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A QUALITATIVE RESEARCH STUDY OF THE EVOLUTION OF SYMPTOMS IN INDIVIDUALS IDENTIFIED AS PRODROMAL TO PSYCHOSIS

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Abstract

Because schizophrenia is difficult to treat and exacts large personal and societal costs, there is an effort underway to identify adolescents and young adults at high risk for psychosis. Theory-derived criteria of subthreshold positive symptoms identify a “prodromal” or clinically at-risk population who have conversion rates to psychosis of 40 to 50% within one to two years. However, further characterization of the psychosis prodrome by qualitative research methods could increase the predictive value of the “prodromal” designation. We conducted open-ended interviews with 20 parents of prodromal adolescents that focused on changes observed. The narratives fell into two thematically distinct subgroups, identified as “declining” and “never normal.” The prodromal adolescents described as “declining” had a higher subsequent rate of conversion to psychosis than did the “never normal” group. Although preliminary, these results suggest that a trajectory of change in personality, relationships, and behavior from an essentially normal baseline may be consistent with increased risk for psychosis among prodromal adolescents.

Keywords

qualitative research; families; prodrome; psychosis; early intervention

INTRODUCTION

Schizophrenia is a serious disorder with great morbidity that is difficult to treat and as yet, nearly impossible to cure. It is costly both in terms of economics (1) and also in terms of personal cost for both patients and their families (2). Thus, there has been a move to identify individuals who are at risk for the disorder before the onset of frank psychosis.

Approaches to characterization of risk factors for schizophrenia have included longitudinal cohort studies and prospective characterization of individuals with enhanced genetic risk for the disorder, namely children of patients with schizophrenia. General population birth-cohort studies have confirmed that children who go on to develop schizophrenia have more delays in developmental milestones (walking and talking), more isolated play at ages 4 and 6, speech problems, clumsiness at ages 7 and 11, and poor school performance and social anxiety during their teens (3,4). Although these early deficits are more prevalent in individuals who go on to develop schizophrenia, they have low specificity, which means they are common among individuals who will never have schizophrenia. Therefore, they alone cannot be used to identify an at-risk population.

Longitudinal studies of offspring of schizophrenia patients have identified early predictors of later schizophrenia-related psychosis in individuals with enhanced genetic risk, including behavioral problems (5), thought disorder and negative symptoms (6), and deficits in verbal short-term memory, gross motor skills, and global attention (7). However, prospective studies of genetic high-risk individuals take decades to complete, as children are followed into adulthood beyond the range of ages of onset of schizophrenia. Also, although children of offspring have an approximately tenfold greater risk of schizophrenia and nonaffective psychosis compared with the general population (8), this still amounts to less than 20% of offspring of schizophrenia patients developing schizophrenia themselves. (9). This means that about four fifths of the sample in longitudinal genetic high risk studies will not develop schizophrenia and that large sample sizes are needed for these studies, which further add to the cost. An additional limitation of genetic high risk studies, apart from cost, is that they only characterize schizophrenia patients who have a family history of the disorder. As familial schizophrenia may differ from sporadic or nonfamilial schizophrenia, these studies may only characterize risk factors for a subset of all patients with schizophrenia.

Given these limitations, there has been an effort to identify and characterize adolescents and young adults who by virtue of demonstrating subclinical psychotic symptoms, or a significant decline in function in the context of genetic risk, provide an enriched sample of individuals who are at risk of developing nonaffective psychosis within a short period of time. These individuals have been called “prodromal” or clinically at-risk for psychosis. The plan for identifying individuals who have subthreshold symptoms of any disorder is known as indicated prevention. These efforts have been in place now for several years, beginning in pioneering clinics in Australia and in the Northeastern United States, and expanding to several sites worldwide. Measures now exist that can identify adolescents and young adults who have a 40 to 50% risk of developing psychosis within 1 to 2 years, based on symptoms and genetic risk (10,11,12). Of note, these studies all involve help-seeking individuals with significant morbidity, who have serious impairments in thought, emotion, behavior, relationships and performance in school or work.

One goal of these efforts, which is ambitious, is primary prevention. However, it is not clear that identification and treatment of these prodromal individuals, with either medications, such as atypical neuroleptics, or psychosocial treatments such as cognitive behavioral treatment, will prevent the onset of psychosis. Instead, the current evidence suggests that identification and treatment may delay the onset of psychosis in these vulnerable individuals. Nonetheless,

such delay of psychosis onset, as well as concurrent improvement in present morbidity, may be important in preventing significant psychosocial morbidity. There are many essential developmental tasks in adolescence and young adulthood, such as academic and social achievement, consolidation of identity and esteem, and formation of adultlike friendships and romantic attachments, that can be radically disrupted by both “prodromal” and psychotic symptoms. Further, a program of early identification and treatment of prodromal individuals may shorten the average duration of untreated psychosis, which in some studies has estimated to be as long as 2 years, and which may be related to worse outcome (13,14,15).

Identifying a population that has a 40–50% conversion to psychosis within 1 to 2 years is impressive, though it still means that 50–60% of individuals identified as at risk for a stigmatizing condition may never develop psychosis, and therefore be exposed unnecessarily to powerful medications which have unknown long-term effects on the developing brain. There is therefore a mandate to improve the predictive value of the prodromal designation.

As it stands, individuals are identified as prodromal or clinically at risk for developing a psychotic disorder largely on the basis of subthreshold psychotic symptoms. For example, one of the measures that identify the prodromal state, the Schedule of Prodromal Symptoms, was derived from the Positive and Negative Symptom Scale (16). The use of subthreshold symptoms to designate risk is a reasonable theory-based construct that has yielded good predictive value. However, it is possible that other factors, aside from subthreshold psychotic symptoms (and genetic risk) may contribute to being at risk for psychosis. In a recent study of prodromal patients, however, none of the following variables that are traditionally evaluated for schizophrenia risk were found to increase risk for psychosis beyond having subthreshold symptoms: obstetric complications, developmental milestones, childhood behaviors, premorbid adjustment, or any neuropsychological variables (11).

As the prodrome to psychosis is a relatively new construct formulated largely from theory, delineating its aspects may depend on moving beyond the implementation of established quantitative measures and instead employing the use of qualitative methods. Moller et al (2000) aimed to learn how first-episode schizophrenia patients and their families perceive initial prodromes naturalistically, as “the essential components of this phase, particularly the subjective experiences, remain unsettled” (17). They found four dimensions of prodromal behavior, including 1) significant decreased attendance and performance in school and/or work, 2) a major and persistent change in interests that was evident to others, 3) significant social withdrawal, isolation and passivity and 4) clear and lasting change in appearance and behavior. Disturbance in self-perception and preoccupation with overvalued ideas were also described in retrospect by first-episode psychosis patients and their families. It should be noted that these dimensions are not at all equivalent to the subclinical psychotic symptoms now used to define the prodrome, and include functioning and social behavior. Also, it is noteworthy that the concept of change is primary in each of these dimensions.

Given that a pattern of temporal changes in the evolution of problematic behaviors may elucidate the prodrome to psychosis, we have aimed to characterize the prodrome to psychosis not in retrospect, but as it is occurring. We decided to interview family members of individuals identified as prodromal to psychosis, instead of the prodromal patients themselves, for a host of reasons. First, we considered that symptomatic individuals may have difficulty in describing their experience when “prodromal,” given possible limitations in insight, sensory misperceptions, suspiciousness, emerging negative symptoms and cognitive impairment. This decision, made in 1999, was borne out by the findings of Moller et al (2000) that first-episode patients reported that they had had difficulty understanding and speaking about their “prodromal” experiences at the time they occurred (17). Second, it was evident among participants at the PRIME (“Prevention through Risk Identification, Management and

Education”) prodromal research clinic at Yale that prodromal patients are normally adolescents and young adults who live with their parents, who in turn know them well, are normally concerned about their welfare, and can describe changes in their behavior. Third, we hypothesized that family members would more frequently be the ones who seek help, as is common even for adults with serious mental illness (18).

SUBJECTS AND METHODS

The study sample included family members of individuals identified as prodromal to psychosis using the Structured Interview for Prodromal Symptoms (SIPS)/Scale of Prodromal Symptoms (SOPS)/Criteria of Prodromal States (COPS) (16). This study had approval from the Institutional Review Boards at the Yale School of Medicine, New York State Psychiatric Institute, and the Columbia Presbyterian Medical Center. “Prodromal” patients gave verbal (Connecticut) or written (New York) assent or consent for family members to be invited to participate in the study, and family members themselves gave written consent for participation. To capture as large a sample as possible, the only exclusion criteria for family members was an inability to speak English and/or inability to give informed consent.

Patients were asked which family member they thought could describe them best and who might be willing to participate in the study. With the assent or consent of the prodromal patient, family members were telephoned and invited to participate in an open-ended audiotaped interview that focused on what they had observed in their affected family member over time.

Participating family members had open-ended interviews that focused on the following points:

1. What changes have you perceived in the patient?
2. How have these changes affected you and your family?
3. What has been helpful or not?
4. What are your expectations for the future?

Data analysis followed established qualitative data analytic procedures (19,20,21). First, the interviews were audiotaped and then transcribed, and each of the three members of the research team separately read each interview and noted evident themes in writing. Second, consensus review and appraisal of themes for each transcript was done by the research group and documented. Third, the researchers then separately reviewed the consensus notes for each transcript and determined themes common across interviews. Fourth, the research team then met to perform a consensus review of common themes. Finally, review of the text of all interviews was done to ensure that these themes did in fact describe the completed interviews.

RESULTS

Nineteen of the twenty “prodromal” individuals were patients at the PRIME (“Prevention through Risk Identification, Management and Education”) research clinic at Yale University. In contrast, one “prodromal” individual was an inpatient at the Schizophrenia Research Unit at New York State Psychiatric Institute. The demographics of the family members interviewed comprised a mix of familial roles and ethnicities: 12 mothers and 8 fathers, and 12 Caucasian, 4 African-American and 4 Hispanic.

Themes Evident from Interviews

Qualitative analysis of transcripts was done for the 20 interviews of family members of prodromal patients. The narratives fell into two subgroups, which captured different themes and which described the prodromal family member in disparate ways.

The smaller subgroup consisted of 5 of the 20 transcripts and will herein be called the “never normal” group. Typically, in this subgroup, the prodromal individual is described as having always been different from the rest of the family, and by always being marked as having something wrong. Many of these prodromal individuals are described as having problems since birth, with clear developmental delays, early introduction into special education programs, and chronically being the target of teasing. The family members describe discouragement and exhaustion, and attest to neither a sense of hope or of loss, as opposed to the larger group of 15. The prodromal individual in this smaller subgroup of narratives is described as having always been broken or alien. Some family members express the wish that the child disappear or just be taken away and fixed.

In the larger subgroup of 15, herein called the “declining” group, the prodromal individual is described as having been essentially normal but vulnerable. Behavioral changes, including social withdrawal, odd behavior and anger outbursts were noted, such that the prodromal individual was perceived as “not like himself.” Family members describe evolving confusion, loss and sadness as they grapple with these changes. They often ascribe behavioral and personality changes to drugs, the wrong crowd, stress or the storminess of adolescence. They wonder if there is a voluntary aspect to the individual’s behavior, and they seek help from extended family, friends, the school and the church. Eventually, symptoms evolve to the point where they are seen as clearly problematic, and include the appearance of voices, poor hygiene, aggression, and anger. There is a crisis of hope and families then seek help from mental health professionals. There is a guarded hope for the future.

The “Never Normal” Group

The Prodromal Individual Is Seen as Never Having Been Quite Normal—It is typical that in this group, the prodromal family member is perceived as having been different, even as a baby. One woman reported of her older son “You know, he was a quiet baby. At five months, he got pneumonia and from then on he was just different. It was hard for me. He didn’t like to eat. When he was two, I took him to a doctor because I was worried. He stopped talking. The doctors, they sent us to the schooling for special, specialized kids. Many things after that came really slow. And, you know, it took a long time for him to learn a new thing.”

Of her younger son, who was also enrolled in the PRIME prodromal research clinic, she said, “The first thing I thought when he was born was that it took him forever. And he was born with the cord around his neck. They put him on my stomach and I remember thinking why isn’t she taking him off, this kid is heavy.” She added, “He was like a rug runner. He would wake up in the morning and run up and down, breaking things. All day long. He’s always been like that.”

Another mother reports “He had problems with his walk. I’ve been taking him to doctors since he was two. He would run a lot and fall and hit his head a lot. He couldn’t balance. Something was wrong. Kids would pick on him and tease him all the time. He had a speech problem. He was a little slower.”

In the two remaining cases in this smaller subgroup, the children were identified as being worrisome simply because of their histories of having a psychiatrically ill parent who abused or neglected them, and further behavior then confirmed that they were fundamentally different from other members of the family.

In the first case, a woman describes her son, who was allegedly sexually abused by his psychotic father when he was young. She said, “I have been concerned about him for years and I always felt that he seemed kind of paranoid. I was told that when he hit adolescence I might kind of have to watch it. He was always a very sensitive kid, fearful in a lot of different ways. You

could never count on him to sort of go along with anything routine. He was always a little bit touchy. He just doesn't seem to have a whole lot of sense. He and his biological father are so alike physically—their body type, their appearance, even their handwriting. Even when he was a baby, he was an edgy little kid. He didn't want to bounce, he didn't want to cuddle.”

Another woman describes her foster daughter: “She moved into my house at eight years old. She had a pervasive mood of unhappiness and put a wet blanket on everything. There are two things about her that are difficult to live with. One is her tone of voice. It is either totally bored, or snide and sarcastic. The other, which could be part of her personality, is that she never went anywhere or did anything. She is just a loner. People ignore her because they are tired of engaging her. She is like a vessel that is never full. No matter how much you give her it is not enough. She will always find something wrong no matter what you do. I sometimes think it is real selfishness on her part.”

It should be noted that although these five prodromal patients were identified as not ever having been truly normal, some parents describe a further escalation of late, especially regarding problematic behavior. Of the two boys described initially, the older one started getting into fights, shoplifting, talking to himself, staying in his room, and calling his mother a bitch and threatening to kill her. The younger boy started to play with fire and kept a knife under his bed. The boy who was sexually abused by his psychotic father in his teen years began shoplifting and stealing from family and friends, getting suspended from school, and spending hours in front of the mirror, calling himself a jerk or retard, and threatening to kill himself.

Family Members Describe Exhaustion and Feeling as if They Are Out of Options

—In this never normal group, the family members display a sense of fatigue and hopelessness. Prominent problems since childhood have only worsened. The mother of the two boys in the prodromal clinic said of her older son, “After a while, I quit listening to him. I just tune him out. My mother kept saying that all he needed was a spanking. The only thing that would help him would be to slap him.” She adds “How do I deal with it? Sometimes I don't. He just gets annoying. At work, I know what I'm doing, but at home, I don't think so. At work, if something breaks, I know how to fix it. But at home, something happens, and most of the time, I don't know what to do. It's a little late. Nothing is specific or definite. I just hope that they won't grow up too crazy.” She adds that her older son told a friend that his family doesn't love him enough and that his mother doesn't pay enough attention to him, and she laughed and said, “Sometimes it's true.”

Of her younger son, she said “I lost my patience and I haven't tried anything for a long time. The parenting classes, you sit there and you're listening to all these people. The last time I went I was there by myself watching a video. Not very helpful. How tired I am. It takes a lot of energy. Just to get out, just to get up in the morning. To find some more energy from somewhere. You go through all these things. It's kind of a little too much. I never pay attention to his grades because I don't know if they're real or not. They keep passing him from grade to grade to grade and he doesn't know anything.” Another mother echoed this sentiment: “The schools have been terrible. They don't understand that he's different.”

The mother of the son whose father was ill stated “It's not easy. We put up with a lot. He is just an overweird kid that is hard to cope with at this point. If he got a diagnosis, I would feel vindicated as a parent. He says now he'll kill himself but he's just being manipulative. There doesn't seem to be a sufficient solution, let's put it that way, and none of it is helpful. I guess part of me thinks that somehow if he could just get taken someplace and be fixed and sent home again, maybe our problems could be solved. I think there is really something different about his brain.”

The mother of the daughter who entered her home at eight reported “Nothing has been helpful. Because nobody has ever been able to find a key that helps her to be anything different. Except maybe to accept the fact. I’ll tell you one thing that I guess helped. Her therapist told us she doesn’t want to be a part of our family. That she is a boarder in our house. With her, it is like putting life in a corpse sometimes. It is so different from raising my other kids, which is like taming these wild acting out kids. It’s easier for me to do that than for me to have somebody for which there is nothing.”

The Declining Group

The Prodromal Individual Was Normal but Vulnerable—In this subgroup of 15, the declining group, the prodromal individuals were described as essentially having been normal when younger. Some were described as entirely normal, and quite social and related: “He was always bubbly, wanted to get you on his side. He is creative and very visual.” “If you walk next to her you could just feel the warmth. This glowing being. It’s incredible. Extremely gentle. An immense feeling for animals.” “He was a nice kid, a very caring person.”

More often, however, the adolescents in this group were described as essentially normal, though with some vulnerability, such as shyness: “He has always been a little bit of a loner, even as a child.” “My son was always shy and withdrawn. People laughed at him, made fun of him and hurt his feelings.” “He had always been shy and timid.” “One part of her is like a typical teenager but the other is abnormal shyness, to the point that kids pick on her.” This shyness, however, is frequently clearly delineated from the more recent emergence of fear or profound social withdrawal: “He was always shy, but he wasn’t fearful. Shy is not fearful. You can tell when a person is shy and when a person is fearful. And this now was like fear.”

Other vulnerabilities that parents describe include a liability for outbursts, or being overly generous or especially compliant, or having little initiative:

“He is a bigger than normal kid, and he is very lovable and easygoing. But if he makes up his mind that he doesn’t want to do something, he’s just not going to do it. So he had outbursts when someone pushed his buttons.”

“He didn’t ask much – a nice polite kid who gives everyone everything. He was shy and I had to make him do things. He can be taken with the flow—others are stronger. He’s gentle.”

“She was always easy to get along with, very agreeable, and hardly ever talked back. But I wasn’t comfortable leaving her alone.”

“My son is basically a normal teenager – you tell him to do something fourteen times and he doesn’t. He is middle of the road, not exceptional. He’s no Bill Gates. He’s a stumbler, never been a leader, always the middle of the pack.”

The Change Involved a Transformation, Such That the Person Was No Longer Himself—Of great surprise was that parents frequently described their children as having undergone a profound alteration i.e. “It was like a whole different person.” “He adopted a whole new identity.” “Now my daughter is a case study.” The language that is used to describe this metamorphosis can be striking, even evoking possession and monsters:

“I didn’t know if he was possessed by the devil because he was himself one day, and then dramatically different and not coming back. So I called my mother. Mental illness never entered my mind.”

“Everything changed about him. It’s like a different person. Like we don’t even know him. Like a stranger. His brothers are scared of him because he talks to himself. It’s hard because I don’t even know this person. He’s always been a lovable person and then this monster came out. The big change in him—that was the hardest thing for me to realize and get over.”

Profound Changes Are Comprehensive and Involve Personality, Mood, Behavior, Hygiene, and Social Withdrawal

Of the boy above who was described so dramatically, the changes appeared to include a whole host of dimensions:

“It’s just the change in school, behavior. The attitude with the kids around the house. With his brothers, just being violent to them. Telling me what he’s not going to do. Compared to the way he was, anything that I would say, he would say ‘okay, I will do that in a minute’. Just all changed. Smoking, hanging out, drugs. Just the whole big turnaround. Everything has changed. The teachers noticed he became more quiet, sitting in the corner in the back. He wouldn’t talk to anyone and lost all his friends. The calls stopped. The girls stopped. His appearance changed. Before, he wanted to get haircuts every week and have the best of clothing. Now, he didn’t care what he put on, he would just grab it off the floor. Just everything changed, everything. He was very particular about his clothing, about his hair, and then during the past year and a half, two years, he just goes all reverse. He used to joke around with his friends. Now none of that. He talks to himself in his room, and just starts laughing for nothing. He just stays in his room the whole weekend and won’t bathe, won’t do anything.”

Changes Are Seen in Dimensions Reported for First-Episode Patients, Including Interests, School Performance, and Social Interactions

As was reported for the prodrome for first-episode patients, prodromal individuals have a change in interests i.e. “Now he’s changed. He doesn’t like to do those things no more, like go to the movies or to stores, or to ride his bicycle or play basketball.” School performance also commonly declines, and was seen in more than half of the sample. For example:

“School is the big issue. He doesn’t feel he has to do homework. He doesn’t feel he has to go to school. He just wants to be a bum and go to the Library of Congress just to sit there and read. He merely went to school, showed up and that’s all he did. He purposely would select the wrong answer. In October, he chose to give up. He failed every class.”

“Certainly, his academic status – he was struggling, whereas he never struggled before. He was failing one course and not doing well in a second, but in essence, up until 8th grade, he was an A or an A/B student.”

Social withdrawal (and social fear) are also commonly reported, again in the majority of prodromal teens:

“From the beginning he was having problems at school, at home. He was fearing people might watch him. We just try to all tell him, nobody is looking at you. It got so bad that he wouldn’t go to school. Because he was feared.”

“He runs away and locks himself in his room. He feels uncomfortable, he feels like he doesn’t want anybody to see him now. He doesn’t like to go out and he doesn’t like to go anywhere. He doesn’t want to go to school. He complains he feels uncomfortable there.”

“His minimal number of friends disappeared. He spends a great deal of time in his room. Getting him to come out can be like pulling teeth. His social skills are not good and they got worse in the past couple of years.”

Although Changes Are Profound, They Can Be Insidious in Onset and Therefore Often Fully Understood Only in Retrospect

Family members frequently describe that the changes that have occurred in the prodromal individual were gradual and were therefore either not fully appreciated or seemed to warrant a wait-and-see approach, or were ascribed to the vicissitudes of adolescence, including acting out. For example:

“I have treated her as a lot younger than she is for quite a long time. I didn’t even realize I was doing it. I was getting concerned that she totally believed in Santa Claus and eventually I had to tell her. She would walk around pacing, and it would drive me crazy. She had a mental story going on in her head. Her coordination was way off. She was always a little bit clumsy – it was kind of a joke. All this time I thought she was trying to get the other kids to laugh. But I realized she doesn’t have control over it.”

“He seemed angry. He would clench his fists and bite his fingers. Seemed so nervous. For two months. I kept thinking something wasn’t right here, so I watched and waited. I didn’t know what was happening. Then, it became apparent something was wrong. I wish I had jumped on it faster. I kept thinking something wasn’t right. My gut reaction was to take him to someone to talk to, but I didn’t, and I regret it.”

“At first I thought he was just acting out. Then I realized that something had to be mentally wrong with him, because he is not that kind of person.”

“So what I thought was a developmental bump was the first sign of a gradual decline to disability.”

The Breaking Point

Despite the insidious changes that warrant concern and create confusion on the part of parents, eventually behaviors and/or symptoms emerge that are identified as truly problematic and outside what was considered possible for the individual. These include cursing, suicidal ideation and intent, dangerous behavior, cruelty to animals, and the reporting of auditory hallucinations or voices.

“My son was not himself – he became violent and indifferent and he chose the street. I knew something wasn’t normal and I had to show others. So I called the police. When he cursed, I knew something was wrong because he had never been disrespectful before. His language was foul, that’s not him.”

“When I came back, my son was showing suicidal signs. I saw the signs and I called the emergency hotline and he was hospitalized.”

“We had an episode where in fact he blockaded himself in his room. And we were concerned. He was assuring us he wasn’t going to hurt himself, but we couldn’t see him. We thought it was a dangerous situation, so we got several people on the phone. One of them was a psychiatrist.”

“She was killing a mouse, which is very unlike her. I mean she loves animals. She would like mice as pets. So immediately I called her family doctor and asked where to go from there.”

“But when he heard voices, my wife and I both thought he should see a psychiatrist.”

“It was like a bombshell when my wife and I heard how he was into drugs, not finishing work, had behavioral problems at school. I saw the fear and trembling of the school counselor and it was like a wake-up call.”

Parents’ Reactions to the Changes Observed in the “Declining” Group are Varied, and Include Grief and Sadness, As Well As Respite from Religion and Family, and Plans of Action

As mentioned earlier, the narratives that comprised descriptions of the “never normal” group had themes of exhaustion and hopelessness among family members. In contrast, sadness and great pain permeate the narratives describing the “declining” group. Poignant statements by parents include:

“It made me cry to see this peaceful, smiling child, who is full of life, be in a state of helplessness – it hurt me to the heart.”

“I felt helpless, like pounding on a brick wall. It hurt because this is my daughter.”

“I feel bad for him. He is my son and I love him.”

“It’s difficult to watch him not be happy. Happy defined in a very broad way – happy slash successful. Happy growing. I feel he’s missed out on so many fun things for teenagers.”

As with the parents of the “never normal” group, the family members of the prodromal individual express anger and frustration. However, they appear to differ in that the focus of this anger and frustration may be more general, such as a rage against mental illness itself or institutions, instead of the individual himself (or herself). The frustration expressed by these parents also seem to be more energized and less imbued with a sense of defeat. Examples include:

“I feel that he’s swimming against the tide, not with the tide. There’s a lot for us to do to get him to the point where he’s reasonably treading water. Another thing I have found frustrating, and maybe it’s part of what we’re learning about mental illness, is how long it has taken to get almost nowhere in our understanding of how to help him.”

“My family uses black humor to cope. I hate HMO’s. I have to work hard and I have financial difficulties. My family’s world has shrunk – no church, we don’t get out. I don’t want to parade around the mentally ill. I’m pessimistic. I lost my older son to mental illness – he died and no longer exists. I worry my younger son will go too. Each moment is precious because he may slip away.”

Corresponding to these differences between the two subgroups, there appears in the family members of the “declining” group to still be a sense of efficacy, reflected in plans for action, garnering support from family and friends, and a reliance on faith. Examples include:

“I knew something wasn’t normal and I had to show others. Prevention is part of my culture – herbs and prayers. A tree doesn’t grow by itself.”

“I would really just like to know what direction to go in to help her.”

“I would say, “Somebody can help him, I just have to wait and find them.”

“There really are going to be things that can’t be fixed. He’s going to be the person who he is, on the one hand. On the other hand, ferreting out the person who he is from the other things that are sitting on his shoulders at the moment, is really our goal.”

“I don’t know if I’m due for another ‘oops,’ so I am all eyes and ears looking for any little sign.”

“I knew he was good and I prayed for him.”

“I went to see a healing priest from Boston.”

Attributions

Among the narratives describing the “declining” group, there appears to be a greater effort by family members to consider and determine the causes of the problems they perceive in the prodromal teenager, perhaps because clear and fairly recent changes have been observed from an essentially normal baseline. These attributions are truly varied, and include stress, drug use, the storminess of adolescence, the wrong crowd, and even spiritual crises and physical origins.

The consideration of stress as a factor is prevalent among these narratives, and may correspond with the popular notion of a “nervous breakdown.” Pressure was frequently cited: “It went too fast. It was too much pressure.” “A new environment, peer pressure and just the fact that he felt overwhelmed.” “The pressure that goes on in school – that must be the trigger.” The metaphors used to describe stress included congestion and also weight: “He had too much on his plate. His mind was like a highway backed up.” “It was like he had one of those new buildings in New York – a skyscraper – on his shoulders.” Added another parent: “It was too many things to be in a young boy’s mind of 16 to 17 years old.”

Adolescence itself, with its assumed storminess, as well as the wrong crowd, and experimentation with drugs, were also considered as possible sources of perceived changes, as seen in the following quotations:

“I just hope it’s an adolescent thing that will be self-correcting.”

“For a long time I was in denial. I just thought he was acting out. I couldn’t see that my child needed help mentally.”

“I thought she was being spoiled or unappreciative because I didn’t understand. Now I realize she couldn’t help it.”

“He had been with other kids with trauma – they were loud, fighting, smoking, doing what they want, piercing their ears and talking about sex. They had some influence on him.”

“I wondered if someone put hallucinogens in the punch at a party. Maybe LSD can send someone who doesn’t have a strong mind on a neverending trip.”

“Was it drugs? Was it addict behavior?”

Spiritual crises and physical causes were also considered by parents of the prodromal individuals whose descriptions fit the “declining” category:

“Maybe the devil has something to do with his headaches. That girl’s from a place with witchcraft. Maybe she’s sticking pins. My wife blames the Catholic Church. I think my sons may have trouble because my wife left the Catholic Church. It’s not good to go against God – you can lose your soul.”

“He is struggling in Jesus Christ and God.”

“I wonder if his back injury caused his problems – you know, the spine is hooked up to the head.”

“I was exposed to Agent Orange. I think that maybe Agent Orange gets in your blood and it affects your kids. I’ve met other vets whose kids have weird stuff. He did get a lot of X-rays, they didn’t cover him up. Maybe he got too many dosimeters or REM’s.”

As with some of the prodromal individuals who were seen as never normal, genetics are considered as an attribution, specifically in those cases in which a family history is known. One father reported that many people have noticed that his ill wife and now prodromal daughter are very similar, in terms of being very compliant, saying off the wall things, and in being inattentive to clutter. His daughter even asked him if he hadn’t noticed the resemblance, and if so, why he didn’t bring her for help sooner. Another father wondered “Maybe I have a fearful gene for shyness, a bad one that snuck in. Maybe my weakness was too weak and spilled into my son.” And a grieving father complained: “My wife’s brother has schizophrenia. Her family is full of people who balloon up and fall out of society.”

Expectations for the Future

Another profound way in which the family members of the “declining” group differed from the parents of the “never normal” group was in their retaining of hope for the future, even though these expectations were diminished and they were worried about their children. Parents mostly describe simply wishing that their children will be happy and functioning, no matter what they choose. There are many poignant examples.

“I want him to have peace of mind, find his own self, but I worry he’ll be led and swallowed.”

“I want my son to go out, make a living, have a positive influence. I’m worried he’ll get into drugs or the wrong crowd. I’d like to be a grandfather some day. I want him to be the best at what he wants, provide himself with amenities, and go on vacation when he wants.”

“I want him to be a good husband and decent guy who is close to the Lord.”

“I want to be able to see him functioning to the point that he is happy with what he does, even if that is sweeping the streets.”

“Whatever he chooses. And if he chooses to be an auto mechanic that’s fine too.”

“I want him to be productive and be able to take care of himself, just be an outstanding good all-around man. I want him to be able to take care of himself. Understand what he wants to do and know that he has to do it in order to survive. I want college for him but if he wants to go to trade school, I want him to go. My worst fear is that he’ll be in jail or dead or even living on the streets.”

“I want to be optimistic but I feel maybe she can only be helped so much and then this will happen again. I fear she will backslide. My only hope is that she will be happy and enjoy life. I hope a bomb won’t fall, like in the past.”

“I just want him to have a good life and he hasn’t had that for a long time. His ability to go to Yale, for example, was his dream, which he probably could have done. And it’s not going to happen. We’re thinking about a local community college at this point, which is not a bad thing, but it’s a sad thing.”

CONCLUSION

The narratives of family members of prodromal individuals in this sample of 20 appeared to sort into two subsets thematically, with the most evident difference between the subgroups being the degree of change that was noted. This difference between individuals who were seen as never quite right and those who were normal but then gradually declined can explain many of the other variations in themes seen between the two groups. For example, exhaustion may be expected in response to longstanding serious problems whereas an evolution from essentially normal to greatly troubled would be predicted to lead to grief, sadness, anger, planning and action, and seeking of respite in family and religion. A transformation over time might also be expected to lead to the generation of many theories of causation and also the hope, although attenuated, that the individual may return to some extent to what he or she was, and be able to achieve happiness and independent function.

The themes that emerged from the “declining” subgroup are similar to those described by Moller et al (17), and include changes, specifically in school and work performance, interests, appearance and behavior, and in social functioning. These themes, again with an emphasis on an evolution from normal but vulnerable to abnormal, also characterizes what we found with a sample of fifteen family members of first-episode psychosis patients (unpublished data). This similarity to what is recalled by first-episode patients and their families adds to the validity of the findings in a prodromal sample that a progressive change in several dimensions may be an important aspect to the prodrome to the psychosis. It should be noted that although preliminary, and not statistically significant, different rates of known conversion to psychosis were found in the “never normal” group (40%) and the “declining” group (60%) in this sample. The rate in the “declining” group may in fact be larger as 5 of the 15 prodromal patients in this group either dropped out or were lost to follow-up, so that only one individual survived to completion of the study without conversion or dropout. In contrast, 3 of the 5 “never normal” individuals completed the PRIME study without conversion to psychosis, including the two boys of the same mother, and the troubled adopted girl.

This is one of the first studies to employ qualitative research methods to more fully characterize the prodrome to psychosis. The findings add to what is known from first-episode studies, and obviate a potential criticism of a first-episode study, specifically retrospective attributional bias. The findings here suggest that temporal patterns may be important for the characterization of the psychosis prodrome, beyond expression of subclinical psychotic symptoms and genetic risk. It also belies the assumption that the seemingly most ill individuals with longstanding problems would have the highest risk of developing psychosis. These individuals may have symptoms that overlap with prodromal symptoms but which may in fact represent other disorders, such as the “multidimensionally impaired” syndrome or MDI, which is characterized in children and adolescents as having poor attention and impulse control, psychotic symptoms, and poor affective control (22). This is consistent with paradoxical findings among prodromal individuals, such as smaller baseline volumes in some brain regions in the prodromal patients who do not become psychotic (23).

Alternatively, the differences between the two groups may not be a real difference in psychopathology or attributable to patient factors, but might instead reflect characteristics of the family members. A woman raising by herself two children who are hard to handle may very well feel exhausted and hopeless. Lack of biological relatedness, real or perceived, may also influence a parent’s perception of the normalcy of a child. Further studies are needed to tease apart individual and family factors in the construction of narratives of the prodrome, and whether these confound clinical descriptions of the course of the evolution of psychosis.

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