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Family burden predicts functional outcome in the early course of schizophrenia beyond psychiatric symptoms and baseline functioning

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Abstract

The goal of this study was to determine if family burden experienced by the families of individuals with a recent-onset of schizophrenia is associated with whether the individual is able to work or attend school during the first year of treatment. Forty-one participants with a recent first episode of schizophrenia and their families enrolled in two NIMH-funded protocols through the UCLA Aftercare Research Program completed a measure of family burden at baseline. Amount of work during this time was also recorded. Baseline family burden was associated with work status (no work, part-time work, or full-time work) at both the six-month, $r = -0.321$, $p = .04$, and one-year time point, $r = -0.47$, $p = .002$. Family burden was also associated with hours participated in work/school hours at the six-month time point, $r = -0.390$, $p = .012$, and at the one-year time point, $r = -0.492$, $p = .01$. Further exploration into the family burden measure shows that family perceived limited opportunities resulting from the individual's psychiatric disorder was associated with worse functional outcome at all three time points beyond psychiatric symptoms and baseline functioning. Missed opportunities due to a family member's illness may reduce the level of support provided to the individual and thus impact their psychosocial functioning. Our findings suggest that this dimension of family burden is highlighting the importance of and need for more balanced family support to boost functional outcome.

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Contributors

Drs. Nuechterlein, Ventura, and Subotnik and designed the study. Dr. DeTore conducted literature searches, undertook the statistical analysis, and wrote the first draft of the manuscript. All authors contributed to and have approved of the final manuscript.

Conflicts of interest

Dr. Subotnik has served as a consultant to Janssen Scientific Affairs, LLC, has been on the speaker's bureau for Otsuka America Pharmaceutical, Inc., and has received research support from Genentech, Inc., and Janssen Scientific Affairs, LLC through grants to Drs. Nuechterlein and Ventura.

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Dr. DeTore reports no financial relationships with commercial interests.

Keywords

First episode; Schizophrenia; Family burden; Functional outcome; Recovery

1. Introduction

Work and school functioning is considered to be one of the most essential aspects of socialization and recovery for those with schizophrenia as it provides financial support, positive socialization, heightened self-esteem, and a purpose in life (Drake et al., 2013; Rinaldi et al., 2010). Being able to work or attend school are some of the most commonly identified psychosocial goals for those diagnosed with a severe mental illness such as schizophrenia (Rinaldi et al., 2010; Secker et al., 2001).

For those experiencing a first episode, developmental independence is often interrupted, preventing the person from gaining employment and becoming independent (Redmond et al., 2010; Roy et al., 2013; Seltzer et al., 1997). Reported rates of unemployment early in the course of schizophrenia have ranged from 35% to 77%. In addition, families of individuals in a first-episode miss an average 1.2% of work in order to attend to the care of their loved one (Guest and Cookson, 1999; Rinaldi et al., 2010; Turner et al., 2009), in some cases resulting in missed wages, therefore increasing the financial strain and possible family burden associated with the illness.

Few studies have examined the relationship between family support and work and school in enough detail to identify predictors (Gupta et al., 2012; Rinaldi et al., 2010). Studies have found a general causal relationship between functional outcome and family burden showing that lower family burden was associated with higher levels of functional outcome and motivation to return to work in individuals with schizophrenia (Hjarthag et al., 2010). Higher levels of support from social networks during the early course of treatment have also been shown to predict higher levels of work and school functioning in the subsequent five years (Norman et al., 2012).

Family burden is a complex construct, often defined by both objective impacts of the illness on the family and subjective feelings experienced by the family as a result of the illness (Awad and Voruganti, 2008; Jones, 2009). This study defines family burden as a lack of family integration, a reduction in opportunities for the family, and financial problems related to the illness as measured by the Questionnaire of Resources and Stress for Families with Chronically ill or Handicapped Members (QRS; Holroyd, 1974). This study will examine the relationship between family burden and functional outcome in first-episode schizophrenia to determine if family burden predicts different aspects of subsequent work and school outcome beyond psychiatric symptoms and baseline work and school functioning. We hypothesized that work and school outcome will be lower among families experiencing higher levels of family burden based on previous research by Hjarthag et al. (2010). We hypothesized that psychiatric symptoms would be predictive of work and school functioning, as prior research has shown that specifically negative symptoms significantly predict functional outcome in schizophrenia (Rabinowitz et al., 2012). Additionally, to better understand the relationship between family burden and functional outcome we hypothesized

that living at home will moderate the relationship, as family exposure would be heightened. Lastly, we will explore the specific QRS subscales to better understand the family burden measure.

2. Method

2.1. Participants

This is a secondary analysis that utilized a sample consisting of 41 individuals with a first-episode of schizophrenia originally enrolled in two NIMH-funded protocols as part of the Developmental Processes in Schizophrenic Disorders study through the UCLA Aftercare Research Program along with their families (MH-037705 & MH-066286 Dr. Nuechterlein, PI; Nuechterlein et al., 2011; Subotnik et al., 2011). All subjects participated in one of two longitudinal treatment protocols for approximately 1.5 years where they were seen weekly by a case manager, followed closely by a psychiatrist, and randomized to an antipsychotic medication during their treatment. The randomized medications included: oral Risperidone, long acting injectable Risperidone, oral Prolixin and Prolixin Decanoate. All participants gave informed consent to participate and all study practices were approved by the UCLA Institutional Review Board.

Participants were recruited through the UCLA Aftercare Research Program and both samples met the same participant selection criteria. Inclusion criteria included: between the ages of 18–45, no presence of manic symptoms, experiencing psychotic symptoms for less than two years, no previous head trauma causing loss of consciousness, and an IQ above 70. Participants were diagnosed with either: schizophreniform disorder, schizophrenia disorder, schizoaffective disorder, depressive type or psychotic disorder NOS based on the Structured Clinical Interview for the DSM-IV (SCID; First et al., 1997). A diagnosis of schizophreniform disorder and psychosis NOS were given as a provisional diagnosis based on duration of symptoms at intake and was later reassessed and amended. All participants were later reassessed with schizophrenia disorder. All assessments used in this study were conducted by two masters or doctoral level raters trained to criterion levels of interrater reliability and obtaining extensive supervision, training, and quality assurance checks on rater fidelity. Demographic information for both the participant sample and their family members can be found in Table 1.

2.2. Measures

2.2.1. Family burden—Ratings of family burden were made using the QRS, which is a 285item true-false measure administered to family members at baseline in this study. The QRS is a multidimensional, objective test measuring not only the burden imposed on the family, but also the emotional response to burden, and was originally developed to evaluate the psychological impacts of caring for a disabled or chronically ill family member.

The QRS was administered to multiple family members when available, therefore, when more than one QRS was obtained per participant, only the QRS of the family member with the most frequent contact with the participant was used, as this increased possible exposure to family burden. In the case of no clear difference between frequency of participant contact,

the QRS items were averaged across the family members in order to maintain both family members perspectives.

The QRS measures 15 clinically determined subscales although this study only examined Scales 8–10 measuring the family burden sub-scale, which were totaled to determine an overall family burden rating. Subscale 8, “Lack of Family Integration”, includes 23 items measuring emotional problems such as: not getting along with one another, trouble including the individual in family activities, and rejection of the individual. Subscale 9, “Limits on Family Opportunity”, includes nine items measuring opportunities lost as a result of the individual such as: jobs, education, and social activities. Lastly, subscale 10, “Financial Problems”, includes 17 items measuring the cost of care, income, and expenses directly related to the illness.

QRS psychometric data were reported in the QRS Manual (Holroyd, 1974) and showed acceptable reliability for the three sub-scales that will be used in this study with $r = 0.78$, $r = 0.69$, and $r = 0.74$ respectively. Results showed evidence supporting strong criterion validity and ability to differentiate stress as a function of mental disorders (Holroyd, 1974). A study by Anderson & Lynch (1984) used the same three subscales utilized here from the QRS with a chronically mentally ill sample, measuring family stress related to illness and found significant correlations on all subscales. These three sub-scales were also seen as the most reflective of family problems and family burden beyond mothers of those with intellectual disabilities (Holyrod and McArthur, 1976). The overall family burden alpha found in this current sample was $\alpha = 0.83$. The alphas for each family burden subscale were: subscale 8, $\alpha = 0.71$, subscale 9, $\alpha = 0.60$, and subscale 10, $\alpha = 0.77$. The QRS was administered to family members only at baseline in this study.

2.2.2. Functional outcome—The Modified Social Adjustment Scale (Mod-SAS; Subotnik et al., 2016) is a modified version of the Social Adjustment Scale developed by Weissman and Bothwell (1976). The SAS was developed in order to better assess the functional outcome of individuals with psychiatric illnesses, relating to major areas of functioning. The Mod-SAS, modified by the UCLA Aftercare Research Program, examines number of hours worked per week across three domains: working at home, employment, and school. For this study, the Mod-SAS was administered to all 41 participants at baseline, six months, and one year. The Mod-SAS in our sample had an alpha of $\alpha = 0.64$ at six months, and $\alpha = 0.53$ at one year. So few participants were working or in school at baseline that it was underpowered and thus not presented here.

Psychometric data of the SAS were provided by the Weissman and Bothwell (1976) SAS manual using those diagnosed with depression and reported agreement between self-report and practitioner interview as Pearson correlation of $r = 0.72$ for overall agreement. Agreement between participant self-report and an informant such as a family member or care provider were incorporated into each rating for this study.

2.2.3. Positive and negative symptoms—The Brief Psychiatric Rating Scale (BPRS; Ventura et al., 1993) was used to rate positive and negative symptoms and was administered by trained raters. BPRS ratings were collected every two weeks according to the larger study

design. This secondary analysis used the BPRS rating obtained closest in date to the QRS ratings. Most BPRS ratings were within a few days, with the longest gap being less than two months. This study used the negative symptom and positive symptom factors to examine psychiatric symptoms (Ventura et al., 2000). Negative symptoms included: blunted affect, emotional withdrawal, and motor retardation. Positive symptoms included: unusual thought content, hallucinations, and conceptual disorganization.

2.3. Statistical analyses

Pearson correlations were used to examine the relationship of family burden to work status (defined as no work, part-time work, and full-time work) and the number of work/school hours, at baseline, six months, and one year. We additionally conducted t-tests and chi-squared analyses to explore the relationships between several demographic characteristics and both family burden and functional outcome. Point-biserial correlations were used to examine the relationship of work status at all three time points to both the positive and negative symptom factors. Pearson correlations were used to examine the relationship between psychiatric symptoms and hours of work and school at all three time points. Moderated multiple regressions were used to analyze living with the family as a potential moderator of the relationship between overall family burden and functional outcome by adding a linear interaction term (Aguinis, 2004). We then explored any potential demographic differences between the two groups (living at home vs. not) using t-tests.

To further explore the family burden measure, we conducted Pearson correlations between the three family burden subscales (Lack of Family Integration, Limits on Family Opportunity, and Financial Problems), psychiatric symptoms, and functional outcome at baseline, six months, and one year. We then used stepwise multiple regressions to determine the variance in functional outcome explained by each of those three family burden subscales controlling for positive and negative symptoms, and baseline work status. After finding that the Limits on Family Opportunity subscale was the most predictive, we ran post-hoc Pearson correlations between the clinical, demographic, and work variables with only that subscale. We then conducted additional post-hoc moderated multiple regressions to examine the possible moderating effect of live at home status on the relationship between the Limits of Family Opportunity subscale and functional outcome.

3. Results

3.1. Relationship between family burden, work status and hours of work/school

Family burden was not significantly associated with work status at baseline, $r = -0.200$, $N = 41$, $p = .209$, but family burden was significantly higher in those families whose relatives were not in work or school at both the six-month, $r = -0.321$, $N = 41$, $p = .041$, and one-year, $r = -0.471$, $N = 41$, $p = .002$, time points. Family burden was not significantly associated with fewer hours worked, $r = -0.25$, $N = 41$, $p = .114$, at baseline. Higher levels of family burden were however significantly correlated with fewer hours worked, $r = -0.390$, $N = 41$, $p = .012$, at both the six-month time point and the one-year time point, $r = -0.492$, $N = 41$, $p = .01$.

3.2. Clinical and demographic associations

No significant correlations were found between psychiatric symptoms (positive and negative symptoms) and baseline family burden or the work and school variables. Time, as measures in days, from illness onset to the QRS date was also not found to be significantly correlated to either the overall family burden measure or the Limits on Family Opportunity subscale. None of the demographic characteristics, gender, ethnicity, race, or live at home status were found significantly related to either baseline family burden, the Limits on Family Opportunity, or the work and school variables.

3.3. Family burden measure exploration

Subscale 9, the Limits on Family Opportunity subscale, was significantly correlated with hours of work or school and work/school status at all three time points (see Table 2). The Financial Problems subscale was significantly correlated with hours of work or school at the later time points and the Family Integration subscale was significantly correlated with work status at the one-year time point. None of the three family burden subscales were significantly correlated with psychiatric symptoms or any of the demographic or clinical characteristics.

Linear multiple regressions with the three family burden subscales entered stepwise along with positive and negative factors and baseline work status are presented in Table 3. The Limits on Family Opportunity subscale from the QRS was found to be the only significant family burden predictor of hours and status of work and school at each time point with none of the other QRS subscales entering the regression models. Baseline work status was also a significant predictor of six-month and one-year functional outcome.

3.4. Living at home as a moderator

There was missing live-at-home status data for 10 participants, thereby decreasing the sample of this analysis to 31. Twenty participants lived at home with their families, while 11 did not, living alone, or with other non-relatives. When exploring demographic differences between the two groups (living at home vs. not), we did not find age, gender, ethnicity, or marital status to be significantly different between the two groups using t-tests. When examining living at home, we found it was not a significant moderator of the relationship between family burden and work status, $F(1, 27), =0.20, p = .655$, or hours in work/school, $F(1, 27), =0.16, p = .690$, at the six-month time point. Living at home was additionally not a significant moderator of the relationship between family burden and work status, $F(1, 27), =0.27, p = .603$, or hours in work/school, $F(1, 27), =0.08, p = .780$, at the one-year time point. Post hoc analyses also indicated that living at home was not a significant moderator of the relationship between the Limits on Family Opportunity subscale and work status, $F(5, 25), =2.22, p = .518$, or hours of work/school, $F(5, 25), =2.22, p = .518$, at six months or work status, $F(5, 25), =2.18, p = .598$, or finally hours of work/school, $F(5, 25), =2.54, p = .655$.

4. Discussion

Baseline levels of family burden, as measured by the Limits on Family Opportunity subscale, were significantly predictive of work status and of the number of hours working or going to school at six-months and at one-year. This subscale captures the extent to which the family sacrifices opportunities such as social events, employment, and education directly due to the individual with schizophrenia. These effects were above and beyond the role of positive and negative symptoms and baseline work status, demonstrating that family burden might provide important information for providers in assisting an individual in returning to work or school after a recent first episode of schizophrenia. The Limits on Family Opportunity subscale was identified as the strongest of the three family burden subscales in the prediction of functional outcome at all three time study follow-up points.

Previous literature has shown that whether individuals with schizophrenia live with their families or not, families are often involved financially with their care, assuming the costs of both providing treatment and wages lost due to the illness (Awad and Voruganti, 2008). Consistent with that literature, living at home was not a significant moderator of the relationship between family burden with work and school in this study. These results seem to indicate that family burden is more influential than previously thought and therefore can significantly impact the individual, independent of whether they live at home. There were additionally no significant demographic differences found between those individuals living at home and those individuals who do not. We recognize however that limitations due to small sample size, limited our ability to examine additional variable such as gender, ethnicity or marital status, which would have added to our findings.

The limitations of this study are first the small sample size, which impacts our ability to generalize these results. This study also included a diagnosis of schizophreniform disorder and psychosis NOS (nine participants). Although all participants were later reassessed and obtained a diagnosis of schizophrenia, the inclusion of those who did not initially meet criteria for schizophrenia likely did not adversely impact the findings. Additionally, we only included one measure of family burden, from which only one subscale was found predictive. Future studies should examine this relationship using more than one measure of family burden to more fully understand the active ingredient in family burden that may be predicting functional outcome. We also did not examine the role of cognition which has been shown to predict functional outcome in schizophrenia (Green et al., 2000).

This study found baseline levels on the Limits on Family Opportunities subscale significantly predicted status and hours of work and school six-months and one-year later. Family burden was assessed prior to the functional outcome assessments, which gives the impression that family burden “caused” the functional impairment. However, this cannot be definitively concluded. In fact, previous reports have speculated that the opposite direction is the case; that is, the individual’s functional impairment creates burden for the family (Hjarthag et al., 2010). However, because family burden predicted functional outcome even when controlling for baseline work/school status, this lends more support to the idea that family burden is potentially impacting functional outcome. The Limits on Family Opportunity subscale might be a more sensitive measure, capturing something beyond just

functioning, possibly level of family support. Missed opportunities due to one's illness may reduce the level of family support provided to the individual and thus impact their psychosocial functioning.

Among the family burden subscales, the Limits on Family Opportunity subscale was most notably predictive of work outcome. This sub-scale might be indirectly measuring the impairment of the individual that begun to emerge as early as the initial psychotic episode, leading family members to provide additional care and thus forgo important opportunities. Psychosocial impairments can be seen early in the illness as both a decrease in work/school functioning and in social relationships (Ballon et al., 2007; Green et al., 2000) and often mirror psychosocial difficulties one might face in the future (Hooley, 2010). The relationship between family burden and the individual's impairment may have become more obvious to the individual's relatives over time as the symptoms of the first episode begin to resolve. The Loss of Family Opportunities subscale may then serve as an early measure that can be used to predict the functional ability of the family member with schizophrenia early in the illness, beyond psychiatric symptoms.

The implications of these findings suggest increased family intervention early in the illness. Family interventions and social support have been shown to reduce risk for relapse in schizophrenia (Alvarez-Jimenez et al., 2012; Bird et al., 2010). Our findings suggest that this Limits on Family Opportunities dimension of family burden is highlighting the importance of and need for family support. The implications of these findings support a more balanced approach for family members to supporting the family member with schizophrenia to boost functional outcome, but without increasing the magnitude of family burden. Further research should focus on efforts to both better understand the dimensions of family burden and reduce the experience among relatives of individuals experiencing a recent-onset of schizophrenia in an attempt to improve the individuals' work and school outcomes.

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- Weissman MM, Bothwell S, 1976 Assessment of social adjustment by patient self-report. *Arch. Gen. Psychiatry* 33 (9):1111–1115 [PubMed: 962494] Requests for the original measure, its derivation and psychometrics should be directed to Multi-Health Systems, Inc., P.O. Box 950, North Tonawanda, NY 14120-0950, phone 1-800-456-3003, or 1-416-492-2627, or e mailed to customerservice@mhs.com. Short and screener versions are also available. Modified by Subotnik, K.L., Nuechterlein, K.H., Kelly, K.A. Kupic, A.L., & Brosemer, B., Turner, L.R. (2016) for use at UCLA. Requests for information on this modification can be directed to Kenneth Subotnik, Ph.D., 300 UCLA Medical Plaza, Room 2240, Los Angeles, CA 90095-6968, phone (310) 825-0334.

Table 1

Patient and QRS family respondents demographic and clinical characteristics.

	Patient		Family member	
	n	%	n	%
Sex				
Male	26	63.4	15	38.5
Female	15	36.6	24	61.5
Ethnicity				
Hispanic	13	31.7	12	29.3
Non-Hispanic	28	68.3	29	70.7
Race				
Black or African American	9	22.0	10	24.4
Asian	6	14.6	6	14.6
White	24	58.5	23	56.1
Mixed	2	4.9	2	4.9
Live at home	20	64.5		
Does not live at home	11	35.5		
Diagnosis				
Schizophreniform disorder	8	19.5		
Schizophrenia disorder	27	65.9		
Schizoaffective disorder, depressive type	5	12.2		
Psychotic disorder, NOS	1	2.4		
	M	SD	M	SD
Age	24.6	4.4	50.5	9.9
Education	13.5	1.8	13.0	4.0
Age of onset	22.9	4.8		
Baseline BPRS positive symptom ratings	7.4	4.2		
Baseline BPRS negative symptom ratings	7.0	3.5		
Relationship of relative with the most contact with the patient			n	%
Biological mother			17	42.5
Biological father			12	30.0
Step mother			2	5.0
Step father			1	2.5
Sibling			5	12.5
Grandparent			2	5.0
Aunt/uncle			1	2.5

Note. 10 participants were missing live at home with family data and relationship of family member to the patient data. Two family members were missing sex data and one family member was missing relationship of relative data.

Table 2

Pearson correlations examining relationships between QRS family burden subscales and hours of work and school, work/school status, and clinical factors (N = 41).

	Lack of family integration		Limits on family opportunity		Financial problems	
	r	p	r	p	r	p
Work/school status						
Baseline	-0.09	0.56	-0.48	0.002	-0.15	0.36
6 months	-0.15	0.36	-0.52	0.001	-0.38	0.01
1 year	-0.29	0.07	-0.50	0.001	-0.38	0.01
Work/school hours						
Baseline	-0.11	0.51	-0.42	0.006	-0.12	0.46
6 months	-0.06	0.70	-0.49	0.001	-0.31	0.05
1 year	-0.40	0.01	-0.51	0.001	-0.27	0.09
BPRS symptoms factors						
Positive symptoms	-0.04	0.80	0.08	0.60	0.25	0.12
Negative symptoms	0.01	0.95	-0.08	0.64	-0.03	0.87
Time from illness onset	0.27	0.09	0.09	0.59	0.11	0.50

Table 3

Stepwise multiple regressions using three QRS family burden subscales, psychiatric symptoms, and baseline work status, measured at baseline to predict work/school status and hours of work and school at the six-month and one-year time points (N = 41).

	Std. β	t	p	Adjusted R ²	F	p
6 month work/school status				0.22	12.1	0.001 +
Limits on family opportunity	-0.49	-3.48	0.001			
1 year work/school status				0.24	13.4	0.001 +
Limits on family opportunity	-0.51	-3.66	0.001			
6 month work/school hours				0.33	10.9	0.000 +
Limits on family opportunity	-0.38	-2.63	0.012			
Baseline work status	0.34	2.38	0.022			
1 year work/school hours				0.30	9.54	0.000 +
Limits on family opportunity	-0.36	-2.45	0.019			
Baseline work status	0.33	2.24	0.031			

Note. Full model included the three QRS family burden subscales, positive and negative symptom factors, and baseline work status entered stepwise into one block. Only significant variables that were included in the model are shown for each linear regression.+ Overall model statistics.