

Observations of a Small Sample of Adolescents Experiencing an At-Risk Mental State (ARMS) for Psychosis

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Some commentaries express concern that the At-Risk Mental State (ARMS) designation can be stigmatizing and induce a lasting sense of personal fragility. However, no studies have actually explored the personal perspectives of those so categorized. The purpose of this study was to explore how adolescents with an ARMS label understand and experience their condition medically and personally. Six participants receiving an ARMS diagnosis were interviewed and the data analyzed using interpretative phenomenological analysis. Three superordinate themes emerged: “It is better to say it,” “How others would take me,” and “Just to have somebody to talk to.” The participants’ experiences of being labeled were generally positive with limited instances of stigmatization by family and friends. Like most psychiatric diagnoses, the ARMS label has the potential to generate stigma. In practice, however, this sample of young people appeared to respect being told about the condition and to value the opportunity of talking about their experiences with mental health professionals and significant others.

Key words: psychosis/risk/prodrome/youth

Introduction

It is quite likely that a psychosis risk syndrome (or “At-Risk Mental State”—ARMS) for psychosis will be included in *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.^{1,2} However, the validity and utility of the construct is not universally accepted with some concern that the term could create anxiety and stigmatization.³

Previous research related to genetic testing report that people are not always eager to know their own risk status.⁴ On the other hand, positive effects of applying a diagnosis have been observed in depressed teenagers who report “relief” insofar as the label validates their distress and decreases a sense of isolation.⁵ Observations from

research clinics suggest that when confronted with the news of risk some young people and families experience relief and enhanced focus,^{6,7} whilst others demonstrate concern, skepticism, and denial.⁷ Supporters of the risk concept assert that those presenting to such services are already ill and have a right to be offered treatment.⁸ The label can have positive leverage by triggering effective treatment, thereby reducing symptoms and in turn decreasing stigma.⁹

Skeptics suggest that any use of a “psychosis” related label can obstruct a patient’s communication with others, encouraging them to withdraw socially even from those accepting of their condition.^{9,10} For adolescents, anticipated peer rejection almost always remains a major concern,¹¹ making it a sensitive time regarding the formation of self-concepts. A mental health label may distort this process and truncate the acquisition of social competencies.¹² Moreover, acquiring the label of illness could become central to the young person’s identity, caustic to a sense of normality. At worst, stigma associated with labeling could reduce self-esteem and social contact, making relapse more likely.⁹

To date, one qualitative study has explored interpersonal relationships and communication styles in ARMS patients. Those involved with early detection and intervention services appreciated being able to communicate their psychological distress and expressed that this improved their ability to cope with symptoms. Cognitive therapy was also perceived to promote interpersonal collaboration with clinicians.¹³

Since “no studies to date have systematically examined how any potential stigma induced by the label of psychosis risk might affect identified patients”^{9(p43)} and the fact that “there is an alarming ignorance of the subjective perspectives of preschizophrenic patients,”^{18(p111)} the aim of the present investigation was to explore the understanding and experiences of adolescents categorized as having an ARMS.

Methods

Participants

Interviews were conducted with 6 participants who had been identified as having an ARMS using the Melbourne ultrahigh-risk criteria¹⁵ and the Comprehensive Assessment of At-Risk Mental States¹⁶ 6 months previously. The sample size was guided by the recommendations of Smith et al¹⁷ and drawn from participants recruited for another research study aimed at categorizing how adolescents with ARMS initially present to mental health services. Six of the first 7 participants recruited to this study were interviewed. The one individual not interviewed was deemed inappropriate because of limited verbal ability. Participants were 3 males and 3 females between ages 13 and 18 years. Names of people and places have been changed to preserve anonymity.

Procedure

Qualitative data was obtained via semistructured interviews lasting between 25 and 40 minutes. Interviews were recorded for later transcription. Informed written consent was obtained from all participants and from parents/carers from those aged below 14 years of age. All participants were reimbursed for their time. The interviews focused on the individual's personal understanding, thoughts, and feelings relating to the ARMS label and their experiences of support offered to them by mental health services (see online Supplementary materials 1.1).

The study was approved by the Durham University School of Medicine and Health ethics committee and the Durham and Tees National Health Service Research Ethics Committee (UK).

Analysis

The data were analyzed using interpretative phenomenological analysis (IPA) via the procedures outlined by Smith et al.¹⁷ IPA focuses in detail upon how individuals experience and perceive major life events.¹⁸ It combines psychological, interpretative, and idiographic practices. Interview transcripts were obtained and analyzed to generate related and superordinate themes that capture the major personal and contextual experiences associated with a phenomenon. The primary analysis was conducted by the principal author (P.W.) and reviewed and modified by the study supervisor (P.T.).

Results

From the interview transcripts, 3 superordinate themes emerged and representative quotations from the participants were identified that succinctly summarized the content of each theme.

“It is better to say it” (Frederick)

The overall consensus of participants was one of wanting to be informed about their condition. For Frederick,

it was a refreshing experience for mental health services to be honest and upfront:

You were really straightforward and that's the way I prefer it. I don't like it when people tiptoe around things 'cos then, when you actually realize it (that you are ill) it just hits you hard and causes too much stress. (Frederick).

For Ethan, the label confirmed that other people have similar difficulties and helped him normalize his prepsychotic experiences and self-perceptions.

It felt more of a relief to sort of know you weren't alone you feel a lot more sort of comfortable knowing that you are not a freak (Ethan).

This sentiment was echoed by Andy who reasoned that if the condition has been recognized and has a name then mental health services should be able to help him. Andy also reported feeling reassured by professional validation of his beliefs that something was wrong.

I knew there was obviously something wrong and the fact that somebody acknowledged that and I kind of had something to go away with that I knew somebody else had already noticed, then I could work with that ... If I hadn't been given anything then I might have been more worried about the future and stuff because I didn't know what was going on. With, the At-Risk Mental State kind of label it was helpful 'cos then I could read up and I knew how it was going to be dealt with (Andy).

“How others would take me” (Claire).

Whether or not to communicate the label to other people was a commonly expressed concern. Both Bethany and Claire especially felt anxious about what people might say about them in the future (“they are going to look at me and think ‘what's wrong with her’” Claire). For this reason, remaining quiet was seen as the best option (“I don't go mentioning it to anybody.” Bethany). Nevertheless, their anxieties and presumptions did not match up to actual experiences. Two chance incidents for Bethany and Frederick brought their conditions out into the open. For Bethany, a friend reading her thought diary was positive because she was not critically perceived as “crazy”. Moreover, the incident indicated to Bethany that despite her condition people were willing to be her friend.

I kept a diary of my thoughts and feelings and I took it to school in case I had an experience. As I was writing, one of my closest friends, who didn't actually know about my problems, snatched it off me 'cos she thought it was just like a regular journal. Then she had a look and she felt so sorry for me. It made me a bit more happier that she didn't exactly think I was completely crazy (Bethany).

For Frederick, his unveiling experience served to confirm that his friends were both supportive and concerned about his well-being.

Most of my friends saw me taking my medication. They realized that it wasn't multivitamins because they saw the

actual pill packet and asked what I was doing. I thought, well there is no point in hiding it anymore and I told them, and they just asked how I got to the state I was in and if there was anything they could do to help (Frederick).

Some individuals did report occasional negative experiences with their peers. Bethany had been particularly worried about experiencing stigma but when it occurred it did not appear to be particularly upsetting. It was offset by the positive opinions and acceptance of her friends (“I have the odd few people who take the mick out of me but then I have my close friends” Bethany).

The reaction of family members was also important. For all participants, home life appeared to be largely unaffected. Ethan, for example, was surprised by this but also relieved that his parents did not react in an overprotective manner.

They seem (my parents) quite supportive ... no drastic changes or anything, I wasn't suddenly sort of shunned or nothing like that (laughter) ... I was worried that they might become a bit protective but they understood that it didn't actually make anything different (Ethan).

“Just to have somebody to talk to” (Donna)

This quote by Donna nicely summarizes what participants found particularly valuable in their encounter with mental health services. Talking allowed them to share their problems in a safe environment without upsetting others who were close to them.

I just get everything out in the open and I don't have to worry about anything ... cos I don't exactly want to go and tell my mam about like if I have had an experience or anything. I just don't want to make her feel upset (Bethany).

For others, sharing upsetting experiences and teenage problems seemed to be cathartic. Andy discussed how his therapy sessions resembled weekly “chats.”

It was mainly about working week by week and every time I went (they) would ask if there was anything happening and if anything had stressed me out. And if anything had happened they would say, ‘how could you cope with that better? Could it have been worse?’ It was mainly just talking things through (Andy).

Frederick attested to the value of talking with a peer, ie, someone who can provide real empathy because of their own personal experiences.

Sometimes when you are talking to people and they are giving you advice you can't help but think they don't really get what you are going through ... you don't feel like they fully grasp the situation. That would be a time when it would be useful to talk to someone who has either been through a similar situation or has the same thing as you (Frederick).

Discussion

The interviews indicate that young people are eager to know about their condition and respect clinicians who

can provide information. The ARMS label appears to signal that treatment is forthcoming which is perceived positively, possibly because individuals are not currently psychotic and retain insight.⁶ These findings also echo the feelings of validation and relief reported by depressed teenagers on receiving a diagnosis.⁵ The reactions of concern, skepticism, and denial to the news about being at risk observed by other researchers^{4,7} were not apparent in our sample.

The hostility and stigma often experienced by people who are psychotic⁹ was feared but not experienced. Unlike many patients with psychosis, this group did not perceive or experience a loss of contact with friends.¹⁰ For the most part, these young people reported no major changes in how they were perceived by their family and friends and therefore appeared to cope well when and if any hostilities arose.

Stress reduction appeared to follow by simply talking to mental health professionals rather than from any specific intervention per se. The findings are in keeping with the experiences of adult Early Intervention in Psychosis service users who valued therapy most highly which allowed them to communicate their difficulties and which promoted interpersonal interactions with clinicians.¹³ The perceived benefits of talking to someone other than parents, especially a peer with an ARMS label, was also highlighted.

Strengths and Potential Limitations

To the author's knowledge, this is the first study to interview young people about how they understand and experience having an ARMS. However, the potential for a positive response bias during the study is high. Participants may have found it difficult to voice more negative or critical commentary and resist the ARMS label presented because they were receiving clinical care from a free early intervention in psychosis service. Furthermore, our sample was restricted to at risk subjects and did not include persons who had made the transition from risk state to full blown psychotic illness. Such individuals may have significantly different experiences, and future studies would do well to include them. Because of the risk of bias in this small sample of participants, it is important to be cautious about drawing any firm conclusions regarding stigmatization associated with the ARMS label.

Conclusion

Young people with an ARMS label feel gratitude at being told about their “probable” condition. They describe few if any significant negative changes in their interactions with peers and family, and they perceive talking to a mental health clinician as a form of treatment and support. More qualitative research such as this with families and with cases that convert is required to broaden our understanding of what it is like to be “at risk.”

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Supplementary Material

Supplementary material is available at <http://schizophrenia-bulletin.oxfordjournals.org>.

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