Self-reported coping strategies in families of patients in early stages of psychotic disorder: An exploratory study

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Abstract

Aim—Coping by families of patients with schizophrenia include "approach" strategies considered to be adaptive (eg reinterpretation) and potentially maladaptive "avoidant" strategies (denial/disengagement, use of alcohol and drugs). Little is known about coping strategies used by families of individuals with incipient or emergent psychosis.

Methods—Self-reported coping styles were assessed in family members of 11 ultra high risk and 12 recent-onset psychosis patients, using a modified version of Carver's Coping Orientations to Problems Experienced questionnaire.

Results—Families reported moderate use of "approach" coping (eg planning, seeking social support, positive reinterpretation, acceptance, and turning to religion) and rare use of "avoidant" coping strategies (denial/disengagement and use of alcohol and drugs).

Conclusions—The greater endorsement of "approach" coping by these families is consistent with findings for families of first episode psychosis patients, and is in contrast to more prevalent "avoidant" coping by families of patients with more chronic psychotic illness. Early intervention could plausibly help families maintain the use of potentially more adaptive "approach" coping strategies over time.

Keywords

coping; psychosis; family; prodrome; risk

Introduction

Caring for a young person with incipient or emergent psychotic symptoms is challenging, as families are typically instrumental in caring for and finding treatment for their ill loved one[1,2,3]. Yet little is known about the strategies these families use to cope with new caretaking demands. Disparate coping strategies have been traditionally conceptualized as "adaptive" vs "maladaptive" *or* as "problem-focused" vs "emotion-oriented".[4,5] Problem-focused coping (problem-solving, planning, taking action) has been seen as adaptive, and

emotion-oriented strategies (venting and denial) have been seen as maladaptive.[5] Some have challenged these categorizations, suggesting that the adaptive function of coping strategies may depend on environmental context and individual characteristics.[5,6] Stanton and colleagues have thus suggested an alternative rubric for understanding coping, categorizing "approach" strategies (including both problem-focused and emotion-oriented coping strategies such as seeking support and expressing emotions) vs. "avoidant" strategies (denial, disengagement).[6] In their conceptualization, approach strategies predict better adjustment over time[5,6,7], though others have suggested that denial and avoidance may be adaptive after an acute stressor such as a new diagnosis.[8] Nonetheless, approach vs. avoidance is a useful and non-judgmental construct for understanding coping.

Families of patients with established schizophrenia utilize approach strategies such as seeking social support and education, positive reframing and problem-solving, and reliance on religion[9,10,11,12], as well as avoidant strategies include denial and disengagement[11,12]. Families of patients experiencing a first episode of psychosis similarly used approach coping strategies including emotion-focused and problem-solving coping strategies to manage problematic behaviors, and spiritual coping to deal with stigma[13]. To our knowledge, no studies have been published yet which describe coping by families of young people identified as at heightened risk for psychosis. Herein, we describe coping strategies endorsed by a small cohort of families of individuals in early stages of psychotic disorder, who have either recently experienced an index episode of psychosis or who are demonstrating attenuated positive symptoms consistent with increased risk for psychosis.

Methods

Participants

This ethnically diverse cohort of twenty-three family members has been described previously[2,3,14,15]. In brief, they were family members (87% parents) of eleven ultra high risk (mean age 16.7 (SD 3.1)) and twelve recent-onset psychosis (mean age 20.8 (SD 3.0)) patients identified at specialized research programs at academic centers. Patients were primarily male (83%). Ultra high risk status was identified using the Structured Interview for Prodromal Syndromes (SIPS)[16]. Among patients with recent-onset psychosis, all had received first treatment for psychosis within the past year: of these, six had only just begun treatment during their current hospitalization. Estimated durations of psychotic symptoms at time of interview were: 3 years ($n = 3$), 1 year ($n = 3$), 6 months ($n = 1$), 2 months ($n = 3$) and 'unknown' ($n = 2$). Diagnoses were determined by chart review: six with schizophrenia and six with psychosis not otherwise specified. Of note, selection of patients was not random and represented a sample of convenience. Patients were asked to nominate a preferred family member to be invited for study participation. The only exclusion criterion for families was an inability to speak English. No individuals (patients or families) refused participation in the study. Both patients and family members provided informed assent and/ or consent and the study had approval from the Institutional Review Boards at the Yale School of Medicine, New York State Psychiatric Institute, and the Columbia University Medical Center.

Measures

Coping was assessed using a modified version of Carver's Coping Orientations to Problems Experienced questionnaire (COPE)[17], which comprises fourteen subscales (Table 1). The modification to the scale entailed changing the language in items to make them specifically relevant to coping with a relative's mental illness i.e. the original item "I try to grow as a person as a result of the experience" was modified to "I try to grow as a person as a result of my relative's mental illness". Also, four items from the original scale were omitted as

possibly redundant and an additional subscale was used to evaluate the use of alcohol or drugs as a coping strategy. Each item was read aloud and verbatim by a member of the research team, and the family member then rated each item as to their frequency of use along a four-point Likert scale: 1 = *not at all* to 4 = *a lot*.

Data analysis

Self-reported frequency of use of different coping strategies was described. Associations with demographic variables were also evaluated in an exploratory fashion. Associations with family burden and stigma were not evaluated, as these have been found to be consistently low in this cohort. [14,15]

Results

There was a gradient of frequency of employment of disparate coping strategies, with approach coping more commonly endorsed, and avoidant strategies less so (Table 1). Many approach strategies were endorsed as being done "a medium amount" on average (i.e. score ~3.0), including active coping, planning, suppression of competing activities, seeking social support, positive reinterpretation and growth, acceptance, venting of emotions, and turning to religion. By contrast, avoidant coping strategies such as denial and disengagement were reported less frequently, between "usually don't do this at all" and "usually do this a little bit".

There was no clear differentiation of use of coping strategies by whether affected family members had experienced an index episode of psychosis or were identified as at heightened risk for psychosis (Table 1). No ethnic differences in coping strategies were observed (data not shown). Men tended to report greater use of positive reframing (subscale 7; 3.6 vs. 3.2), venting of emotions (subscale 10; 2.4 vs. 2.0) and use of drugs and/or alcohol (subscale 14; 1.8 vs. 1.3) whereas women appeared more likely to use "religious" coping (subscale 9; 3.3 vs. 2.8). These differences were not statistically significant in this small sample.

Discussion

In this exploratory study of coping styles used by families of individuals with emerging psychotic illness, coping strategies categorized as "approach" strategies were endorsed as being employed with a "medium" frequency, while avoidant styles (denial and disengagement, including through use of alcohol or drugs) were endorsed as being used only "a little bit" or "not at all." The approach coping strategies endorsed were comparable to that reported by families of patients with established psychotic illness[19], including problem-focused coping and the use of social support and education[9,10,11,20], and coping through religion[10,11,12]. Similar use of these strategies has previously been described in families of young people with an index episode of psychosis[13], suggesting some continuity or similarity of approach coping strategies by families over time. This is further supported by our finding of comparable coping patterns by families of young people identified only as at risk for psychosis.

By contrast, the avoidant coping strategies described as rare in our cohort, have been more frequently described for families of patients with more chronic disorder, including denial and disengagement[10,11]. This apparent increase in frequency of use by families of avoidant coping strategies for more chronic illness suggests increased fatigue and burden for families over time. This is supported by the previous finding (using the same coping scale utilized in the current study) that for families of more chronic patients, less burden and distress are related to increased use of coping strategies such as active coping, reinterpretation, acceptance, and turning to religion. A putative downward spiral over time of avoidant

coping strategies and family burden could plausibly be interrupted through family support and intervention21·22·23, with potential advantages accruing to patients and their families alike. A variety of (mostly cognitive-behavioral) interventions have been developed to influence coping strategies, though it remains unclear which coping styles and strategies are most amenable to intervention.24 Furthermore, caution must be taken to balance these potential advantages with the possible risks of such intervention, such as stigmatization25.

Limitations

This is a small exploratory study of coping strategies described by families of individuals in early phases of psychotic disorders. The cohort is nonrandom and of limited generalizability, and there was insufficient power for evaluating associations of coping with demographic characteristics and with indices of family burden. The descriptive nature of this small study is such that it largely provides data which can inform further research on the nature of coping in families of young people with emerging psychosis, such that intervention strategies may be developed to help these patients and their families.

An additional potential limitation is that these self-report data may be subject to both recall bias and social desirability bias; however prevalent avoidant coping strategies have been found in other cohorts using this same measure of coping (Fortune et al., 2005), suggesting such effects may not account for the finding of rare use of avoidant coping strategies in this sample.

Acknowledgments

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Table 1

Self-reported Coping Strategies in Families

Modified COPE scale (Carver et al., 1989) 1 = "*I usually don't do this at all*" 2 = "*I usually do this a little bit*" 3 = "*I usually do this a medium amount*" 4 = "*I usually do this a lot*".	ULTRA HIGH RISK (N = 11)	RECENT ONSET PSYCHOSIS (N = 12)
	Mean (SD)	Mean (SD)
1) Active Coping	**3.6 (0.5)**	**3.7 (0.5)**
I concentrate my efforts on helping my mentally ill relative do something abut his/her illness	3.6 (0.7)	3.8 (0.6)
I do what has to be done to see that my relative gets services and care for his/her mental illness	3.8 (0.4)	3.8 (0.6)
I do what has to be done for me to cope with my relative's mental illness	3.7 (2.0)	3.6 (0.5)
2) Planning	**2.9 (0.8)**	**3.2 (0.8)**
I try to come up with a strategy about what to do	2.7 (1.3)	3.2 (1.0)
I make a plan of action to deal with the problems	2.8 (1.1)	2.9 (1.2)
I think hard about what steps to take	3.3 (0.8)	3.5 (0.8)
I think about how I might best handle the problems	3.3 (0.8)	3.2 (1.3)
3) Suppression of competing activities	**3.0 (0.7)**	**2.8 (0.8)**
I put aside other activities in order to concentrate on this	3.2 (0.9)	2.9 (1.2)
I focus on dealing with this problem and if necessary let other things slide a little	2.9 (0.9)	2.9 (1.2)
I keep myself from getting distracted by other thoughts or activities	2.5 (1.2)	1.9 (1.3)
I try hard to prevent other things from interfering with my efforts at dealing with this	3.8 (1.9)	3.3 (0.8)
4) Restraint coping	**2.1 (0.8)**	**1.9(0.8)**
I force myself to wait for the right time to do something	1.8 (0.8)	1.5 (0.9)
I hold off doing anything about it until the situation permits	2.6 (2.3)	1.8 (0.9)
I make sure not to make matters worse by acting too soon	2.5 (1.3)	2.3 1.4)
I restrain myself from doing anything too quickly	2.0 (1.1)	1.9 (1.1)
5) Seeking social support for instrumental reasons	**3.0 (0.7)**	**2.7 (0.9)**
I ask people who have similar experiences with their mentally ill relative what they did	1.6 (0.9)	2.2 (1.3)
I try to get advice from someone about problems I have with my mentally ill relative	3.3 (0.9)	2.8 (1.1)
I talk to someone to find out more about particular situations I encounter with my mentally ill relative	3.8 (2.0)	2.7 (1.3)
I talk to someone who I think could do something concrete about a problem I have with my mentally ill relative	4.0 (1.7)	3.3 (1.1)
6) Seeking social support for emotional reasons	**3.1 (0.8)**	**2.7(1.2)**
I talk to someone about how I feel about my mentally ill relative	2.8 (1.2)	2.5 (1.4)
I try to get emotional support from friends or relatives about my relative's mental illness	3.0 (1.1)	2.6 (1.3)
I discuss my feelings about my mentally ill relative with someone	3.5 (0.8)	2.7 (1.2)
I get sympathy and understanding from someone about my relative's mental illness	3.1 (1.2)	2.8 (1.3)
7) Positive reinterpretation and growth	**3.1 (0.9)**	**3.5 (0.5)**
I try to see my relative's mental illness in a different light, to see the strengths and positive characteristics of my relative	3.3 (0.9)	4.5 (2.2)
I try to learn from the experience of having a mentally ill relative	3.0 (1.1)	3.9 (1.7)
I try to grow as a result of my relative's mental illness	3.09 (1.0)	3.9 (1.7)

Modified COPE scale (Carver et al., 1989) 1 = "*I usually don't do this at all*" 2 = "*I usually do this a little bit*" 3 = "*I usually do this a medium amount*" 4 = "*I usually do this a lot*".	ULTRA HIGH RISK (N = 11)	RECENT ONSET PSYCHOSIS (N = 12)
	Mean (SD)	Mean (SD)
8) Acceptance	**3.1 (0.6)**	**2.4 (1.0)**
I have learned to live with my relative's mental illness	3.7 (2.0)	3.6 (2.8)
I accept the fact that my relative has a mental illness and I cannot change the fact	3.2 (1.0)	2.5 (1.3)
I have gotten used to the fact that my relative has a mental illness	2.8 (1.0)	3.6 (2.8)
9) Turning to religion	**3.0 (1.0)**	**3.4 (0.9)**
I seek God's help	3.1 (1.2)	3.4 (1.2)
I try to find comfort in my religion	2.8 (1.2)	
I pray	3.0 (0.9)	3.3 91.2)
10) Focus on and venting of emotions	**2.2 (0.6)**	**2.0 (0.8)**
I get upset and let my emotions out	1.9 (0.9)	1.7 (0.9)
I let my feelings out	2.1 (1.0)	2.3 (1.2)
I find myself expressing feelings of emotional distress	2.3 (1.0)	2.3 (1.1)
I get upset and I am really aware of my feelings	2.6 (0.9)	1.9 (0.7)
11) Denial	**1.3 (0.3)**	**1.6 (0.8)**
I refuse to accept the situation	1.1 (0.3)	1.4 (0.9)
I pretend there is no problem	1.4 (0.7)	1.5 (1.0)
I act as though there is no problem	1.6 (0.7)	2.0 (1.2)
I say to myself "this isn't really happening"	1.3 (0.5)	2.6 (2.3)
12) Behavioral Disengagement	**1.5(0.5)**	**1.4 (0.5)**
I just give up trying to solve the problem	1.5 (0.8)	1.3 (0.8)
I admit to myself that I can't deal with it and quit trying	1.6 (0.8)	1.3 (0.6)
I reduce the amount of effort I am putting into solving this problem	1.6 (0.7)	1.5 (0.9)
13) Mental Disengagement	**2.0(0.6)**	**1.6 (0.6)**
I turn to work or other substitute activities to take my mind off this problem	2.6 (1.1)	1.8 (0.9)
I go to the movies or watch T.V to think about the situation less	1.5 (0.5)	1.5 (0.7)
I daydream about other things	2.2 (1.1)	1.4(0.9)
I sleep more than usual	1.7 (1.1)	1.5(0.9)
14) Alcohol-Drug Disengagement	**1.6 (0.7)**	**1.3 (0.5)**
I try to lose myself for a while by drinking alcohol or taking drugs	1.7 (1.1)	1.4 (0.9)
I use alcohol or drugs to help me get through the situation	1.5 (0.7)	1.1 (0.3)