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Comparable family burden in families of clinical high-risk and recent-onset psychosis patients

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Abstract

Aim—Family burden is prevalent in psychotic disorders, but little is known about burden experienced by families of patients in early illness. In this exploratory study, we examined the extent of burden reported by families of patients during a putative prodromal period and in the after-math of psychosis onset.

Methods—Family burden was assessed in 23 family members of patients with emerging or early psychosis. The Family Experiences Interview Schedule was used to assess both objective and subjective burden. Objective burden is comprised of increased resource demands and disruption of routine. Subjective burden includes worry, anger/displeasure and resentment at objective burden.

Results—Family burden was comparable for the clinical high-risk and recent-onset psychosis patients. Worry was as high as previously reported for more chronic patients. By contrast, there was a relative absence of displeasure/anger. Family members endorsed assisting patients in activities of daily living, although not ‘minding’ doing so, and reported little need to supervise or control patients’ behaviour.

Conclusions—Early in emerging psychotic illness, families report helping patients and worrying about them, but their lives are not yet disrupted and they do not have much anger or resentment. This may be an ideal time then for intervention with families, as worry may motivate help-seeking by families.

Keywords

family; prodromal; psychosis

INTRODUCTION

Schizophrenia and other psychotic disorders exact a high financial and emotional cost not only from patients, but also from their families, including parents and siblings.^{1–3} Family members experience high levels of burden with diminished quality of life,⁴ functional impairment,⁵ and decrements in health and well-being. Family burden has been associated with high levels of emotional distress,^{5–7} as well as anxiety, insomnia, social dysfunction and depression.⁵ Among family members, parents appear to be particularly vulnerable to such burden⁸ as they take on more tasks and also contribute more financially.⁹

Significant family burden is evident early in psychotic disorder, even with the first onset of an episode of psychosis.^{10–13} It is not yet known what burden families incur when a member is at heightened clinical risk or putatively ‘prodromal’ for a psychotic disorder, on the basis of having attenuated or subthreshold psychotic symptoms, or functional decline in the context of family history.¹⁴ Even before the onset of frank psychosis, this ‘ultra-high-risk’ state is characterized by cognitive deficits^{15,16} and social dysfunction,¹⁷ which have both been associated with family burden in patients with psychotic disorders.^{18–22} Therefore, burden may be as high among families of ultra-high-risk individuals as has been observed in families of first-episode psychosis patients.

Family burden has been conceptualized as consisting of both objective and subjective burden;²³ a common scale, the Family Experiences Interview Schedule (FEIS),²⁴ probes both. Objective burden includes financial expenditures, assistance in daily living, supervision of problematic behaviours and negative impact on daily routines. Subjective burden involves the psychological consequences of an individual’s illness for the family, such as an increase in worry and displeasure. The FEIS has demonstrated among families of patients with serious mental illness both objective and subjective burden, specifically worry²⁵ and a factor it loads with – increased resource demands and disruption of routine.²⁶ Analysis yields four factors of the FEIS in chronic schizophrenia patients: problem behaviour; resource demands and disruption of routine; impairment in activities of daily living; and perceived patient helpfulness.²⁶ In the present study we systematically evaluated burden using the FEIS. We chose not to use the factor solution derived for the measure with families of more chronic patients as it may not apply for families who have members at much earlier stages of psychotic disorder. We hypothesized that both objective and subjective burden would be similar for family members of both recent-onset and prodromal or ultra-high-risk patients.

METHODS

Sample

Patients were identified from both the New York State Psychiatric Institute and Yale’s Department of Psychiatry. Both clinical high-risk and recent-onset episode psychosis patients (and their families) also participated concurrently in a qualitative research study examining trajectories of symptoms and help-seeking patterns.^{27,28} The sample size is smaller here as the survey was administered after the audiotaped interview, and some families did not have sufficient time to do both. Selection of patients was not random and represented a sample of convenience. The only exclusion criterion was an inability to speak English and/or inability to give consent. 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. The clinical high-risk group of patients was identified as ‘prodromal’ to psychosis using the Structured Interview of Prodromal Symptoms/Scale of Prodromal Symptoms/Criteria of Prodromal States.¹⁴ For the recent-onset psychosis patients, diagnoses for patients in New York were made using the Diagnostic Interview for Genetic Studies²⁹ whereas diagnoses for patients in the Yale psychiatric system of care were obtained from chart review (using the most recent diagnosis documented). Patients were asked to nominate a preferred identified family member for assessment of family burden. Patients provided consent for their family members to be contacted and to be invited to participate. At both sites, family members provided written informed consent for participation.

Measure

Family burden was evaluated using the FEIS, a 180-item structured personal interview. The FEIS²⁴ is used to evaluate family burden in patients with mental illness. It assesses multiple components of burden associated with caring for a family member with psychiatric symptoms

and it queries the past 30 days. Objective domains include (i) provision of assistance in daily living; (ii) supervision of bothersome or troublesome behaviours; and (iii) impact on family members' daily routines (see Table 1). Subjective domains include affective responses such as (i) worry; (ii) displeasure/anger; and (iii) resentment at objective burden incurred (see Table 2). For each objective burden item, family members were also asked the extent to which they 'minded' the provision of assistance. Sums of ratings for each 'objective domain' and means of ratings for each 'subjective domain' were calculated. Each domain of objective burden has a possible range from a low score (all yes) to a high score (all no). Each domain of subjective burden yields a mean of ratings on Likert scales for each item. Of note, in each family burden domain, *lower* scores are associated with *greater* burden.

RESULTS

There were 11 prodromal and 12 recent-onset psychosis patients. As expected, both patient groups were primarily male (91% and 75%), and prodromal patients were younger ((16.7 (SD 3.1) vs. 20.8 (SD 3.0)), as were their family members (41.2 (SD 8.0) vs. 48.1 (SD 7.6)). Family members interviewed were primarily parents (91% and 83%, respectively), in particular mothers, although each group of informants included one adult sibling (who lived with the patient), and the recent-onset psychosis family group included an aunt who had raised her nephew. Family members of prodromal patients were primarily white (64%) with 27% African-American and 9% Hispanic. By contrast, family members of recent-onset psychosis patients were more ethnically diverse: 33% white, 25% African-American, 25% Hispanic, 9% Asian-American and 9% 'other'.

Burden reported by the two groups were similar. As for objective burden (see Table 1), the requirement to assist the patient in activities of daily living was high, but there was little need to supervise or control behaviours reported. Impact on daily routine was intermediate for both groups, reflecting endorsement of slightly more than 50% of the items. As for subjective burden (see Table 2), both groups worried at a frequency between 'sometimes' and 'often', and there was little displeasure or anger endorsed. Although patients required assistance in daily living, family members expressed very little resentment in doing this.

DISCUSSION

In this small exploratory study, we compared burden among families of recent-onset psychosis patients with that of families of individuals identified as prodromal or at elevated risk for psychosis. To our knowledge, this is the first study to examine family burden associated with a clinical high-risk or 'prodromal' state. Overall, levels of both objective and subjective burden were comparable in the two groups of family members. Family members reported frequently assisting patients in activities of daily living but denied any resentment or subjective burden in doing so. They largely denied needing to supervise or control behaviours in patients and described only moderate impact on their own daily routine. Worry was a common sentiment among family members, yet very little anger or displeasure was endorsed.

The finding of substantial assistance with activities of daily living is comparable to what has been reported by families of patients with established psychotic disorder,⁹ although family members in this study do not report the marked reduction in leisure activities described by families of patients with more chronic illness.³⁰ These early illness stages, with less symptom severity and chronicity, may require involvement by family without yet incurring significant disruption in their lives. This is consistent with families not 'minding' the provision of assistance with activities of daily living.

Subjective burden in this group of family members followed a similar pattern, with levels of worry comparable to what is described for more chronic patients,²⁵ but a relative absence of displeasure/anger and resentment.³¹ The average rating for worry on the FEIS among family members in this study, intermediate between ‘sometimes’ and ‘often’ (2.5 for recent-onset psychosis and 2.7 for prodromal patients), is comparable to that seen for more chronic patients (i.e. 2.2).²⁵ By contrast, the subjective burden of displeasure/anger and resentment expressed by parents in this study is less than what has been reported by families of more chronic patients:³¹ specifically 3.7 for prodromal patients and 3.9 for recent-onset psychosis patients (where 3 = ambivalent and 4 = disagree) versus 2.3 for chronic patients (2 = agree).

Therefore, early in illness, families report helping patients and worrying about them, but their lives are not yet disrupted, and they do not have much anger or resentment. This may be an ideal time then for intervention with families, as worry may motivate help-seeking by families.^{3,32,33} It is promising that among ultra-high-risk adolescents, positive family environment (with higher levels of caregiver emotional involvement, positive remarks and warmth) has been shown to predict improvement in symptoms and social functioning among adolescent patients.³⁴ Family psychoeducation^{35,36} in these early illness stages could plausibly alleviate family burden^{36,37} and improve patient outcome. This is consistent with the interactive/hybrid model for patients with early psychotic illness, whereby ‘feedback loops exist, with the family responding in certain ways, which in turn affects the individual and so on’.³⁸

Limitations in this study include the potential for selection bias, especially regarding ethnicity, as inability to speak English was an exclusion criterion, and there was a greater prevalence of ethnic minorities among recent-onset patients and their families. This imbalance may be due to delays in seeking help from mental health services in ethnic minorities,^{39–43} which may be related to stigma,^{44–46} fear or cultural mistrust^{47–50} and/or socioeconomic status.^{51,52} The differential ascertainment is unlikely to be due to population differences, as both groups were ascertained from the same sites. Overall, as the recent-onset group had a greater prevalence of ethnic minorities, we would not expect this disparity to obscure an association of family burden with more advanced stages of illness. However, this is a preliminary study with a small sample size. A larger study is needed to better understand the determinants of family burden in early psychosis, so that effective interventions can be designed.

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TABLE 1

Objective burden: probes and responses

Burden	Probes	Prodromal	Recent onset
Objective	Mean (SD)		
Assistance in daily living (ADL)	During the past 30 days, did you help or remind (patient's name) to		
1 = yes	... do things like grooming, bathing or dressing?	1.3 (0.5)	1.7 (0.5)
2 = no	... take his medicine?	1.2 (0.4)	1.2 (0.4)
	... do his housework/laundry?	1.3 (0.5)	1.3 (0.5)
	... do shopping for groceries, clothes and other things?	1.8 (0.4)	1.7 (0.5)
	... cook for him or help him prepare meals?	1.1 (0.3)	1.3 (0.5)
	... give him a ride or help him use transportation?	1.1 (0.3)	1.4 (0.5)
	... help him manage money?	1.5 (0.5)	1.5 (0.5)
	... make use of his time, such as going to work, or school or aftercare, or visiting with friends?	1.2 (0.4)	1.5 (0.5)
ADL's total – possible range of 8 (all yes) to 16 (all no)		9.8 (1.2)	11.2 (1.9)
Supervision/control of behaviours	During the past 30 days, did you try to prevent or stop (patient's name) from		
1 = yes	... doing something embarrassing in public or before company?	1.7 (0.5)	1.8 (0.4)
2 = no	... making excessive demands for attention?	1.8 (0.4)	1.8 (0.4)
	... keeping anyone up at night for any reason?	1.9 (0.3)	1.8 (0.4)
	... striking or injuring anyone, including you?	1.7 (0.5)	1.9 (0.3)
	... threatening to strike or injure anyone, including you?	1.7 (0.5)	2.0 (0.0)
	... talking about committing suicide?	1.8 (0.4)	1.9 (0.3)
	... making threats to commit suicide?	1.8 (0.4)	2.0 (0.0)
	... actually attempting to commit suicide?	2.0 (0.0)	1.9 (0.3)
	... having too much to drink?	1.9 (0.3)	1.9 (0.3)
	... using drugs or pills such as marijuana, cocaine, amphetamine or heroin?	1.9 (0.3)	2.0 (0.0)
Supervision total – possible range of 10 (all yes) to 20 (all no)		18.2 (1.9)	19.2 (1.0)
Impact on daily routine	During the past 30 days,		
1 = yes	... did you miss, or were you late for (school/work) because of your involvement with (name)?	1.5 (0.5)	1.3 (0.5)
2 = no	... were your social and leisure activities changed or disrupted because of (name)?	1.7 (0.5)	1.6 (0.5)
	... was your housework or domestic routine disrupted or changed because of (name)?	1.7 (0.5)	1.6 (0.5)
	... did taking care of (name) prevent you from giving other family members as much time and attention as they needed?	1.6 (0.5)	1.7 (0.5)
	... has (name)'s illness caused you to make more or less permanent changes in your daily routine, work or social life?	1.5 (0.5)	1.5 (0.5)
Daily routine total – possible range of 5 (all yes) to 10 (all no)		7.9 (2.0)	7.7 (1.9)

Burden	Probes	Prodromal	Recent onset
Objective		Mean (SD)	

TABLE 2

Subjective burden: probes and responses

	Subjective	Prodromal	Recent onset
		Mean (SD)	
Worry	Do you worry		
1 = constantly or almost constantly	... about (name)?	2.6 (1.2)	2.7 (1.7)
2 = often	... about the kind of help and treatment (name) is receiving?	2.7 (1.6)	3.4 (1.8)
3 = sometimes	... (name)'s social life?	2.2 (1.0)	2.3 (1.1)
4 = seldom	... about (name)'s physical health?	3.0 (1.1)	2.5 (1.4)
5 = never	... about (name)'s current living arrangements?	3.8 (1.3)	3.2 (1.6)
	... about how (name) would manage financially if you were not there to help him?	2.4 (1.3)	1.9 (1.2)
	... about (name)'s future prospects?	2.3 (1.0)	1.8 (1.2)
Worry – overall mean – possible range of 1 to 5		2.7 (0.8)	2.5 (0.9)
Displeasure/anger	I		
1 = strongly agree	... am very disappointed in (name).	3.9 (1.0)	4.4 (0.9)
2 = agree	... am tired of having to organize my life around (name).	3.9 (1.0)	3.6 (1.5)
3 = ambivalent	... get more irritated with (name) as time goes by.	3.5 (1.2)	4.1 (1.3)
4 = disagree	... feel critical of the things (name) does.	3.3 (1.3)	4.0 (1.4)
5 = strongly disagree	... am very angry with (name).	4.1 (0.8)	4.4 (1.0)
	... get depressed when I think about (name).	3.1 (1.4)	2.9 (1.5)
	(Name)'s behaviour embarrasses me.	3.8 (1.3)	3.8 (1.3)
	Taking care of (name) is a heavier burden than I can bear.	4.1 (0.8)	3.9 (1.3)
Displeasure – overall mean – possible range of 1 to 5		3.7 (0.9)	3.9 (1.0)
Resentment (as to assistance in ADL's probed above)	How much did you mind helping, reminding or encouraging (name)		
	... with things like grooming, bathing or dressing?	2.9 (1.3)	2.0 (0.7)
1 = a lot	... to take his medicine?	3.3 (1.0)	2.9 (1.1)
2 = some	... to do his housework/laundry?	2.7 (1.1)	2.5 (1.1)
3 = very little	... to shop for groceries, clothes and other things?	4.0 (0.0)	2.3 (1.5)
4 = not at all	... to cook or prepare meals?	3.7 (0.7)	3.2 (1.2)
	How much did you mind helping (name)		
	... with his transportation needs?	3.1 (1.0)	3.0 (1.1)
	... manage his money?	3.8 (0.4)	2.8 (1.3)
	... make use of his time?	3.0 (1.1)	2.4 (1.1)
Resentment – overall mean – possible range of 1 to 4		3.2 (0.9)	2.8 (0.9)

ADL, assistance in daily living.