The Meanings and Experiences of Relapse from the Perspectives of Patients and Caregivers Receiving Services for a First-Episode Psychosis: A Qualitative Focus Group Study

Executive Summary

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Background

Rates of relapse are alarmingly high in young people diagnosed with a first-episode psychosis. The majority (82%) will experience a relapse of the first-episode within the first five years of illness, of which 78% will experience a second relapse within the same time frame.[1,2] Even when patients are treated in specialized early intervention programs, rates of relapse still remain a substantial barrier to recovery.[3,4] Relapses often result in psychiatric hospitalizations,[5] which can have a negative impact on social and community functioning (e.g., performance at work and school). Individuals who have recurrent episodes of relapse are at high risk for developing a chronic trajectory of the illness with important functional decline and an increased risk for suicide.[6-8]

Reducing risk of relapse remains one of the greatest challenges in the treatment of psychosis during the early phase of the illness. We lack the capacity to predict/assess risk of relapse in patients receiving treatment for an FEP with any degree of accuracy. There is a need for an assessment tool that incorporates all known risk factors and generic early warning signs, as well as perspectives of patients and their families on the meanings of relapse and early signs of relapse. Such a tool would equip clinicians to create individual risk profiles for relapse in their patients and for early identification of an impending relapse. However, there is no available tool for assessing the risk of relapse during the first five years following an FEP, nor is there knowledge on the experiences of relapse from the perspectives of young people and caregivers.

Objective

The **objective of this study** was to gain an in-depth understanding of relapse as understood and experienced by patients and caregivers. An in-depth understanding of patient and caregiver views of relapse in terms of its process, reasons why relapse occurs, early warning signs, and factors contributing to and/or preventing relapse can help to inform the development of relapse assessment tools and prevention interventions.

Methods

A qualitative approach using focus group methods was used to obtain in-depth information on subjective experiences, understandings, and knowledge of relapse in first-episode psychosis. Patients and caregivers were recruited from four early intervention programs for psychosis in Canada, namely PEPP-Montreal at the Douglas Mental Health University Institute in Montreal (QC), the Nova Scotia Early Psychosis Program in Halifax (NS), PEPP London at the London Health Sciences Centre in London (ON), and the Today not Tomorrow (TNT) program in Chatham (ON). Eight focus groups with patients and caregivers were conducted separately.

Results

A total of 26 patients, with a mean age of 24.8 (s.d. 5.3), of which 20 were male, participated in the focus groups. A total of 24 caregivers, with a mean age of 49.6 (s.d. 8.7), of which 18 were female, participated in the focus groups. Sociodemographic characteristics for the patients and caregivers are displayed in Appendices 1 and 2.

The findings are organized in relation to the key interview topics that were addressed, namely: importance of relapse, conceptualization of relapse, recognition of relapse (including early warning signs), factors contributing to relapse, and factors preventing relapse. Participant quotes are provided throughout the following sections to illustrate common themes that were identified in the data.

Importance of Relapse

The topic of relapse generated ***interest*** from most of the participants:

- *Patient: It's very important that we detect our symptoms and some of the signs that can lead to relapse and prevent them, so that we don't start again from scratch, so that we are able to move forward and lead a happier and healthier life as the future goes on.*

- *Caregiver: I think it's very important because, well I'm always afraid of that, actually. Because you're not there every day to see if he's taking his pills… but you're always afraid of what's going to happen…So I think it's important, I hope it's never going to happen again, but you never know.*

Patients often elaborated on the ***importance of relapse by discussing its consequences*** such as: reducing confidence; not being able to function at school; not being able to get a job; having to start from scratch; losing friends; affecting family relations; affecting interactions with people; being judged and blamed for the relapse; suicide; issues with the law and violence.

- *Patient: I don't know about anybody else, but whenever I get a relapse, big consequences are you lose some of your family and some of your friends because they don't want to put up with your episodes again. I've lost almost all my friends because of relapse and going back to hospital so many times.*

Participants described their *fear of having a relapse,* although this theme was more commonly expressed in the caregiver group.

- *Caregiver: I know that she has a follow-up with the psychologist and that she is followed and everything, but I'm always afraid that she'll do something or she'll relapse, I don't know, in six months or whatever, I don't know.*

Conceptualizing Relapse

When asked to define the term relapse, some participants expressed ***uncertainty*** about the meaning of the term:

- *Patient: I still haven't really had a clear definition what that means.*

In part, the uncertainty was related to ***not knowing the necessary features associated with the concept of relapse***:

- *Patient: Like I heard loud voices and became extremely paranoid about them...But then I slept it off and it went away. So I'm not sure if that's a relapse.*

In general, however, ***most patients and caregivers described and defined relapse*** in relation to a ***change in symptoms, substance use, behaviour, functioning, physical state, and hospitalization.***

Some patients had ***multiple understandings*** of the term:

- *Patient: I guess there's relapse in the psychosis sense, where you've recovered from your symptoms of psychosis and then they start to show themselves again and make their way back into your life. And then there's relapse in the addiction sense.*

Recognizing Relapse

Difficulties recognizing relapse

Caregivers expressed ***concern and uncertainty regarding their ability to recognize a relapse***. They attributed this to being *unable to notice early warning signs preceding the first-episode*. They described the first-episode as having a sudden appearance, and were concerned if this would reoccur in a similar way:

- *Caregiver: Well, before his episode, I didn't see any change of behaviour or anything... Like I haven't seen nothing and then boom, the episode, like where he went completely crazy. So would it be the same? Would I see a change in his behaviour or, you know? I don't know... is it going to go boom!? Like I'm going to find him a drastic, I don't know…I'm not sure I would see something.*

Caregivers struggled with being able to *discern normal states* with signs of relapse. Some of this difficulty was in relation to not knowing if their loved one was in recovery yet:

- *Caregiver: I want to know what wellness looks like… Because I keep saying relapse, I'm still looking for the completely well to relapse from*

- *Caregiver: When you're watching and you see some subtle change and you go, "Mm, is that a symptom of a relapse? Is that a relapse starting or is that just normal human nature? This person just happens to be not in a good mood today or, you know..."*

Patients also highlighted ***difficulties in recognizing relapse,*** due to *insidious onset*, *lack of conceptual certainty* on when to call it a relapse (in terms of defining features, severity, duration), *limited past experience* with relapse, and *difficulties accepting/acknowledging* that relapse might be happening:

- *Patient: Sometimes it's hard because it slowly builds up. It starts out as something small. I mean, you start to recognize it but it's a slow kind of process*

- *Patient: I guess you need to have had at least one relapse in the past to be able to recognize when it happens…. It took quite a while for me to understand that it was the same thing going on because I had never relapsed, you know? I believe that to identify a pattern, you need to have seen the same symptoms at least twice. If you have seen it only once, you cannot say, maybe you cannot understand that it's this*

Some patients suggested that others (e.g., caregivers, friends) might be better able to recognize a relapse through noticing *irritability and speech content*, whereas other patients highlighted that they had become good at *masking symptoms* through controlled behaviour:

- *We don't usually realize what we're saying, but if we're talking to someone else they would be like, "What are you talking about?"*

- *I've become good at hiding it to a certain extent...like in my mind, my mind's spinning, but as far as my behaviour, I kind of like play it off like nothing*

Early Warning Signs

Most **patients** recognized relapse by *changes in symptoms (voices, paranoid thinking, depressed mood, increased irritability, mood swings, anxiety)* and *behavioural functioning.* Regarding the latter, several patients highlighted that the *key defining feature* of a *real relapse* is when a person is *not functioning normally anymore*. A few patients also highlighted the following as ***early signs of relapse***: *changes in cognitive functioning, physiology, and perceptual certainty*. *Recognizing patterns in the change and triggers* were also highlighted as being important. Some patients highlighted that *changes in behaviour would be subtle,* whereas others highlighted that it would have to be quite a 'big' and *noticeable change*.

Similar to the patients, several **caregivers** recognized relapse by *changes in symptoms* (voices, paranoid thinking, mood). However, in most cases they spoke more in-depth about observable changes such as *changes in self-care, social behaviour, weight, increased anxiety, bodily concerns, and aggressivity/argumentation* as a key sign of impending relapse. Some caregivers highlighted that since their loved ones do not speak to them about their *symptoms, functional and behavioural changes are their main point of reference*.

Factors contributing to relapse and its prevention

The following table presents an overview of the various factors that patients and caregivers identified as contributing factors to relapse and/or its prevention.

	Contributor	Preventer
Medication	X	X
Substance use	X	
Social environment/relationships	X	X
Sleep and lifestyle	X	X
Stress, anxiety, fear of the future	X	
Self-perceptions	X	X
Life events and unresolved past trauma	X	
Stigma	X	
Caregiver self-care		
Internet, social media, music, technology	X	X

Patient Perspectives on Medication and its Relation to Relapse

Most patients highlighted *taking medication as a key factor in preventing relapse*, some expressed *mixed feelings regarding need for medication, skepticism regarding pharmaceutical industry, regulations, and research,* and/or emphasized that *medication was only part of the solution for preventing relapse*, and a few also brought up *medication as a contributing factor* to relapse.

Taking medication to prevent relapse

- *Patient: I was just having relapses over and over again. It was because I wasn't taking my medication and I learned from that I had to take it and ever since then I just haven't stopped, so I've been taking my medication just constantly.*

Mixed feelings towards medication

- *Patient: I'd say that I'm both for and against medication. I'm for medication because when I was in a state of crisis and when I had really severe symptoms, medication was absolutely necessary to calm me down and to bring my feet back on earth. I really needed it at that point. It really was the first step to getting somewhere, getting in a more stable state when I can start recovering.*

Medication not a panacea

- *Patient: But I also think that one should not rely on medication to recover, because it's not going to make it, it's not going to do the trick. What I mean by that is that if you accept the idea that somehow mental illness is a chemical imbalance and in your brain and there's nothing you can do, it's biologic or you can't do anything about it, if you accept that idea and rely on medication to stay healthy, then it kind of de-responsibilizes you…It brings you to think that you don't have the ability to fix yourself.*

Bad experiences with medication

- *Patient: Some of the medication was causing massive weight gain and it kind of stuck with me, so it caused a lot of stress and now I have to kind of push it off and get rid of all that weight that I gained from it. Like, I gained over a hundred pounds or so.*

Skepticism regarding medication research, regulations, industry

- *Patient: The overall effectiveness of medication. The FDA hasn't really been put on the spot, but they've been known to disseminate false information… falsify all clinical trials and they literally just sign a page releasing it to the general public.*

Caregiver Perspectives on Factors Contributing to Relapse

Some **caregivers** had a difficult time describing factors that could contribute to relapse in their loved ones as they were uncertain regarding factors that contributed to the first-episode:

- *Caregiver: He had a great job out west, was doing fabulously and then just bang. So whatever set it off, whatever precipitated it, he had been doing great in December and then the end of April just whatever changed I don't know.*

Caregivers expressed the need for more suggestions from treatment teams on concrete things they could do:

- *Caregiver: I'm not looking for reassurance, I'm looking for specific tasks that we can do to move this forward.*

Caregivers also expressed the need for more interactions with other caregivers, in the form of a support group, but also which has the presence of a health care provider.

- *Caregiver: I think the actual interaction of parents and/or caregivers… having with the sort of the doctor or facilitator who actually when we have questions or things we don't understand or something like that; that way we have a better understanding and more support and not feeling so alone.*

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Appendix 1: Patient Characteristics

Characteristic (n=26)	
Gender	
Male	20
Female	5
Other	1
Age (M ± SD)	24.8 +/- 5.3
Population Group (Stats Canada classification)	
White	22
Black	3
Latin American	1
Living Situation	
Alone	5
With parents or siblings	10
With roommate/friend	2
With partner and/or children	7
Missing	2
Months of Patient Follow-up (M ± SD)	26.2 +/- 13.5
Marital Status	
Single	17
In a relationship	3
Legally married	3
Separated or divorced	1
Missing information	2
Current Work/School Status (Does not add up to an *n* of 26 as some patients checked off more than one category)	
School part-time	8
School full-time	5
Working part-time	7
Working full-time	4
Working as a volunteer	1
Caregiving for child(ren) and/or dependent(s)	2
Neither in school, nor working, nor caregiving	3

Appendix 2: Caregiver Characteristics

Characteristic (n=24)	
Gender	
Male	6
Female	18
Age (M ± SD)	49.6 +/- 8.7
Relationship to Patient	
Mother	16
Father	5
Spouse	3
Population Group (Stats Canada classification)	
White	22
Black	1
Latin American	1
Living Situation of Family Member Receiving Services	
Alone	3
With me	15
With roommate/friend	2
With partner and/or children	1
With other family (siblings, etc…)	2
Missing	1
Months of patient follow-up (M ± SD) (n=15)	23.2 +/- 17