

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

Shalini Lal, PhD<sup>1</sup>, Gina Marandola, BA<sup>1</sup>, Phil Tibbo, MD<sup>2</sup>, Rahul Manchanda, MD<sup>3</sup>, Richard Williams, MD<sup>4</sup>, Ridha Joober, MD<sup>1</sup> and Ashok Malla, MD<sup>1</sup>

<sup>1</sup>Prevention and Early Intervention Program for Psychoses, Douglas Mental Health University Institute (PEPP-Montréal); <sup>2</sup>Nova Scotia Early Psychosis Program;

<sup>3</sup>Prevention and Early Intervention Program for Psychoses, London (PEPP-London); <sup>4</sup>Victoria Early Psychosis Intervention Program

## 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<sup>1</sup>, and even when patients are treated in specialized early intervention programs, rates of relapse are a substantial barrier to recovery<sup>2,3</sup>.

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<sup>4</sup>.

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 of 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 symptomatology 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 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.

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

## References

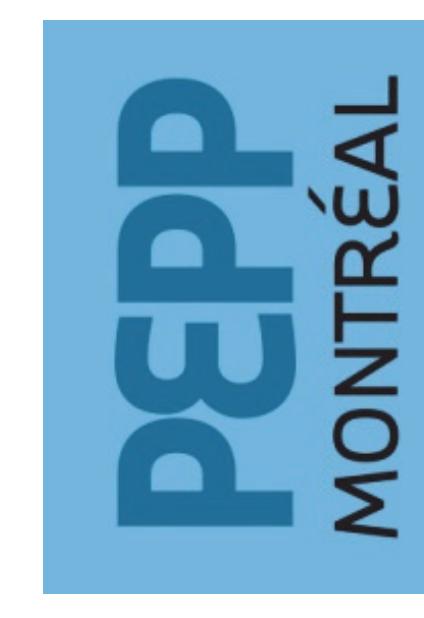
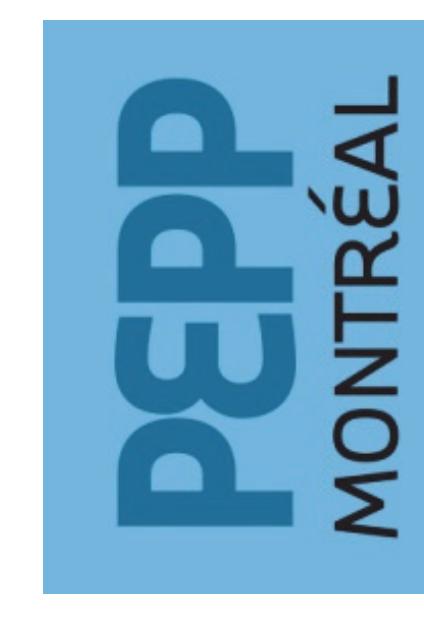
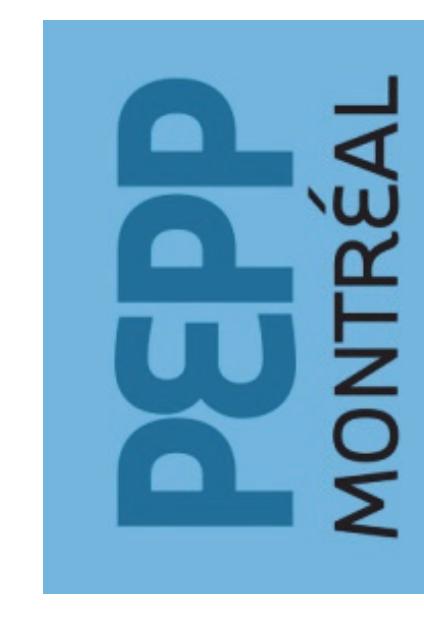
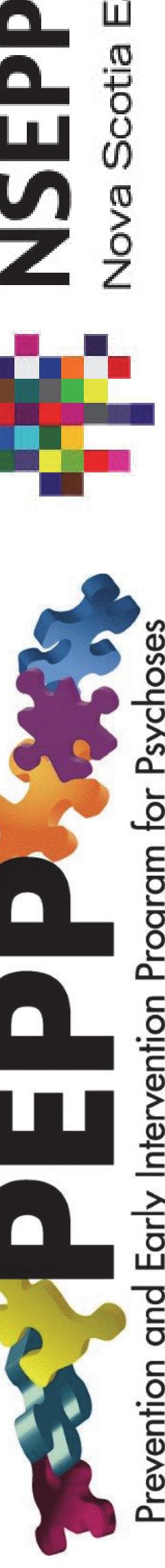
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## Acknowledgements

The authors would like to acknowledge the participants of this study, and the assistance of Jennifer Dell'Elice in ethics preparation and formatting of this poster.

Support for the caregiver focus groups was provided by the Schizophrenia Society of Canada Foundation.

Support for the patient focus groups was provided by Otsuka Canada Pharmaceutical Inc and Lundbeck Canada Inc.



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