (a) have a family member with a diagnosis of a psychotic disorder who was within the first 2 to 5 years or treatment; (b) have regular (at least once a week) contact with this patient; and (c) be 18 years or older.

Preliminary Findings

In this presentation, we report preliminary findings from two of the focus groups conducted with caregivers, addressing the following questions:

1. How do caregivers understand and recognize relapse?
2. What factors do caregivers perceive contribute to relapse?

CAREGIVER PERSPECTIVES ON RELAPSE

Defining relapse

Caregivers defined relapse in terms of a recurrence of symptoms, a change in behavior, and a reduction in functional capabilities. Some participants expressed uncertainty in terms of what duration and degree of change in behaviour, function, and symtomatology constitutes relapse.

Perceiving the importance of relapse

All caregivers perceived the topic of relapse to be a very important one. For example, one participant said: *Relapse, I think it's very, very, very important, because he thought I was the Devil. So I think it's an important, I hope it's never going to happen again, but you never know (MCF1)*. Caregivers described the importance of relapse in relation to: worry/fear, acquiring knowledge and skills on how to recognize it, and uncertainty on how to address the subject in their interactions with their family member: *Relapse is a scary word for me. Fearful, scary, unknown (HF3); it's important at least to know what can happen and to see the signs happen, so it's a good topic (MCM2); it's hard for me every time I ask him questions, are you okay, how are you feeling, are you hearing voices? (MCF2).*

Recognizing the early warning signs of relapse

Caregivers depended on changes in behaviour, functioning, and interpersonal communication to identify a potential relapse. They highlighted that this was necessary as their family members would be less likely to acknowledge/speak about a return of psychotic symptoms.

The following are examples of early warning signs that caregivers identified: *staying out late, increased alcohol/drug consumption, hanging out in new places with new friends, limited/decreased sleep, not willing to come out for family functions, a change in level of activity, increased isolation, increased disorganization, saying unusual things at school, talking more about things others think are not important, increased aggressivity*.

Factors contributing to relapse

Caregivers identified the following contributing factors to relapse: not taking medication, increased substance use, relationship breakups, unresolved traumatic events, stigma/shame in the family, loss of a job, not succeeding at school, general stress in terms of school and work (e.g., starting a new job), deterioration of physical health, general life stress, anxiety, depression, not sleeping enough, negative life events, limited self-confidence, feeling like a burden to the family.

Table 1 – Participant Characteristics (n=9)

Characteristic	
Sex	
Male	3
Female	6
Age (M ± SD)	52.2 ± 8.2
Population group (Stats Canada classification)	
White	7
Black	1
Latin American	1
Relationship to patient	
Mother	6
Father	2
Spouse	1
Current living situation of patient*	
With caregiver	3
With other family member	3
With roommate/friend	1
Alone	1
Months of patient follow-up (M ± SD)	11.1 ± 3.5

**Missing current living situation for 1 patient (n=8)*

Discussion and Conclusion

While caregivers are often considered the most critical sources of support for individuals experiencing mental illness, little is known about their perspectives on the topic of relapse[5]. This study begins to address this gap in the literature by inquiring into the subjective accounts of relapse from the perspectives of caregivers.

The preliminary findings show that relapse is a prevalent preoccupation for caregivers that is associated with fear and worry. Caregivers used similar criteria documented in the literature to define relapse, however they depended more on observing changes in behaviour including interpersonal communication. A wide range of factors were identified as contributors to relapse, particularly in relation to school/work and interpersonal relationships. The themes derived from these caregiver accounts will help inform the development of a relapse risk assessment tool that will equip clinicians, patients, and caregivers to predict an impending relapse.

These findings must be interpreted with caution, given the limited sample size and early stage of analysis.

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PEPP Prevention and Early Intervention Program for Psychoses

NSEPP Nova Scotia Early Psychosis Program

McGill

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