2014

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HHS Public Access

Author manuscript

Psychiatr Serv. Author manuscript; available in PMC 2015 December 01.

Published in final edited form as:

Psychiatr Serv. 2014 December 1; 65(12): 1499–1501. doi:10.1176/appi.ps.201300527.

The Subjective Experience of Youths at Clinical High Risk for Psychosis: A Qualitative Study

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Abstract

Objective—Understanding the experience of individuals across stages of schizophrenia is important for development of services to promote recovery. As yet, little is known about the experience of individuals who exhibit prodromal symptoms of schizophrenia.

Disclosures of Conflicts of Interest
The authors have no interests to disclose.

Methods—Audiotaped interviews were conducted with 27 participants at clinical high risk (CHR) for psychosis (15 males; 12 females; mean age 21; ethnically diverse). Phenomenological qualitative research techniques of coding, consensus, and comparison were used.

Results—Emergent themes differed by gender. Themes for males were feeling abnormal or "broken"; focus on going "crazy"; fantasy and escapism; and alienation and despair, with a desire for relationships. Themes for females were psychotic illness in family members; personal trauma; struggle with intimate relationships; and career and personal development.

Conclusions—The finding of relative social engagement and future-orientation of females identified as at risk for psychosis is novel, and has implications for outreach and treatment.

Keywords

qualitative research; prodrome; prodromal; psychosis; social function; gender

INTRODUCTION

Understanding the experience of individuals across stages of schizophrenia is important for development of services to promote recovery. Qualitative research is key to this endeavor. For example, we know from qualitative studies that older adults with schizophrenia describe symptom improvement over time, but variable function[1]. Also, social withdrawal is common in older adults with schizophrenia[1], and in young adults with a first episode of psychosis[2]. Less is known about the putative prodromal stage or clinical high risk (CHR) state for psychosis, characterized by attenuated psychotic symptoms. Qualitative research can help inform service delivery, relevant for prevention and recovery in at-risk youths[3].

As yet, there are only three small (N's = 6, 8, 10) qualitative studies of youths at CHR for psychosis[4–6]. Two involved primarily males, who described isolation and difficulty in social interactions, and a reluctance to describe their experiences to others[4–5]. A third examined pathways to care among mostly girls in high school, noting the importance of family, community and school[6]. Herein, we aimed to characterize more in depth the subjective experience of at-risk youths, interviewing a relatively large group of 27 ethnically diverse males and females who were participants in a prodromal research program, using phenomenological qualitative research methods. The interviews focused on changes experienced over time and their impact, what has been helpful or not, and expectations for the future.

METHODS

Participants were individuals identified as at clinical high-risk (CHR) for psychosis on the basis of attenuated or subthreshold psychotic symptoms, using the Structured Interview for Prodromal Symptoms/Scale of Prodromal Symptoms (SIPS/SOPS)[7]. Participants were ascertained from a prodromal cohort study and interviewed within the year following enrollment. Interviews took place between 2007 and 2011. Exclusion criteria included Axis I psychosis, non-fluency in English, neurological or major medical disorder, risk for suicide or violence incommensurate with outpatient treatment, and attenuated psychotic symptoms better explained by another disorder. Written informed consent was obtained from

participants 18 or older, and from parents of participant minors, who themselves provided written assent. This study was approved by the local Institutional Review Board.

Qualitative data were collected through open-ended, narrative interviews. Interviewers were trained in qualitative interviewing by an expert (LD) in phenomenological research methods[8], which were chosen to emphasize the person's own subjective experiences rather than the degree to which he or she endorsed elements of investigators' theories. Over approximately one hour, participants were queried as to the following areas; interviewers provided additional clarifying questions if they were not discussed spontaneously.

1. What changes have you perceived over time?
2. How have you been affected by these changes?
3. What has been helpful or not?
4. What are your expectations for the future?

Data analysis followed established phenomenological procedures, with interview themes identified through thematic analysis[8–10]. Specifically, transcripts were first read separately by each team member, who catalogued evident themes. Second, researchers met to compile a consensus list of common themes across interviews, reviewing interviews to identify any subgroups that could be identified by emergent themes. Third, team members then separately re-read and re-reviewed transcripts, to evaluate if consensus themes accurately captured the interviews accurately. Fourth, the first and senior authors re-read and re-reviewed all transcripts to identify any missing emergent themes. Throughout, areas of initial disagreement were discussed until common ground established.

RESULTS

There were twenty-seven participants, ages 16 to 27 (mean(SD) = 21.4±3.3), comprising fifteen males (mean(SD) age = 20.5±2.9) and twelve females (mean(SD) age = 22.6±3.4]). Participants were ethnically diverse, with twelve Caucasians, five African-Americans, four Asian-Americans and six individuals self-described as "more than one race". Ten identified as Hispanic (across ethnicity). Full-time engagement in work, school or a combination thereof, characterized 47% of males and 75% of females. Half of males, but only 17% of females, were unemployed. Psychosis prevalence in a first-degree family member was 26% for males and 58% for females. Of the twenty-seven participants, five (3 men, 2 women), e.g., 18.5%, developed nonaffective psychosis within two years following participation. Socioeconomic status of origin was similar for males and females, as indexed by parental education, with ~1/3 of fathers having a high school degree or less, and 2/3 having some advanced education.

Qualitative analysis suggested broad gender differences in emergent themes, with some overlap. Further illustrative quotations are listed in the appendix online.

For males, themes included feeling abnormal or "broken"; a focus on "going crazy"; fantasy and escapism; and alienation and despair, in the context of mostly desiring relationships. For

females, themes included psychotic illness in family members; personal trauma; struggle with intimate relationships; and career and personal development.

Themes among males were as follows:

- *Feeling abnormal or "broken"*: One third described feeling "broken" or "abnormal", variably ascribed to genes or abnormal development or immigration. One male described, "maybe in my head something did not develop properly or there is something missing. If I had never come to the United States maybe I would not be the same person I am now. I would be more normal." Another male attributed, "things that happen in the brain and things that I experience are probably just in my genetic code. I was born with it."

- *Focus on "going crazy"*: One third used the word "crazy" during their interview while others used related slang terms, e.g. "if I had to deal with everything I am supposed to deal with, I would go insane." This fear of going "crazy" was common e.g. "the anxiety about being crazy was worse than forgetting a meal."

- *Fantasy and escapism*: Half described fantasizing about and desire for escape. One male described leaving home, as he hated it there, in search of magic and dreaming of a utopia where "everyone can accept and just love each other equally." Another male endorsed "hitchhiking" and "bohemianism". Another said, "I fantasize about living in worlds with different laws of physics, different cultures, societies, ways of life, everything. What would it be like to live like an animal?" Half of the males described withdrawal, spending hours surfing the web and playing video games instead of going to class, sleeping more, and living like "a hermit."

- *Alienation and despair, with desire for relationships*: Alienation and despair were described by half of the males. One said, "The future feels bleak. I feel pointless right now. I'm getting old. I didn't finish college. I don't have a girlfriend, never really had a girlfriend. It feels like a shard of glass in my mind. You know, it irritates. I don't plan to find the future, because somehow in my mind the future always ends up with me with a big beard, very dirty and homeless". Another male said, "I want to communicate to other people, but sometimes I feel like I'm just mumbling over some kind of mountain. I'm trying to make myself understood, but they just can't hear me, no matter how hard they try". Many described a wish for relationships, e.g. "I just want to have a special someone".

Themes among women were as follows:

- *Psychotic illness in family members*: More than half described psychosis in a family member, usually mothers. All females with a previously documented family history of psychosis (ascertained in the prodromal research program) brought this up spontaneously. One said, "My mom is a schizophrenic. She's been schizophrenic my whole life." Another said, "There is such a history in my family of thought disorders and I have pretty much known my whole life that I had a higher chance of going nuts than other people."

- *Personal trauma*: More than half spontaneously brought up a history of trauma, including neglect, abuse, parental separation, and witnessing violence. One female said, “I grew up completely neglected and abused – they didn’t explain to me why I was getting hit.” Another described her childhood, “There was one summer we went like entirely without food – we lived in a homeless shelter for a year.”

- *Struggle with intimate relationships*: Half described being in an intimate relationship, yet struggling, e.g. “relationship troubles.” They described fear of being hurt or abandoned, and struggling interpersonally. One explained, “I have a boyfriend, but I am scared of getting close to him to the point where he is going to hurt me or he is going to just disappear somehow or something is going to happen to him where he is not in my life any more.”

- *Career and personal development*: More than half described motivation and plans for a career, speaking of “academic progression,” “a series of credentials,” and “the analogy of the staircase.” One said, “Most of my life, kind of the goal I have for myself was just being able to be independent in any way, to have a little apartment – it’s kind of like my ultimate goal.”

DISCUSSION

Emergent themes in these interviews were largely different for males and females. Males described alienation and despair, feeling broken, and a fear of going “crazy.” They desired relationships but were alone instead, escaping into fantasy. They had a vague hopefulness things might improve in the future, but no real plan going forward. By contrast, the females described being in the thick of things, managing relationships and building careers, while dealing with the sadness of ill family members and past trauma.

These data are consistent with earlier qualitative studies in males[4, 5] and females[6] at CHR for psychosis, and with our prior findings based on structured interview in the extended risk cohort, namely greater negative symptom severity among males[11]. The emphasis on career and personal development among females here is consistent with their greater participation in the workforce and in educational programs. However, despite comparatively better social and role function, the females were still at appreciable risk for psychosis, as two of the twelve (17%) developed psychosis. Of note, a general pattern of superior functioning in females has been described across early stages of schizophrenia – in other CHR cohorts[12–13] and among first episode psychosis patients[14].

Our qualitative data complements our prior studies[4–6] and breathes life into their numbers. Negative symptoms and depression in males are experienced as alienation and despair. Attenuated psychotic symptoms for males are interpreted as going “crazy”. The existential pain for them is such that they seek escape, largely into fantasy. This constellation poses a significant challenge for treatment and recovery, as it reflects low self-esteem (“broken”) and maladjusted coping (“escape”); however, their desire to have relationships represents a potential base for forming treatment alliances in supportive and behaviorally based therapy. Outreach via the Internet to males may be useful, given their isolation. By contrast, the females are largely pragmatic and future-oriented, in the process of building a career,

juggling obligations to others, and grappling with the emotional aftermath of trauma. Females might benefit from treatment services with extended hours that accommodate their busy days of work and school, and more trauma-oriented therapy focused on emotion regulation.

Emergent themes in our study echo findings from interviews with older adults with schizophrenia, specifically early exposure to trauma and family mental illness, desire for escape, social isolation in the context of desiring relationships, and finally despair[1]. Whereas older women interviewed in previous studies generally had a sense of resignation[1], our data suggest hopefulness and energy among younger women at risk.

Participants generally reported finding it useful to talk about their experiences, common in qualitative studies across stages of schizophrenia[1–2, 4–6]. This is a promising basis for engagement and treatment alliance. “Telling one’s story” can be empowering, counteract stigma and isolation, and promote recovery for individuals with schizophrenia[15].

CONCLUSIONS

While preliminary, this qualitative study suggests gender differences during a putative prodromal stage marked by attenuated psychotic symptoms. Males at risk describe alienation and despair, with escape through fantasy, though with continued desire for social connection. By contrast, females at risk describe social engagement and career aspirations, while dealing with the sadness and pain of ill family members and past trauma. This finding of relative preserved social and role function in females at risk using qualitative methods is a novel finding, and has implications for tailoring outreach and treatment strategies. Further qualitative study is needed to confirm gender differences, and to better understand subjective experience and phenomenology in the at-risk state, for the purpose of nosology, and for improving preventive interventions and service delivery for individuals at risk.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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