

# THE PERSONAL MEANING OF RECOVERY AMONG INDIVIDUALS TREATED FOR A FIRST EPISODE OF PSYCHOSIS



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**EARLY INTERVENTION IN PSYCHOSIS:  
CURRENT KNOWLEDGE AND FUTURE DIRECTIONS**

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# BACKGROUND



- There is little known about the personal experience of recovery from a first-episode of psychosis.
- Examining the subjective experiences of recovery following a first-episode of psychosis can enhance our understanding of the *critical change processes* and experiences that prevent chronicity and promote positive outcome, offering new and important insights by which to improve early intervention services and practices.
- Provides valuable insight into what is subjectively *meaningful* to service-users in recovery

# OBJECTIVE



To explore both commonalities and variations in the personal meaning of recovery and the early recovery experiences for individuals who received early intervention care following their first-episode of psychosis.

# RESEARCH QUESTIONS



- What does “recovery” mean to individuals?
- What is the recovery experience following a first-episode of psychosis
- How is early intervention treatment experienced by these individuals?

# PARTICIPANTS



- Interviews were carried out with thirty individuals in early recovery following a first-episode of psychosis at the Prevention and Early Intervention Program for Psychosis in London, ON
- Participants were invited to participate in the interview as part of a study on long-term outcome
- Participants were receiving step-down care and were at either three, four or five years post treatment initiation at the time of interview

# INTERVIEW



- A semi-structured interview guide was designed to elicit in-depth accounts of the individual's subjective experience of psychosis and recovery from time of first onset.
- Individuals were asked to identify critical turning points in treatment and recovery.

# DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

Gender: 76.7% Male  
23.3% Female

Age: M= 25.9 (SD = 5.3)  
Range: 19 to 42 years

Education: M = Grade 11

Primary Diagnosis:  
53.3 % Schizophrenia  
26.7% Schizoaffective  
10% Psychosis NOS  
6.7% Substance-induced  
3.3% Bipolar I

Year of treatment:  
52% at Year 3  
28% at Year 4  
20% at Year 5

# DEMOGRAPHIC AND CLINICAL CHARACTERISTICS



The majority of participants (86.7%) remitted following their first-episode of psychosis

Twelve individuals (40%) had not relapsed following remission from their first episode.

Participants had an average of one ( $M = 1.08$ ,  $SD = 1.29$ ) relapse following their first-episode of psychosis, ranging from zero to five relapses

An average number of two psychiatric hospitalizations since the onset of illness



# ANALYSIS



- Interpretative Phenomenological Analysis (IPA) was used to examine the subjectively identified meaning of recovery, and important processes and turning points over the early course of illness and recovery.
- The goal of IPA is to develop an in-depth understanding of the meanings used by informants to make sense of their experiences as it relates to a particular topic.

# RESULTS



- Analysis of themes regarding recovery revealed seven common early recovery processes that fell broadly into three domains of early recovery:
  - ✦ Illness (N=24, 80% of participants)
  - ✦ Psychological and personal (N=20, 67% of participants)
  - ✦ Social and functional (N=18, 60% of participants)

# “Illness Recovery”



- Regarded by many (77%) as an essential criterion of recovery
- This category incorporates various aspects of alleviation of psychiatric symptoms.
- A relief from distressing symptoms was often described as the **initiation** of recovery, allowing for recovery processes in other domains to unfold.
- 53% of participants identified illness-specific (psychosis and/or affect) turning points
- Turning points occurred at various time-points in recovery (within weeks to many years following treatment initiation)

# “Illness Recovery” Experiences



- *I look back at myself and go, “You know, I was thinking that, but that’s not true.” At the time, it felt like it was true or it sounded good to me, but it wasn’t a real thought -- and it wasn’t until I could actually say, “No, that’s not true” that I reached that turning point.*

Elimination of symptoms was experienced as sudden and complete, for others it was experienced as an incremental process:

- *I went to Seroquel, which started to work pretty well. At that point...I probably would’ve said then that I was recovered. But when I went to Clozapine, it was like another level*

Improvement in symptoms was nearly always attributed, at least in large part, to medication:

- *...the first time they put me on Seroquel -- it was such an unbelievable change. I went from being delusional and having hallucinations to being free of that in two weeks.*

# “Psychological and personal recovery”



- This category encompasses experiences of developing a meaningful and personalized understanding of the illness experience, regaining a sense of control and restoring a coherent sense of self.
- Twenty participants (67%) included one or more subthemes of psychological recovery in their recovery definitions. These processes were described by most individuals as essential before moving forward in social recovery.

# The question for meaning and acceptance



## Turning points and processes:

- 1) “recognizing” a psychological problem
  - 2) “reconciling” the personal meaning of the experience
- These processes were described as essential before moving forward in recovery
  - Resolving the explanation-seeking and sense-making processes differed between individuals
  - Critical recovery processes in early recovery

# Developing Meaning: The first step



- “Knowing something was wrong” was described as an awareness of change in one’s self-experience.
- The “recognition” turning point -- a realization that something had changed within himself or herself. This often followed an initial period where the psychotic symptoms were normalized until an awareness that something more serious was happening
- This turning point was described as occurring through various experiences
- Identification of the change as psychological in nature was crucial for the initiation of explanation (and help) seeking.

# Developing Meaning: The second step



## “Understanding/accepting the illness”

- Becoming reconciled with one’s perspective on the meaning of the experience.
- Whether the experience is an illness, and if that illness will be short term or chronic.
- This resolution constitutes creating a coherent and plausible framework or explanation for the experience of psychosis congruent with the person’s experience and beliefs.
- Large variability in the duration and distress associated with this recovery process



# “ACCEPTANCE”



## Explanation-seeking:

- - Seeking an explanation and forming a coherent account for the experience were critical in early recovery. This quest to “understand” was highly individual, depending on personal notions of mental illness, messages received from influential others, and direct illness experiences.

## Reconciling the meaning of the illness (“acceptance”) and implications for the future:

- - Generally included accepting one’s potential long-term vulnerability to relapse.

Shifting from conceiving of the experience as an isolated event to that of an enduring illness was an essential experience in the recovery for many individuals

The experience of relapse was frequently identified as an important turning point in “acceptance”

*After I relapsed I'm thinking, “Huh, ever since I took the Olanzapine, all that went away after all, just like it did when I took the Risperidal.” And I was like, “Oh, it's an illness.” That was actually the, the pinnacle –But it took awhile for me to get...to realize that.*

# Reconciling the “meaning” of psychosis



- Included adjustment to the idea of having a mental illness and all of the perceived ramifications on personal and social identity.
- Some individuals described experiencing feelings of powerlessness and multitude of losses associated with the experience:
- *And I had this huge, uh, breakdown because I thought that here I was living for, like...two years and I thought I knew who I was but then it's like...that idea is...not true, so then you have to rebuild who you are all over again.*

# Barriers to reconciling meaning



- Some participants described a prolonged struggle before reaching this point of constructive acceptance of illness. They inevitably identified and emphasized this process as an essential turning point in their recovery:

*I think I was just putting the schizophrenia aside. And I wasn't dealing with it. I think the reason why I relapsed was, I still hadn't dealt with acceptance - a big part of turning things around for myself was no longer worrying about -- the stigma.*

# Psychological or Personal Recovery: Restoring Self



- This category encompasses various processes of self-enhancement and reconstruction, whereby individuals rebuilt a positive identity.
  - ✦ 1) Enhancing self-concept
  - ✦ 2) Redefining self

# Psychological or Personal Recovery: Restoring Self



- The rediscovering of previous talents, abilities or positive traits promoted a positive self-concept, enhancing a sense of worth and accomplishment, and providing linkages between “pre-illness” and current identities.
- The discovery of new abilities or positive traits, often as a result of the illness experience, was also described as beneficial for self-regard and self-confidence.

*I feel like I've grown and I feel like a better person -- I think before I was just letting life go by and living for the next party. I've grown -- and I've found...a new passion.*

# SOCIAL AND FUNCTIONAL RECOVERY



- Eighteen (60%) participants included domains of both social and functional recovery in their recovery definition
- This category incorporates the themes of being able to or knowing how to talk to people, working or going to school, having friends, and having a partner or spouse
- Main themes: Role resumption and relationship engagement and repair

# ROLE RESUMPTION



- Twelve individuals (40%) indicated specifically that return to role was a critical *turning point* in recovery
- Individuals returning to post-secondary studies spoke with passion about the importance of this role resumption to their recovery
- This role provided an intact sense of continuity, social identity and hope for retention of life goals and expectations for the future



# Resuming Roles



- At its essence, the meaning of social recovery was attaining a positive social identity and social inclusion:

*I'll know if recovery's occurred for myself when I do get a job and I keep the job. And I do make new friends and get into a relationship. So once those things start happening and I'm able to keep those things in my life, then I'll know recovery has happened.*

*School was a pretty good turning point too -- sort of gave me something to concentrate on, focus on and look forward to going to the next week.*

*...going back to university was difficult. But...I got through it and I have the degree to show for it -- and you can't take that away from someone -- it's gonna stay with you for the rest of your life. It makes me stronger knowing that I graduated and got through it.*

# Relationship Engagement and Repair



- Importance of participation in fulfilling relationships
- All types of relationships were identified as important in social recovery: peers, family members, coworkers, romantic partners, and service providers.

# Peer Relationships



- Participation in peer relationships was identified as very important in the recovery process.
- The effect of the illness experience on peer relationships was highly varied, ranging from minimal to severe social disruption.
- Therefore the tasks of social recovery varied according to experienced social consequences of the illness experience, and included re-engaging in friendships, repairing damaged friendships or initiating new friendships.

# Other Relationships



## Family relationships

- Repair and engagement in these relationships was a very important part of the recovery process for many individuals.

## Romantic relationships

- A frequently identified important part of recovery
- Themes of challenges and successes in romantic relationships
- Initiation of romantic relationships was described as very challenging, and success a frequently identified turning point:
- *I changed for the better after – when I met my boyfriend. That’s when I had more...love for life. It’s like...I was feeling so messed up, but after I met him, it was like I had someone to live for.*

# Social and functional recovery



- **Restored social confidence and worth** was a very critical component of recovery for many informants:
- *That's the biggest thing since I've been ill - my confidence has gone way down. I'd let people push me around. I'd avoid conflict and confrontations... and I worried a lot about what people thought. Now my confidence...I started to get my confide-, happiness back.*

# Treatment Negotiation



- Negotiating meaningful and active participation in treatment, while avoiding engulfment in the patient role/label
- The trajectory of change in treatment perceptions and attitudes differed greatly between individuals.
- Treatment-related recovery turning points reflected a *turning towards treatment*, and included:
  - engagement with treatment
  - disclosure of problems and experiences
  - events that engendered trust in the treatment provider(s)
  - a change of medication, or sustained medication adherence/acceptance

# Variation in Recovery Narratives



- Some recovery trajectories were described as relatively simple/quick and others quite complex/prolonged.
- Variations between individuals in the magnitude of described self and social functioning disruption, duration of the illness-acceptance process and the treatment engagement process greatly influenced the experience of recovery.



# “Complicated” Recovery



For those that were prolonged the following factors were often identified as part of the recovery experience:

- Considerable disruption of self-concept
- Difficulty with recognizing illness
- Difficulty with reconciling illness (relapse necessitated revision)
- Difficulty (re)establishing nurturing relationships
- Significant role disruption
- Associated with demoralization prior to illness integration, and guilt and regret post integration
- High risk for service disengagement

# Implications of “Complicated” Recovery: “Acceptance”



- Variations in level of difficulty experienced in **acceptance of illness** suggests that the impact of psychosis on self-concept likely involves a confluence of interactive factors
- The outcome of meaning-making appears to have very important implications in terms of **emotional consequences** (e.g. demoralization) and **behavioural responses** (e.g. medication adherence).
- Therefore, this **development of meaning may be critical in determining future course of the disorder.**
- As these processes are most fluid early in recovery, further understanding of these change processes would aid development of optimal early treatment initiatives

# EIP Service Delivery Implications: Acceptance



- Differences in **illness acceptance trajectories** have important implications for understanding psychological adjustment to the experience and treatment of psychosis
- A critical process in early recovery – a cornerstone for other recovery processes
- Emphasizes the importance of assisting individuals with the construction of meaning following the initial illness experience (e.g. providing meaningful information, meeting clients “where they are at” in the process, fostering peer-to-peer conversations, etc.)

# “Complicated” Recovery: Role Disruption



- These findings emphasize the importance of the subjective experience of role disruption and relationship challenges following onset of the disorder in potentially having long-term consequences for the individual’s sense of self (psychological and personal recovery)
- Critical turning points were frequently cited that occurred after 2 years following illness/treatment onset

# EIP Service Delivery Implications: Social Recovery



- The subjective importance of role resumption and relationship engagement emphasizes the need to **encourage and assist service-users in meeting personally relevant social recovery goals.**
- Together these findings suggest that social rehabilitation in the domain of **friendships** is an essential area where creative intervention efforts can be focused in early recovery to potentially modify this trajectory of entrenched isolation and its potential secondary influences on subjective well-being and illness course.

# Turning Points in Recovery from FEP



- Acceptance of illness/resolving meaning
- Reducing or eliminating substance use/abuse
- Initiating and maintaining positive lifestyle behaviours
- Engagement in treatment
- Modifications in social group for enhancing and maintaining recovery
- Re-engaging in meaningful roles and/or relationships

## SUMMARY

- Recovery journey is highly individual
- Symptom recovery is highly valued by EIP service users
- Making sense of the experience can be a prolonged process
- Recovery is multidimensional and therefore wellness and dysfunction can coincide
- Crucial initial tasks of recovery take longer for some people – often longer than two years post onset
- Therapeutic alliance and treatment engagement are crucial, and often requires patience and persistence
- Engage and assist on dimensions of recovery that are personally meaningful
- Encourage and assist with role resumption and relationships engagement/repair

THANK YOU!

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