



Brief Report

Concerns reported by family members of individuals with first-episode psychosis

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Abstract

Aim: Our aim was to examine the concerns reported by family members and other caregivers of individuals with first-episode psychosis (FEP).

Methods: Family members who attended group psychoeducation selected their top two concerns from a list of nine concerns: stigma, medication, substance abuse, social behaviour, stressful situations, self-esteem and identity, sexuality and intimacy, early warning signs, and resources and support.

Results: Parents, particularly mothers, were a significant majority

of those who attended psychoeducation sessions. In order of frequency of endorsement, the concerns endorsed were self-esteem and identity, social behaviour, substance abuse, medications, stressful situations, early warning signs, resources and support, stigma, and sexuality and intimacy.

Conclusion: Families were most concerned about the self-esteem and identity of their young relatives with FEP. Our findings suggest that early intervention programmes should specifically address issues of self-esteem and identity. Further research on the concerns shared by families of individuals with FEP is needed.

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INTRODUCTION

Much of what has been reported about families caring for individuals with schizophrenia and other psychotic disorders pertains to 'family burden' or the effect of family ambient stress on the course of schizophrenia (e.g. the literature on expressed emotion).^{1–8} Further, most of this literature has focused on families of individuals with chronic schizophrenia.^{3,8} It is only recently that attention has been shifted to families of individuals with first-episode psychosis (FEP) and many questions remain unanswered including the specific concerns of families dealing with the first onset and diagnosis of the illness in their relatives. The content of family interventions for this stage of the illness can be better informed by understanding the specific concerns of families and other caregivers of individuals with FEP, than by assuming that their concerns are similar to those of families of patients with chronic psychosis. Knowledge of such concerns can also

help us ameliorate the distress associated with caregiving,^{7,9–12} promote better engagement of families in the treatment of FEP and help families feel more equipped to render support. The objective of this study was therefore to examine the concerns reported by family members and other caregivers of individuals with FEP.

METHODS

Setting

The study was conducted at a specialized programme for the assessment and treatment of FEP in Montréal, Canada. To be included in the programme, patients had to be between the ages of 15 and 30; meet Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria for a psychotic disorder; have received less than 30 days' treatment with an antipsychotic; and not meet criteria for substance-induced psychosis or organic

disorders (e.g. epilepsy). Based on the framework for specialized early intervention for FEP, patients received assertive case management, pharmacological treatment, family psychoeducation, and medical and psychosocial follow-up for at least 2 years (for details, refer to Malla *et al.*, 2003¹³).

Procedure

As soon as possible, after entry into treatment (usually within the first 3 months), family members of all patients were invited to attend three group sessions of family psychoeducation, modelled after the psychoeducational interventions of Anderson.¹⁴ These sessions were offered separately in English and French. The first two workshops, led by a psychiatrist, covered the topics of symptoms and causes of psychosis, and the rationale for and the use of pharmacotherapy. The third workshop, led by two case managers, covered various psychosocial topics pertinent to FEP with a focus on the role of the family in treatment. During the third session, family members were also shown a video¹³ explaining and depicting nine typical concerns faced by families of individuals with FEP. The nine typical concerns were derived from focus groups with family members of persons with FEP. Informed by these focus groups, scenarios were developed around these concerns and actors were hired to enact these scenarios. The nine concerns included stigma, medication (adherence, side-effects and monitoring), substance abuse, social behaviour (e.g. inappropriate social behaviours, social isolation, difficulty maintaining hygiene, not dressing appropriately, getting in touch with friends after illness onset, etc.), stressful situations (e.g. exams, moving, job interview, stressful situations at home, meeting new people, etc.), self-esteem and identity (e.g. expectations about the future, obstacles to returning to school or work, low self-esteem, etc.), sexuality and intimacy, early warning signs, and resources and support. At the end of the third session, family members were requested to pick the top two concerns that they would like to discuss with their case managers from among the list of nine concerns presented in the video and to list any additional concerns that they might have. The concerns endorsed by family members were the focus of this report.

RESULTS

Between November 2005 and May 2010, 17 family psychoeducation workshops were offered. Out of a total of 217 clients who entered the programme

during this period, family members of 69 clients attended the third psychoeducation session and filled out the concerns questionnaires. Table 1 provides demographic and clinical characteristics of the client sample whose family members attended the third session. The family members included 54 mothers, 27 fathers, 2 stepmothers, 1 stepfather, 8 sisters, 4 brothers, 1 grandmother, 5 partners/significant others, 1 godfather, 1 aunt, 1 sister-in-law, 3 brothers-in-law and 3 friends. Thus, 111 family members filled out 105 questionnaires, with six of the questionnaires being filled out by parents together. A total of 244 concerns were endorsed. Although the instruction was to list two primary concerns, some family members endorsed more than two concerns (range = 0–7). Four mothers in the sample reported no concerns.

Table 2 shows the distribution of concerns by family member and concern type. In order of frequency of endorsement, the concerns listed were self-esteem and identity (19.67%), social behaviour (16.39%), substance abuse (14.34%), medications (13.11%), stressful situations (11.48%), early warning signs (10.66%), resources and support (7.79%), stigma (3.28%), and sexuality and intimacy (3.28%). Twelve family members endorsed the 'other' category, including concerns such as goal setting, communication, autonomy, their young relative returning to school or work, substance abuse in the home, effects on other family members of the illness, and their daughter not wanting the case manager to disclose information to her parents.

Family members of 148 clients did not fill out the concerns questionnaires. Of these, family members of 12 clients attended the third psychoeducation session but were not given the concerns questionnaire by staff; family members of 10 clients attended the third session but did not complete the given concerns questionnaires; family members of 20 clients attended only the first and/or second session; family members of 29 clients lived outside Montréal; and 23 clients dropped out early in their treatment and their families were not invited for psychoeducation. The remaining 54 included clients whose family members could not attend the sessions because of scheduling conflicts, clients with no contact with their families, clients who did not consent to their families being contacted, clients whose families did not speak English or French, and clients whose families did not want to attend the sessions. Whenever possible, the case manager provided psychoeducation in individual meetings to families who did not attend the group sessions.

TABLE 1. Sample characteristics at baseline

	Mean (SD); median	n (%)
Age at entry	22.75 (4.27)	
Age at onset	21.22 (4.04)	
Gender (male)		51 (73.91)
Education (% less than high school)		22 (31.88)
Living circumstances		
With family or friends		52 (75.36)
Homeless		1 (1.45)
Alone		7 (10.14)
With spouse or partner		8 (11.6)
Group/nursing home		1 (1.45)
DUP (in weeks)	86.42 (168.99); 16.71	
SOFAS total	42.33 (12.17)	
SAPS total	35.97 (14.21)	
SANS total	33.7 (15.26)	
SCID-IV diagnosis		
Schizophrenia		27 (39.13)
Schizoaffective disorder		9 (13.04)
Bipolar disorder with psychotic features		8 (11.59)
Major depressive disorder with psychotic features		14 (20.3)
Psychotic disorder not otherwise specified		7 (10.14)

SCID diagnosis not available for four patients.

DUP, duration of untreated psychosis; SOFAS, Social and Occupational Functioning Assessment Scale;¹⁵ SAPS, Scale for the Assessment of Positive Symptoms;¹⁶ SANS, Scale for the Assessment of Negative Symptoms;¹⁷ SCID, Structured Clinical Interview for Diagnostic Statistical Manual of Mental Disorders – Patient Edition.¹⁸

TABLE 2. Distribution of concerns by family member and concern type†

	Stigma	Medications	Substance abuse	Social behaviour	Stressful situations	Self-esteem and identity	Sexuality and intimacy	Early warning signs	Resources and support
Mother	5	15	13	20	11	27	3	14	8
Father	1	9	4	8	6	10	2	4	4
Parents	0	3	3	3	1	3	1	1	2
Siblings	0	2	7	6	4	2	1	3	1
Partner	0	1	2	1	3	1	0	0	1
Relatives	1	2	4	2	2	2	0	2	2
Friend	1	0	2	0	1	3	1	1	1
Total	8	32	35	40	28	48	8	26	19

†In this table, 'mother' includes biological, step and adoptive mothers; 'father' includes biological, step and adoptive fathers; and 'relatives' include grandmother, aunt, godfather, sister-in-law and brother-in-law.

There were no significant differences in terms of age ($F(1,215) = 1.53$, $P = 0.22$), gender ($\chi^2 = 1.02$, $P = 0.31$), parent socioeconomic status ($\chi^2 = 2.70$, $P = 0.61$), diagnostic break-up ($\chi^2 = 0.43$, $P = 0.81$), baseline positive ($F(1,214) = 0.37$, $P = 0.54$) and negative ($F(1,212) = 2.34$, $P = 0.13$) symptoms, age of onset ($F(1,205) = 3.99$, $P = 0.05$) and functioning ($F(1,213) = 0.34$, $P = 0.56$) between the clients ($n = 110$) whose family members attended any of the three psychoeducation workshops and clients ($n = 107$) whose family members attended none.

DISCUSSION

Our principal finding is that families, particularly parents, of individuals with FEP were most concerned about the self-esteem and identity of their young family member. The other main concerns identified by family members pertained to social behaviour, substance abuse and medications. Receiving a diagnosis of a psychotic disorder and perhaps being exposed to psychiatric treatment for the first time can impact the self-esteem of young individuals and contribute to

self-stigmatization among them.^{19–22} Even as early as the time of entry into treatment, low self-esteem significantly contributes to the subjective distress experienced by individuals with FEP.²²

While the significance of self-esteem and the impact on it of psychosis has been reported previously, our findings suggest that parents are well aware of the profound impact, both real and potential, of the illness on the self-esteem of their young offspring and regard this as a major concern. Parents may perceive self-esteem as being important particularly during the adolescence and early youth of their children, and thus may be likely to react with concern at any possible threat to this developing self-esteem and identity.

Of the top four family member concerns in our study, information, support and interventions are more readily available to deal with concerns about medications and substance abuse, and to some extent, those about social behaviours. Given the preoccupation of families with the self-esteem and identity of their young family members with FEP, and the link of reduced self-esteem with relapse and post-psychotic depression,^{19,23–25} it is imperative that early intervention programmes specifically assess and address issues of self-esteem and identity.

In terms of our other findings, mothers (54 out of 111; 48.65%) comprised a significant majority of the family members attending psychoeducation, followed by fathers ($n = 27$; 24.32%). This suggests that parents, particularly mothers, are often involved in the treatment of young people with FEP. Further, individuals who attended family psychoeducation represented a range of relationships. This is in line with the more recent sociological understanding of 'family' as being comprised of not just immediate biological relatives but also or sometimes only of others providing trust, companionship or reciprocated support.²⁶

A large number of families (those of 49% of the clients) did not attend any of the family psychoeducation group sessions. Several of these families (exact number not available) were provided psychoeducation by their case manager in an individual format. Further, we could pinpoint the reasons for some families' absence (e.g. living outside Montréal). Unfortunately, our data did not allow us to examine systematically all the reasons for families not attending.

Future research should examine more systematically and in greater detail the concerns shared by families caring for young people with psychosis. The extent to which families partake of psychoeducation and other interventions offered in early intervention programmes and the factors predicting this must

also be investigated. Such research would allow family interventions to be appropriately tailored to meet the needs of families caring for young people with FEP.

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Original Article

Psychoeducational multi-family group treatment with adolescents at high risk for developing psychosis

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Abstract

Aim: In this study, we investigate the feasibility and acceptability of a 9-month psychoeducational multi-family group (PMFG) intervention for adolescents who are at ultra-high-risk (UHR) for developing psychosis.

Methods: The treatment programme was adapted from those previously shown to be effective in patients with established psychotic illness, but emphasizes content relevant to adolescence and to a pre-onset phase of illness.

Results: Participants report that psychoeducational presentations are

highly useful, they attend the PMFG group sessions regularly and report feeling comfortable in meetings and benefiting from them, and adolescents demonstrate improvement in symptoms and functional outcome.

Conclusions: This study was not a randomized controlled trial and multiple interventions were introduced simultaneously; thus, changes in outcome cannot be attributed to the PMFG intervention per se. Nonetheless, these results establish the acceptability of PMFG to adolescents and families, and encourage further research into the potential positive impact of PMFG with this at-risk population.

Key words: early intervention, psychoeducational multi-family groups, psychosis, psychosocial treatment, ultra-high-risk youth.

INTRODUCTION

Most first psychotic episodes are preceded by a 'prodromal phase' marked by characteristic changes in subjective experience and behaviour¹. Recently, methods have been developed that have demonstrated high inter-rater agreement (93%) in differentiating prodromal from non-prodromal patients,² and high predictive validity for identifying those at ultra-high-risk (UHR) for developing psychosis, such that 30–35% of those identified as UHR have converted to psychosis within 2 years.³ Established methods for early detection of UHR individuals allows for the implementation of early interventions which may prevent transition to psychosis and/ or improve functional outcome for those who do transition. In fact, data from recent

pre-onset randomized treatment trials^{4–6} indicate that active intervention is associated with reduced rates of conversion to psychosis, and that cognitive-behavioural approaches may contribute to symptom reduction without the side effects associated with antipsychotic drugs.⁷ As many studies of first episode psychosis indicate that a shorter duration of untreated psychosis is associated with significantly better outcome⁸ and there is a deteriorating course and reduced rate of treatment response with each episode of psychosis, the body of evidence points to early intervention as a valuable focus of study.

The needs of UHR individuals are different from those with an established illness in that these individuals are younger and often treatment naïve, with significant difficulties navigating the developmental

challenges as well as the unique school, peer and family environments of adolescence. Given that the majority of these adolescents are living with their families and brought to clinics by their parents who are seeking family support and intervention, developmentally sensitive family treatments are likely to be a particularly acceptable and effective intervention. Family members who care for persons with serious psychiatric symptoms are at risk for developing symptoms themselves because of the significant stress imposed by these disorders.⁹ Therefore, family treatments aimed at preventing the onset, chronicity and/or functional impairment of psychosis among UHR youth can be considered preventive interventions for caregivers as well. Evidence from adoption,¹⁰ expressed emotion¹¹⁻¹³ and treatment studies^{14,15} suggests that family environment plays a key role in the evolution of psychiatric symptoms, with environments that are calm, supportive and low in criticism potentially serving a protective factor.

Randomized clinical trials have demonstrated that psychoeducational multi-family group (PMFG) interventions are associated with symptom reduction and improved family well-being among a variety of patient groups, including young adults with first-episode schizophrenia.¹⁶⁻¹⁸ The hypothesized mechanisms of change in the PMFG treatment are: increased knowledge regarding illness, increased social support, improved family functioning, improved problem solving and reductions in internalized stigma, which in turn lead to symptom reduction and improved functional outcome for patients, and reduced burden and distress for families.¹⁶ PMFG interventions in the prodromal phase of a psychotic illness may facilitate changes in attitudes and behaviours when families are maximally receptive to and inclined to benefit from interventions.¹⁹

The study reported here is the first to investigate the feasibility and acceptability of PMFG intervention to adolescents who are at high risk for developing psychosis and their primary caregivers. We hypothesized that families would report benefiting from the psychoeducation provided, attend group meetings regularly and report benefiting from the group treatment. Also, we hypothesized that there would be reductions in adolescents' prodromal symptoms, and increases in functional outcomes from pre- to post-intervention when using patients' pre-intervention functioning as a control. Finally, we hypothesized that improvement in family functioning and adolescent coping skills would accompany participation in PMFG treatment.

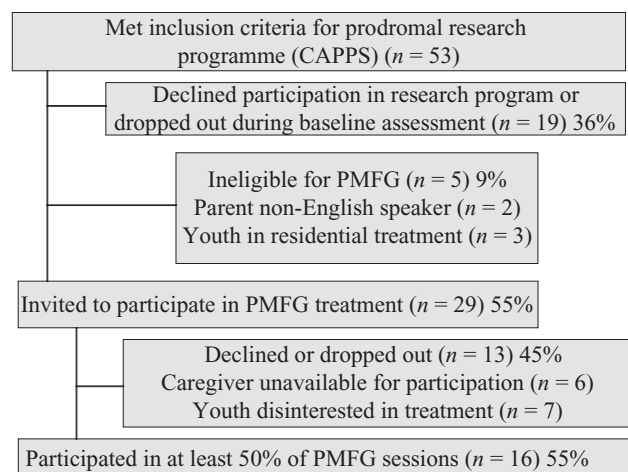
METHOD

Participants

Individuals between the ages of 12 and 22 years who were determined to be at UHR for conversion to psychosis using the Structured Interview for Prodromal Syndromes (SIPS²) were invited to participate in a clinical research programme at the Staglin Music Festival Center for the Assessment and Prevention of Prodromal States (CAPPS) housed within the Semel Institute for Neuroscience and Human Behavior at the University of California, Los Angeles. Participants were referred to CAPPS by local mental health providers, school psychologists or counselors, or by self-referral in response to advertisements or the CAPPS website. Exclusion criteria included a DSM-IV diagnosis of a schizophrenia spectrum disorder, IQ below 70, current drug or alcohol dependence and/or the presence of a neurological disorder. As part of the larger clinical research programme, participants were asked to complete an extensive baseline assessment, including clinical, genetic, neuropsychological, physiological, information processing, social cognition, brain imaging and psycho-social evaluations, and then to participate in 3-, 6-, 12- and 24-month follow-up evaluations. Once individuals signed informed consent documents and completed baseline assessment for the larger study, they were offered the opportunity to receive PMFG treatment for 9 months.

As depicted in Fig. 1, because of attrition from the larger research programme prior to eligibility for participation in PMFG treatment, language

FIGURE 1. CAPPS participants invited to participate in PMFG. CAPPS, Center for the Assessment and Prevention of Prodromal States; PMFG, psychoeducational multi-family group.



limitations and youths' transition to residential treatment facilities in another state, only 55% of youth identified as at UHR by the CAPPs programme were invited to participate in PMFG treatment. Of those 29 families, 45% declined participation or dropped out after one meeting. For approximately half of the families that declined participation, the parent(s) reported that they were too busy with other demands to participate with their young person in treatment. Youth from these families participated in individual therapy at CAPPs ($n = 3$), or with school or local community providers ($n = 3$). The remaining families declined participation because of their youths' unwillingness to accept any form of psychosocial treatment and limited insight regarding the impact of their symptoms on themselves and their families. The 16 families that engaged in PMFG treatment were highly reliable group members, missing only an occasional meeting because of family commitments. All participants were reassessed after completion of PMFG treatment.

Treatment

In the CAPPs programme, we implemented PMFG procedures described by McFarlane.²⁰ Each of the three PMFG treatment groups consisted of approximately five families, and was co-led by two therapists. The first two authors were trained by Dr McFarlane and Donna Downing, and then trained all staff participating in PMFG treatment. Ms. Downing, an experienced PMFG trainer with many years of consulting experience, reviewed videotapes of sessions and provided ongoing consultation throughout this project. Before each group began, approximately three 'joining sessions' allowed the therapists to address individual family concerns and to establish a working alliance with each family. All participants were invited to a psychoeducational workshop during which the group co-therapists provided a PowerPoint presentation about the prodromal state, reasons for early intervention, biological bases for psychiatric symptoms, diathesis-stress theories, psychopharmacological treatment, psychological treatment, school interventions and recommendations for creating a protective environment. Following the workshop, groups met bi-weekly for 90-min sessions over 9 months (i.e. an average of 18 sessions). Meetings were structured to allow for the development of social, communication and problem-solving skills, and to support families' efforts to manage symptoms. The most common topics that emerged during meetings and became the focus of group problem-solving efforts are

TABLE 1. Frequently raised topics for problem-solving discussions

<p>Youth:</p> <p>How can I manage my weight because it seems out of control since I started some new medications?</p> <p>How can I remember to take my medication?</p> <p>How can I increase my tolerance for social situations?</p> <p>How do people find good friends? How do people initiate friendships?</p> <p>How can I improve my grades at school?</p> <p>How can I find sources of inspiration because I feel so unmotivated?</p> <p>How can I get on with my schoolwork despite feeling unmotivated?</p> <p>I wish I cared more about getting things done.</p> <p>How can I manage when I feel overwhelmed and over-stimulated at school?</p> <p>I would like to feel less 'lost' in school.</p> <p>I would like to be on a team.</p> <p>I would like to get a job.</p> <p>How can I spend less time on the computer?</p> <p>How can I convince my parents to say 'yes'? How can young people deal with hearing parents say 'no'?</p> <p>I would like to have a better relationship with my father.</p> <p>I want to feel less sad.</p> <p>How can I deal with emotional distress without hurting myself?</p> <p>How can I cope with having a caregiver in my space because my mom won't leave me home alone?</p> <p>How can I stay on track when there is a lot of complexity at home?</p> <p>Parents:</p> <p>I wish my daughter could be more active.</p> <p>I would like my son to help out more around the house.</p> <p>I would like my son to wake up independently and on time for school.</p> <p>I would like my daughter to take her medications more independently.</p> <p>I would like my son and I to work more effectively together in getting through this next phase of life.</p> <p>I would like to be more helpful to my daughter when she is sad and in pain.</p> <p>I would like my daughter to have a broader array of friends.</p> <p>I would like my son to take more of the initiative in planning social activities with friends.</p> <p>I would like my son to manage time more effectively.</p> <p>How can my son be less irritable around the house?</p> <p>How can we improve the timing of communication around problems/requests?</p> <p>How can I improve communication with my daughter?</p> <p>Which school setting and accommodations would be best for my daughter?</p> <p>How can I structure my son's summer in a way that contains symptoms and helps him to be healthy?</p>
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presented in Table 1. All group participants were provided with case management, advocacy for school accommodations as needed, and feedback regarding repeated clinical and neuropsychological assessments at CAPPs. In addition, referrals were made to psychiatrists as clinically indicated.

Participants were not required to discontinue individual or family therapy to participate in PMFG treatment.

Measures

Data on CAPPS participants' symptoms were obtained by trained MA or PhD level clinical interviewers at baseline and follow-up assessment via the SIPS^{21,22}, and adolescents age 15 years and older completed the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I²³), although participants 14 years and younger were administered the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS²⁴). Detailed information regarding inter-rater reliability and diagnostic consensus procedures is provided in Meyer *et al.*²⁵

All participants met criteria for one of four SIPS definitions of a prodromal state: attenuated positive symptom, brief intermittent psychotic symptom, genetic risk and deterioration, and recent-onset non-specific psychotic syndrome. The first three categories are described in detail in Miller *et al.*²² Our research group added one additional category, recent-onset non-specific psychotic syndrome, which includes those participants who were experiencing recent-onset (i.e. within past 3 months) psychotic symptoms that did not reach DSM-IV diagnostic criteria for a schizophrenia spectrum diagnosis in terms of the duration and/or frequency of symptoms.

Positive, negative, disorganized and general prodromal symptoms were rated on the Scale of Prodromal Symptoms,²⁶ and a Global Assessment of Functioning score, revised for use with the SIPS^{22,27} is also provided. The Strauss-Carpenter Outcome Scale²⁸ contains ratings for the duration and frequency of non-hospitalizations, social contacts with individuals outside of the family and useful employment or participation in school. On these scales, higher ratings indicate higher levels of functioning. Follow-up ratings for all clinical scales described above were based on the past month.

Adolescents were asked to complete the Family Adaptability and Cohesion Evaluation Scales-III (FACES-III);²⁹ and the Brief COPE.³⁰ For the purposes of this study, one constructive coping scale was created which sums all of the items from the following nine scales (18 items in total): active coping, planning, positive reframing, acceptance, humour, religion, emotional support, instrumental support and self-distraction. These are all strategies encouraged during the PMFG.

RESULTS

Characteristics of the study participants who elected and declined participation in PMFG treatment are presented in Table 2. All treatment participants were adolescents living at home with their families. Males and females participated in equal number and most youth were classified with Attenuated Positive Symptom Prodromal syndrome according to the SIPS instrument. Participants met criteria for between zero and four DSM-IV diagnoses based on administration of the SCID-I or K-SADS at baseline. Participants were offered consultation or psychiatric care by staff psychiatrists using the standard of usual and customary treatment for a given class of symptom, and those who entered the study on prescribed psychiatric medications were allowed to continue under the care of their treating psychiatrist. The only significant difference between participants and non-participants on the variables presented was that individuals who opted to participate in the PMFG were significantly more likely to participate in individual treatment as well ($\chi^2 = 4.48, P < 0.05$).

Acceptability and feasibility of PMFG approach

Thirty-five individuals (25 parents and 10 youth) completed evaluations of the psychoeducational workshops. On a scale ranging from 1 (not at all useful) to 5 (extremely useful), the average rating was 4.5. PMFG treatment was offered over an average of 9.5 months (19 sessions). Among the 16 families enrolled in this treatment, the average participation rate was 73%. In other words, the average family attended three out of every four sessions. Each young person was always accompanied by at least one parent, and parents never attended group meetings alone.

After completion of PMFG treatment, 12 adults and 10 youth from the three groups completed two ratings. When asked whether they felt comfortable in PMFG, adults and youth provided ratings of 3.5 and 3.3, respectively, on a scale ranging from zero (never) to 4 (always). When asked whether PMFG addressed issues that were helpful to them, adults provided an average rating of 2.8 whereas youth reported an average rating of 2.6, on a scale ranging from zero (never) to 4 (always).

Co-facilitators adhered closely to the PMFG format, including socialization, a 'go-around' and completion of all steps of problem solving during 90% of meetings. A few sessions were devoted to coping and communication skills training or

TABLE 2. Characterization of PMFG participants and comparison with those who declined

Variable	PMFG participants (n = 16)	Declined participation (n = 13)
Age (years)	15.7 (12.5–18.5)	16.1 (12.5–22)
Gender ratio (M : F)	8:8	9:4
WASI IQ	111.50 (93–130)	103.31 (75–135)
Primary SIPS-defined prodromal syndromes		
Attenuated positive symptoms	12 (75%)	11 (85%)
Genetic risk and deterioration	0	0
Brief Intermittent psychotic symptoms	0	1 (8%)
Psychotic syndrome	4 (25%)	1 (8%)
Converted	3	3
SOPS symptom scales		
Positive symptoms	13.56 (6–22)	13.23 (7–19)
Negative symptoms	13.06 (6–23)	16.00 (2–25)
Disorganized symptoms	7.69 (2–14)	6.38 (2–15)
General symptoms	9.50 (2–16)	8.85 (2–16)
GAF	43.25 (17–61)	44.31 (32–70)
DSM-IV diagnoses		
Psychosis NOS	4 (25%)	2 (15%)
Mood disorders	10 (63%)	6 (46%)
Major depressive disorder	5 (31%)	5 (38%)
Depressive disorder NOS	3 (19%)	1 (8%)
Dysthymia	0	1 (8%)
Bipolar I disorder	1 (6%)	0
Bipolar disorder NOS	1 (6%)	0
Anxiety disorders	11 (69%)	6 (46%)
Obsessive compulsive disorder	4 (25%)	0
Anxiety disorder NOS	5 (31%)	3 (23%)
Social phobia	1 (6%)	3 (23%)
Specific phobia	1 (6%)	0
Generalized anxiety disorder	3 (19%)	0
Panic disorder	1 (6%)	0
Attention deficit hyperactivity disorder	2 (13%)	3 (23%)
Eating disorder NOS	3 (19%)	0
Substance abuse	1 (6%)	1 (8%)
Pervasive developmental disorder NOS	1 (6%)	0
Oppositional defiant disorder	0	1 (8%)
Adjustment disorder	0	1 (8%)
Medication use		
Psychiatric medications at baseline	13 (81%)	9 (69%)
Atypical antipsychotics	9 (56%)	4 (31%)
Other antipsychotics	0	0
SSRIs	6 (37%)	4 (31%)
Benzodiazepines	1 (6%)	0
Mood stabilizers	2 (13%)	2 (15%)
Additional treatments		
Individual therapy	16 (100%)	9 (69%)
Psychiatry	16 (100%)	11 (85%)
School accommodations	11 (69%)	8 (62%)
Race		
Caucasian	13 (81%)	5 (38%)
African-American	0	2 (15%)
Latino	0	3 (23%)
Asian	1 (6%)	2 (15%)
Other	2 (13%)	1 (8%)
Family demographics		
Primary caregiver working	13 (81%)	10 (77%)
Number of parents in the home		
1 parent	7 (44%)	5 (38%)
2 parents	9 (56%)	8 (62%)

TABLE 2. (continued)

Variable	PMFG participants (<i>n</i> = 16)	Declined participation (<i>n</i> = 13)
Number of siblings in the home	0.69 (0–2)	1.31 (0–3)
Distance from UCLA	18.34 miles (3–41)	16.58 miles (3–43)
Parent education		
Junior high school and below	0	1 (8%)
High school	0	2 (15%)
Some college	6 (37%)	3 (23%)
College degree	5 (31%)	1 (8%)
Post college	5 (31%)	5 (38%)

F, female; GAF, Global Assessment of Functioning score; M, male; NOS, Not Otherwise Specified; PMFG, psychoeducational multi-family group; SIPS, Structured Interview for Prodromal Syndromes; SOPS, Scale of Prodromal Symptoms; SSRI, Selective Serotonin Reuptake Inhibitor; WASI, Wechsler Abbreviated Scale of Intelligence.

to celebrations surrounding holidays or group terminations.

Changes in symptoms and functional outcome

T-tests for paired samples were conducted on the symptom and functional outcome scales. PMFG participants demonstrated significant improvement in positive symptoms ($t(15) = 3.94$, $P < 0.01$; mean baseline score = 13.56; mean follow-up score = 8.88) and general symptoms ($t(15) = 2.83$, $P < 0.01$; mean baseline score = 9.50; mean follow-up score = 5.94), improved general functioning ($t(15) = -2.53$, $P < 0.05$; mean baseline score = 43.25; mean follow-up score = 52.25), and work/school functioning ($t(15) = -2.33$, $P < 0.05$; mean baseline score = 2.25; mean follow-up score = 3.38), and increased rates of non-hospitalization ($t(15) = -3.16$, $P < 0.01$; mean baseline score = 3.50; mean follow-up score = 4.0) at follow-up compared with their own baselines. Symptoms and functioning showed improvement from baseline to follow-up on all remaining scales, although the differences were not statistically significant. Follow-up assessments were conducted, on average, 9 months after baseline.

Three PMFG participants and three individuals who declined participation converted to psychosis between the time of the screening interview and follow-up assessment. In the PMFG group, one of the conversions to a diagnosis of schizoaffective illness occurred before initiation of PMFG treatment, and the other two conversions were from diagnoses of Psychosis Not Otherwise Specified to Schizophrenia and Bipolar Disorder with Psychotic features, respectively.

Changes in family process and youth coping

Only a subset of youth who participated in PMFG completed the FACES and Brief COPE instrument at

two time points, baseline and follow-up ($N = 7$). *T*-tests for paired samples conducted on that subset indicate significant improvement in family cohesion ($t(6) = -3.20$, $P < 0.01$; mean baseline score = 23.57; mean follow-up score = 33.29), and adaptability ($t(6) = -3.29$, $P < 0.01$; mean baseline score = 23.71; mean follow-up score = 27.14) as well as constructive coping from baseline to follow-up ($t(6) = -2.31$, $P < 0.05$; mean baseline score = 22.14; mean follow-up score = 27.43).

DISCUSSION

This is the first study to demonstrate that PMFG treatment is feasible and acceptable to adolescents at UHR for psychosis and their primary caregivers. Those participants who attended the psychoeducation presentation were highly likely to attend the PMFG group, and group members attended meetings regularly and reported benefiting from them. The finding that PMFG participants demonstrated improvement in symptoms and functional outcome is encouraging. Of course, this study was not a randomized controlled trial, and multiple interventions (thorough and repeated diagnostic assessment, psychiatric care, case management, school interventions and PMFG) were introduced simultaneously; therefore, changes in outcome cannot be attributed to the PMFG intervention per se. Nonetheless, the results establish the acceptability of PMFG to families and encourage further research into the potential positive impact of PMFG with this at-risk population.

This study found that family processes and individual coping skills hypothesized to underlie changes in symptoms and functional outcome did change significantly over time in predicted directions. Unfortunately, because of the small sample size obtained, we could not conduct a formal

statistical test of a mediation model. Given the difficulties of recruitment and ascertainment inherent to prodromal research, expedited progress in establishing the utility of early psychosocial intervention and prevention efforts hinges on collaborative multi-site efforts with treatment as a primary focus.

Therapists who facilitated the PMFG treatments offered additional insights into potential mechanisms promoting recovery and health. For example, the group context provides an opportunity for parents and youth to better understand each other by observing each other interact in a social context. Family members are less likely to get sidetracked by tangentially related family disagreements, and they tend to stay focused on solving problems and moving forward in the group. Solutions are generated during the group context that would never have emerged during individual and/or individual family problem-solving sessions. For some youth who have high levels of negative symptoms, parent participation is essential in that they initiate discussion of relevant issues that may have been overlooked by treatment providers relying exclusively on youth input. Also, parents often help to constructively engage and cross-parent the subset of youths who would typically be rejected by peers for their unusual behaviours or social judgment.

Of course, given the challenges involved in engaging both parents and adolescents in group treatment, and this study's finding that 45% of the families at a clinical research center for UHR youth declined participation in PMFG treatment, alternative psychosocial interventions for youth and/or parents must also be developed and evaluated. Nonetheless, PMFG treatment is viewed as acceptable and useful by a majority of recruited UHR adolescents and parents, and is well suited to the current early phase of prevention research, when ambiguity remains regarding the risk-benefit tradeoff of using antipsychotic medication with adolescents experiencing sub-threshold psychotic symptoms,³¹ and when coping, problem-solving, communication and social skill building approaches may have the greatest chance of making a difference in the lives of patients and families.

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Shame and guilt/self-blame as predictors of expressed emotion in family members of patients with schizophrenia

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Abstract

Expressed emotion (EE) is a measure of the family environment reflecting the amount of criticism and emotional over-involvement expressed by a key relative towards a family member with a disorder or impairment. Patients from high EE homes have a poorer illness prognosis than do patients from low EE homes. Despite EE's well-established predictive validity, questions remain regarding why some family members express high levels of EE attitudes while others do not. Based on indirect evidence from previous research, the current study tested whether shame and guilt/self-blame about having a relative with schizophrenia serve as predictors of EE. A sample of 72 family members of patients with schizophrenia completed the Five Minute Speech Sample to measure EE, along with questionnaires assessing self-directed emotions. In line with the hypotheses, higher levels of both shame and guilt/self-blame about having a relative with schizophrenia predicted high EE. Results of the current study elucidate the EE construct and have implications for working with families of patients with schizophrenia.

Keywords

Criticism; Emotional over-involvement; Self directed emotions; Five Minute Speech Sample; Self-directed Emotions for Schizophrenia; Scale

1. Introduction

Expressed emotion (EE) is a measure of the family environment that specifically assesses emotions articulated by a key relative towards a family member with a disorder or impairment (Hooley, 2007). EE was first measured by the Camberwell Family Interview (CFI; Leff and Vaughn, 1985). The CFI examines EE on three subscales – emotional over-involvement (EOI), criticism, and hostility. EOI is a composite rating of factors including a relative's exaggerated emotional response; over-identification with the patient; over-intrusive, over-protective, or overly self-sacrificing behaviors (e.g., “I no longer do anything for myself because taking care of his needs is now my top priority”); and excessive concern. (Barrowclough and Hooley, 2003). Criticisms are comments about the behavior and/or characteristics of a patient that a relative resents or finds irritating. Hostility refers to a more generalized version of criticism (e.g., “I can't stand John”). CFI studies have demonstrated that hostility is rarely seen in the absence of high-EE based on criticism. Thus, researchers using the CFI often combine these categories (e.g., Weisman et al., 1998, 2000; Lopez et al., 2009) and newer systems of rating EE, such as the Five Minute Speech Sample (FMSS; Magaña et al., 1986), do not measure hostility as a separate component; instead, it is

combined with criticism. EE is important because it is a robust predictor of illness prognosis across a broad range of psychiatric disorders (Wearden et al., 2000) and, with a few exceptions, across a range of cultures and ethnic groups (Weisman de Mamani et al., 2009). Thus, it is crucial to understand why some relatives respond to a loved one's illness in a critical or emotionally over-involved manner while others do not (Hooley, 2007).

In the current study, self-directed emotions were examined as predictors of EE because some scholars have proposed that both shame and guilt/self-blame may underlie the construct (Jenkins and Karno, 1992). Following Bentsen et al. (1998) who stated that "self-blame is an equivalent of guilt," the current study uses guilt and self-blame interchangeably. Shame and guilt/self-blame are both self-evaluative emotions (Tracy and Robins, 2006). Despite their similarities, however, they are distinct emotions, with different cognitive, affective, and behavioral components (Tangney, 1995). There is some empirical research to support this distinction. For example, Weisman de Mamani (2010) found that increasing shame proneness was positively associated with the general emotional distress (GED) of care-givers. However, increasing guilt proneness was negatively associated with GED.

While guilt/self-blame induces interpersonal engagement and reparation for wrongdoing, Silfver (2007) argues that guilt might be maladaptive, for example, when a person feels guilty for an uncontrollable event like an illness. Hatfield (1981) suggested that high EE is the consequence of guilt. Because guilt encourages reparative behaviors, relatives who feel excessively blameworthy regarding the patient's illness may resort to over-involvement or sacrificing conduct in order to mend behaviors and events for which they feel guilty. Indeed, Bentsen et al. (1998) found that high levels of guilt-proneness, or a tendency to engage in self-blame, were positively associated with the EOI component of EE. Thus guilt may induce reparative behaviors but simply the wrong kinds (those that are maladaptive).

Proneness to shame correlates with a tendency to blame others by making external attributions for shame-eliciting events (Tracy and Robins, 2006). These attributions provoke defensive criticism toward those involved in the shame-eliciting situation, as well as anger, rage, and hostility (Gilbert, 1998). Jenkins and Karno (1992) suggested that shame about having a family member with schizophrenia may underlie EE because shame motivates rage, hostility, anger, and criticism. Ryan (1993) carefully examined the interaction between a man with schizophrenia and his wife, and pointed to verbal and nonverbal evidence of feelings of shame in the patient's high EE spouse. Ryan concluded that relatives' criticism might be a consequence of shame. Low EE family members, on the other hand, may feel less shame about their relatives' symptoms and illness (Harrison and Dadds, 1992).

In a study examining EE in relatives of patients with bipolar disorder, McMurrich and Johnson (2009) found depressive symptoms to be a significant predictor of EE while both guilt-proneness and shame-proneness were not. However, having a relative with bipolar disorder may not be as shame-inducing as having a relative with schizophrenia because bipolar disorder is frequently associated with positive behaviors such as creativity (Santosa and Sachs, 1999) and achievement (e.g. Johnson, 2005). Therefore the experience of shame and guilt may not generalize between the two disorders.

Weisman de Mamani (2010) also examined the relationship of self-directed emotions in relatives of patients with schizophrenia using a dispositional measure of shame and guilt. Dispositional measures assess endorsements of shame and guilt that are trait-like, or inherent, rather than situation-based. However, in this study neither shame proneness nor guilt proneness predicted EE. It is important to note that dispositional measures do not take into account the fact that there are individual differences in the specific types of events and situations that elicit shame, even in people with comparable overall propensity towards

experiencing shame. Thus, Weisman de Mamani (2010) recommended that future studies assess whether EE is associated with relatives' shame and guilt specifically related to their loved ones' illness. This study is building upon the recommendations of Weisman de Mamani to specifically assess self-conscious (referred to in the current study as self-directed) emotions about having a loved one with schizophrenia as predictors of EE.

Unlike the Weisman de Mamani (2010) and McMurrich and Johnson (2009) studies which both used generic proneness measures of self-directed emotions, in the current study we examined the relationships among EE and relatives' feelings of shame and guilt/self-blame as a direct consequence of having a relative with schizophrenia. Based on the literature reviewed above, it was hypothesized in this study that greater shame and guilt/self-blame about having a relative with schizophrenia would each predict the occurrence of high EE in relatives of patients with schizophrenia. On an exploratory basis we examined whether shame and guilt/self-blame predicted the specific components of EE. We expected to replicate Bentsen et al.'s (1998) findings of guilt/self-blame predicting EOI. Furthermore, based on Tangney's (1995) and Gilbert's (1998) views that shame triggers anger, rage, hostility, and criticism, as well as Ryan's (1993) qualitative findings, it was hypothesized in this study that greater shame would predict the occurrence of high EE-critical attitudes.

2. Method

2.1. Sample

The current study was part of a parent study evaluating the efficacy of a 15-week, culturally informed, family-focused treatment for schizophrenia (CIT-S) compared with a treatment-as-usual control condition (TAU). Patients and their family member(s) were recruited from Miami and neighboring cities through the use of local radio, newspaper, and Miami's above-ground rail system advertisements, and community outreach activities (e.g., lectures at support groups for the mentally ill and their family members, hospitals). Participants met the following criteria: the family member(s) had a relative with schizophrenia or schizoaffective disorder, the family member(s) and patient shared at least one hour of contact per week, and participants spoke English or Spanish. Participants were given the option to be interviewed in English or in Spanish and 18 chose to be interviewed in Spanish, while 54 chose to be interviewed in English. An editorial board was used to translate all measures into Spanish. An editorial board approach is considered to be more effective than translation-back-translation and accounts for language variations between Hispanic subgroups (Geisinger, 1994). A native Spanish speaker initially translated all measures from English to Spanish. Next, an editorial board consisting of native Spanish speakers of Cuban, Puerto Rican, Nicaraguan, Colombian, Mexican, and Costa Rican descent, and a non-native Spanish speaker, individually reviewed the Spanish translations and compared them against the original English versions. After independently reviewing the translations, the individuals met as a group along with the original translator to discuss and reconcile discrepancies and concerns with the translations. Board members agreed that the language used in the final versions of all the Spanish measures was clear, comprehensible, and relevant for members of all Spanish-speaking ethnic groups.

Participants consisted of 72 family members of patients with schizophrenia or schizoaffective disorder who completed the baseline assessment of the parent study. In the parent study, there were some cases where more than one family member participated. To ensure the independence of observations, only data from the family member who reported the most contact with the patient were included in the current study.

2.2. Measures

2.2.1. Background information—A demographic sheet assessed respondents' gender, age, ethnicity, religion, educational level, and SES.

2.2.2. Diagnosis confirmation—The diagnosis of schizophrenia or schizoaffective disorder in patients was confirmed using the psychotic disorders module of the Structured Clinical Interview for the DSM-IV Axis I Disorders, Version 2.0, patient edition (*SCID-IP*). The *SCID-IP* (First et al., 2002) is a semi-structured interview designed for diagnosing patients with Axis I disorders according to DSM-IV criteria. The *SCID-IP* has been widely utilized and has demonstrated high inter-rater reliability on individual symptoms and overall diagnosis of schizophrenia (Ventura et al., 1998). For the current study, the Principal Investigator trained all graduate-student interviewers. To assess inter-rater reliability in the current study, the Principal Investigator and all interviewers watched six videotaped interviews and determined an overall diagnosis. Interrater agreement using Cohen's Kappa was 1.0. In other words, there was complete consensus regarding the presence or absence of diagnosis.

2.2.3. Expressed emotion—Expressed emotion was rated using the *Five Minute Speech Sample* (FMSS; Magaña et al., 1986). While the CFI remains the gold standard for assessing EE, the more recently developed FMSS is the second most widely used method and is considerably shorter to administer and to code (Hooley, 2007). Family members spoke, without interruption, for five minutes about the patient, telling the interviewer what kind of person the patient is and how the two of them get along. Family members' responses were audiotaped in order to allow for later coding of their speech sample. Using the criteria of Magaña et al. (1986), family members received a high EE-critical rating if they made a negative initial statement about the patient or the relationship between the patient and themselves, if they reported a negative relationship with the patient, or if they expressed one or more criticisms about their patient. Family members received a high EE emotionally over-involved rating if there was evidence for self-sacrificing, overprotective, or lack of objective behavior toward the patient; an emotional display; or a combination of two or more of the following: a statement of attitude (i.e., feelings of love or willingness to do anything for the relative in the future), five or more positive remarks, or excessive detail about the patient's past. FMSS interviews were inaudible in four cases; therefore EE ratings were only available for 68 families. Of these, 19 were rated as high EE and 49 were rated as low EE. With respect to the specific components of high EE, 9 out of 68 family members received a high EE critical rating, while 11 out of 68 received a high EE-EOI rating.

An undergraduate research assistant and a graduate student participated in intensive didactic training sessions in the *FMSS* scoring system with a trained *FMSS* coder. During the training sessions, the trained coder thoroughly reviewed rating criteria and co-rated 10 training audiotapes with the trainees. The trainees then individually rated 10 additional audiotapes to assess their reliability with the trained coder. The kappa coefficient between the research assistant and the trained coder was 0.80 for rating high versus low EE, 0.86 for rating the critical component, and 0.74 for rating the EOI component. The kappa coefficient between the graduate student and the trained coder was 1.00 for rating high versus low EE, 1.00 for rating the critical component and 0.78 for the EOI component.

2.2.4. Shame and guilt/self-blame—The *Self-directed Emotions for Schizophrenia Scale* was created for the larger parent study described above. This scale is a two-item measure, with one item assessing shame about having a relative with schizophrenia and the other assessing guilt/self-blame about having a relative with schizophrenia. Responses ranged from 1 (Not at all true) to 7 (Very true), with higher scores reflecting a greater degree

of the self-directed emotion in question. The wording of the shame item is “Having a relative with schizophrenia is a great source of shame.” The mean of this scale was 2.16 ($SD=1.92$). The wording of the guilt/self-blame item is “Having a relative with schizophrenia is something for which I feel blameworthy.” The mean of this scale was 1.77 ($SD=1.46$).

2.3. Statistical analyses

This paragraph describes methods used to test associations between the primary study variables (i.e. shame, guilt/self-blame, and EE) and demographic variables. Pearson correlations were conducted to examine relationships between continuous variables (e.g., self-blame) and continuous demographic variables (e.g., hours per week of contact between the patient and family member). Two-way contingency table analyses were conducted to evaluate relationships between categorical demographic variables (e.g., gender) and categorical study variables (e.g., EE). One-way analyses of variance (ANOVAs) or *t*-tests were conducted to examine relationships between categorical variables (e.g., type of relative) and continuous variables (e.g., shame about the illness).

Block-entry binary logistic regressions were used for the primary analyses. When demographic variables were related to study variables, continuous covariates and/or dummy-coded categorical covariates were entered in block 1 and predictors were entered in subsequent steps. Covariates were controlled for only in the relevant primary analyses.

3. Results

3.1. Sample characteristics

The mean age of the sample was 53.44 ($SD=14.23$) and 71% of participants were female. With respect to ethnicity, 52% of participants identified as Hispanic, 29% identified as Caucasian and 18% identified as African American. The following is a breakdown of the type of relationship participants had with the patient, 34 mothers, 9 significant other/spouses, 9 siblings, 7 fathers, 5 long-term friends, 3 offspring, 2 aunt/uncle, 2 cousins, and 1 grandparent.

3.2. Preliminary analyses

Analyses were first conducted to assess for potentially confounding relationships between the primary study variables (i.e. shame, guilt/self-blame, and EE) and the following demographic variables: gender, ethnicity, religious affiliation, religious status, type of relative, education, age, and number of hours of contact per week between the relative and patient. Results of the preliminary analyses indicated that hours of contact per week between the relative and the patient were positively associated with self-blame about having a relative with schizophrenia, $r(34)=0.38$, $p=0.03$. EOI was significantly related to relative's gender, $\chi^2(1, N=68)=5.47$, $p=0.02$. Specifically, 100% of males were low EOI, while 23% of females were high EOI. Finally, a significant difference existed between type of relative and self-reported shame about having a relative with schizophrenia, $F(7, 61)=2.48$, $p=0.03$, such that mothers reported experiencing more shame than siblings and friends.

3.3. Primary analyses

3.3.1. Shame and guilt/self-blame predicting EE—Two block-entry binary logistic regressions were conducted in order to test the hypotheses that greater shame and guilt/self-blame about the illness predict high EE. It is important to note that shame and guilt/self-blame demonstrated a moderately high correlation in this study ($r=0.67$, $p<.01$). Thus, these constructs were analyzed in separate regression analyses to avoid multi-collinearity

(Morrow-Howell, 1994), and to allow us to gain a more valid assessment of the unique predictive power of each independent variable.

To assess whether shame predicted EE, type of relative, which was significantly related to shame about the illness, was first entered into the regression model. Next, shame about the illness was entered. As hypothesized, shame about the illness predicted overall EE status (i.e., high versus low), likelihood ratio $\chi^2=6.65$, $p=0.01$. Using Cohen's criteria, the effect size was large, $Exp(B)=1.55$.

A second block-entry binary logistic regression was conducted in order to assess the hypothesis that greater guilt/self-blame about the illness would predict the occurrence of high EE attitudes. In step 1, hours of contact per week between the relative and patient, which was identified as significantly correlated with guilt/self-blame, was entered. In step 2, guilt/self-blame was added. Results revealed that guilt/self-blame about the illness predicted overall EE status (i.e., high versus low), likelihood ratio $\chi^2=7.37$, $p<0.01$. For each standard deviation increase in guilt/self-blame, the odds of being high EE increased by 0.34. Using Cohen's criteria, the effect size was large, $Exp(B)=2.09$.

We also attempted to replicate Bentsen et al.'s (1998) finding of guilt/self-blame predicting EOI. A block-entry binary logistic regression was conducted in order to assess whether greater guilt/self-blame about the illness predicts the occurrence of high EE-EOI subgroup status. In step 1, hours of contact per week between the relative and patient and gender, which were identified as significantly correlated with one or more variables of interest, were entered. In step 2, guilt/self-blame was added. Results failed to demonstrate a significant relationship between guilt/self-blame and EOI, likelihood ratio $\chi^2=0.37$, $p=0.30$.

Furthermore, based on Gilbert's (1998) and other's view, a block-entry binary logistic regression was conducted in order to test the hypothesis that greater shame about the illness would predict high EE-critical subgroup status. First, type of relative, which was significantly related to shame about the illness, was entered. Next, shame about the illness was entered. Contrary to the hypothesis, results failed to indicate that shame predicts EE-critical subgroup status, likelihood ratio $\chi^2=0.56$, $p=0.46$.

4. Discussion

Expressed emotion is one of the most reliable predictors of relapse across a range of psychiatric illnesses (Hooley, 2007). While previous studies have examined underlying factors of EE such as personality characteristics (Hooley and Hiller, 2000) and locus of control (Bentsen et al., 1997; Hooley, 1998), limited research to date has paid attention to the self-conscious emotions that may underlie EE. The current study was the first to consider the role of a relative's shame and guilt/self-blame specifically about having a family member with schizophrenia as underlying EE. Study results supported the hypothesis that shame predicts high EE, with a large effect size. This finding validates previous research (Harrison and Dadds, 1992; Jenkins and Karno, 1992; Ryan, 1993) that shame underlies high EE and that shame is related to dys-functional family dynamics (Pulakos, 1996). The fact that we used a direct measure of shame specifically about a relative's schizophrenia rather than generally assessing shame-proneness may explain why our findings differ from those of Weisman de Mamani (2010) and McMurrich and Johnson (2009). As research in social psychology strongly indicates, the associations among beliefs, attitudes, behaviors, and emotions are strongest when the constructs and the behavioral or emotional result are assessed in a manner that is highly specific to the context (Myers, 2010).

Similarly, guilt/self-blame for having a loved one with schizophrenia predicts high EE, with a large effect size. This finding contributes to the argument that guilt/self-blame about

having a relative with schizophrenia may be maladaptive (Silfver, 2007; Dost and Yagmurlu, 2008). Family members may defend against the experience of blaming themselves by shifting the blame onto the patient in a critical manner or by engaging in emotionally over-involved behaviors to repair their wrong-doing. Unlike Bentsen et al. (1998), the current study did not find a relationship between increasing levels of self-blame and emotionally over-involved behaviors and attitudes. This null finding may partially be attributable to the fact that there were only 11 family members whose FMSS merited a high EE-EOI rating. Similarly, contrary to hypotheses, this study failed to demonstrate a significant positive relationship between shame about having a loved one with schizophrenia and critical attitudes. The ability to find a significant relationship may have also been underpowered due to the fact that there were only nine out of 68 family members whose FMSS merited a high EE-critical rating.

It is also worth noting that, in the current study, more hours of contact per week were associated with greater guilt/self-blame about having a loved one with schizophrenia. Guilt/self-blame motivates a tendency to engage with others, including the one who was wronged, and to repair wrongdoings. Relatives who feel that they are to blame for having a loved one with schizophrenia may seek more contact with the patient in order to mend the offenses they believe they have inflicted on the patient. Given the current study finding that greater self-blame appears to be associated with high EE, the increased contact between guilt-ridden relatives and patients may actually have detrimental consequences for patients. This hypothesis warrants further attention in future research.

The current study possessed a number of limitations. As noted above, the first was the small sample size, in particular, the number of family members rated as high EE. These small subsamples may have particularly limited the examination of the hypotheses that shame and self-blame would predict high EE-critical and high EE-EOI attitudes, respectively, since these analyses required that the high EE sample be divided into even smaller subsamples. Thus, the small sample and subsamples warrant caution when interpreting this study's non-significant trends and null findings. Future research exploring predictors of EE should be conducted with larger samples. The means in this study for both shame and guilt were quite low. This may be a function of the scale used to assess these self-directed emotions or it may reflect the fact that relatives willing to acknowledge their family member's illness by participating in a research study may be less prone to experience these self-directed emotions than those who are unwilling to participate in a study on mental illness in the family.

A second limitation is that the current study utilized the *Five Minute Speech Sample* to determine EE. While the FMSS is easy to administer, predicts clinical outcome in schizophrenia (Marom et al., 2002, 2005), and correlates with the *Camberwell Family Interview (CFI)* (Magaña et al., 1986; Weisman de Mamani et al., 2007), it appears to be less sensitive than the CFI in the detection of high EE (Hooley and Parker, 2006). With large samples this issue may be less salient. However, in future studies, when sample sizes are expected to be relatively small (as is common in clinical research), researchers may benefit from assessing EE with the CFI.

There were also methodological limitations with the Self-directed Emotions for Schizophrenia Scale. The constructs of shame and guilt/self-blame were measured with just one item each. Longer scales tend to be more reliable and valid (Smith et al., 2000) and should be considered when conducting follow-up work in these areas. Another important limitation of this scale is the wording used to assess guilt/self-blame. This item asked relatives whether having a loved one with schizophrenia was something for which they felt blameworthy. Although Bentsen et al. (1998) considered blameworthiness to be equivalent

to guilt; it is possible that relatives would have responded differently had they been asked if having a loved one with schizophrenia was something for which they feel guilty. For instance, perceptions of self-blame may function more similarly to feelings of shame than to feelings of guilt. It is noteworthy that shame and guilt/self-blame were correlated in this study ($r=0.67$, $p<0.01$). Similarly, both psychologists and laypeople alike often use the terms shame and guilt interchangeably (Tangney et al., 1996). Therefore, it is possible that in the current study, the majority of family members did not make a distinction between shame and guilt/self-blame. Not only would this account for the parallel findings between shame and guilt/self-blame as predictors of high EE, but it might also explain the inability for shame and guilt/self-blame to differentially predict EE-critical attitudes and EE-EOI attitudes, respectively. Finally, the current study's findings for shame and guilt/self-blame may reflect that high-EE relatives are more likely to feel negatively about their family member's illness than are low-EE relatives. As guilt and self-blame were highly correlated in this study, it is possible that both of these constructs are also correlated with other personality factors such as negative disposition. This hypothesis should be evaluated further in future research.

In conclusion, the findings that both shame and guilt/self-blame about having a loved one with schizophrenia predict high EE suggest that clinicians should assess for self-directed emotions directly in response to a family member's illness and aim to alleviate feelings of shame and self-blame around this. Psychoeducation that is aimed at imparting information about the biological underpinnings of schizophrenia (e.g., Falloon et al., 1984) may be effective in this aim. Interventions for shame may also benefit from including broader efforts to reduce stigma, perhaps by encouraging multi-family groups and other social interactions among people coping with schizophrenia. Self-blame interventions might include emphasizing the diathesis-stress model and pointing out that it is unlikely that any single behavior or family member is responsible for onset or maintenance of schizophrenia. Furthermore, recent research indicates that patients from high EE families may benefit from interventions aimed at improving their ability to manage difficult family environments (Meneghelli et al., 2011). Future studies that measure both specific and dispositional measures may offer the greatest insights into how self-directed emotions relate to coping with mental illness in a loved one. Future research that is longitudinal in nature would also be beneficial in further elucidating the role of shame and guilt/self-blame in the development of EE attitudes.

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TIME

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Staying Sane May Be Easier Than You Think

By John Cloud

We tend to view the brain like an alien that happens to reside in the skull. We see it as unpredictable, ungovernable in ways that other organs aren't. Proper diet, exercise, no smoking — these will help prevent heart and lung disease. But diseases of the mind? They strike at will, right? You just can't keep yourself from going crazy.

And yet — what if you can? The most exciting research in mental health today involves not how to treat mental illness but how to prevent it in the first place. Hundreds of studies that have appeared in just the past decade collectively suggest that the brain isn't so different from, say, the arm: it doesn't simply break on its own. In fact, many mental illnesses — even those like schizophrenia that have demonstrable genetic origins — can be stopped or at least contained before they start.

This isn't wishful thinking but hard science. Earlier this year, the National Academies — an organization of experts who investigate science for the Federal Government — released a 500-page report, nearly two years in the making, on how to prevent mental, emotional and behavioral disorders. The report concludes that pre-empting such disorders requires two kinds of interventions: first, because genes play so important a role in mental illness, we need to ensure that close relatives (particularly children) of those with mental disorders have access to rigorous screening programs. Second, we must offer treatment to people who have already shown symptoms of illness (say, a tendency to brood and see the world without optimism) but don't meet the diagnostic criteria for a full-scale mental illness (in this case, depression).

Neither approach is without controversy. Early-detection programs will identify as candidates for mental illness some people who are merely persnickety or shy or eccentric. Some prevention programs even prescribe psychiatric medications, including antipsychotics and antidepressants, to people who aren't technically psychotic or depressed. "This is a big concern," says Joseph Rogers, founder of the Philadelphia-based National Mental Health Consumers' Self-Help Clearinghouse. "Because, gee, if you miss, you can really do more harm with some of these drugs than good."

But those who contributed to the National Academies report say preventing the suffering of people with mental illness is worth the risk of some false positives, partly because of the enormous cost of treating mental illness after it's struck. The National Academies estimates that the total economic cost of mental disorders just among Americans under 25 was \$247 billion in 2007. (There are no such recent figures for all adults, but one 2000 study estimated that in 1992, the total cost of adult mental illness was \$161 billion.) Another 2007 study found that more than a quarter of the costs for young people are incurred in the education and juvenile-justice systems, which must deal with illnesses that, in many cases, could have been prevented.

But how do you predict and stop disorders as capricious and varied as depression and schizophrenia? Though treatment of mental illness is far more costly over time, prevention isn't without up-front costs. In a health-care system already overburdened, who pays? More fundamentally, what kind of country will we have if we attempt to "cure" various odd behaviors and quirky traits — qualities that can sometimes look like symptoms of a coming illness and other times look like evidence of a lively mind?

Prevention Pioneer

In the early 1970s, before Dr. William McFarlane was one of the world's top authorities on preventing mental illness, before his hair had thinned and receded to a salt-and-pepper pouf, back when he was a student at the Albert Einstein College of Medicine in New York City, few psychiatrists talked about prevention. At the time, the U.S. had half a million psychiatric beds (there are 200,000 today), and psychiatrists faced less financial pressure to move inpatients quickly to outpatient care. Many people spent years on locked wards, their brains slowly gelatinizing from the combination of underlying illness and the blunt-instrument antipsychotic drugs of the day.

After he finished school and began seeing patients and teaching, McFarlane, like a few other pioneers, started to wonder if you could do something to stop the cycle before it began. But there was little research at the time on the early stages of mental illness. A key break came in the late 1970s, when a UCLA team began to publish the results of an influential long-term study called the UCLA Family Project. The study found that you could predict, with remarkable accuracy, which 16-year-olds would develop schizophrenia later in life based on only a few characteristics. The teenagers whom the Family Project tracked had already sought treatment for a psychological problem, although the study excluded actively psychotic teens, since it would not have been a surprise if they had developed schizophrenia.

Studying such kids for more than a decade, the researchers discovered that those who became schizophrenic were most often from families that, when first interviewed, displayed "communication deviance" (unclear, unintelligible or fragmented speech) and highly critical and intrusive parenting. These weren't merely families that argued with difficult sons and daughters; they were families that had lost all ability to cope.

McFarlane and others began working with some of the families to address their interactions and teach them how to communicate better — more slowly, with less anger and intrusion. Even after they are on medication, people with schizophrenia have a difficult time tracking rapid, highly emotional speech, yet that's the kind they often hear from frustrated family members. These patients would improve in hospitals but relapse once they got home, even when they continued to take antipsychotics.

For several years, McFarlane developed and tested the Multi-Family Group approach, which brought several families together at a time to learn from one another how they sounded to outsiders. In twice-monthly sessions, the families modeled greater clarity and compassion and troubleshoot daily-living problems like kids' marijuana use or sexual activity. It was a simple intervention that, when combined with antipsychotic drugs, worked to reduce schizophrenic relapse rates significantly more than the drugs alone.

McFarlane wondered if the treatment could work even earlier, to help prevent the illness in largely asymptomatic kids who were at risk for schizophrenia. Such pre-diagnosis would not be easy, but McFarlane knew that once a patient's perception of reality has cracked for the first time, it becomes exceedingly hard to walk back to normality. Indeed, a major study just published in the journal *Neuropsychology* shows that the signature cognitive problems of schizophrenia — deficits in verbal learning and memory along with processing speed — actually begin days or weeks before a first psychotic episode, making the earliest possible detection all the more urgent.

And so in the 1980s, McFarlane began canvassing schools in the New York City area to try to get the staffs excited about preventing schizophrenia among their students. A number of the superintendents "practically threw us out the window," he says. "They just kept saying, 'We don't have mental illness in our high school.'" It was dispiriting: based on the epidemiological data, McFarlane knew that each year about 12 in 10,000 young people suffered a first episode of psychosis. Some of the kids were clearly in those schools, but if he couldn't get through the door to screen them, he couldn't prevent any illness.

A Theory Goes Wide

Even as McFarlane was exploring his schizophrenia-prevention idea, other researchers were having similar what-if moments with respect to other, more routine conditions. Suppose irritable infants who become fearful toddlers who become shy children somehow could be stopped from becoming adults with anxiety disorders. Suppose men and women who go to war or become cops in inner cities could be helped before developing posttraumatic stress disorder. Could you, similarly, identify the children of depressed parents early and give them skills to prevent their own first depressive episode?

In any given year, approximately 17% of Americans under 25 have a mental, emotional or behavioral disorder. (Over our lifetime, 46% of us will receive such a diagnosis.) If we reduce the proportion of young people who become mentally ill by even one-quarter, that would mean about 3.8 million saved each year from what can turn into a lifelong struggle.

But if most mental illnesses have a genetic origin, isn't even that modest 25%-reduction goal unlikely? The science can get tricky here, but the simple answer is that genes aren't destiny. You can't do anything to change your genome, but your environment and experiences have powerful effects on the way those genes are expressed. A susceptibility to cancer may remain just a susceptibility — until you start smoking and kick the disease process into motion. Similarly, change a child's emotional experiences for the worse and you can trigger mental illness; change them for the better and you may hush the problem genes. One concrete example of this: in 2003, a study in *Science* found that the larger the number of copies an individual carries of a serotonin-transporter gene called 5-HTTLPR the greater the risk of developing major depressive disorder and suicidality — but only if the individual suffers stressful early-life experiences like abuse.

How long is the window between first symptoms and actual diagnosis? The National Academies report says that across several mental illnesses — including obsessive-compulsive

disorder, depression and substance dependence — we have about two to three years to intervene and keep short-term symptoms from becoming long-term afflictions.

Depression offers particularly good evidence of this idea at work. Currently, about 5% of adolescents experience an episode of clinical depression in any given year. Rates of depression are three to four times as high among the children of depressed parents as among those whose parents aren't depressed. Dr. William Beardslee of Children's Hospital Boston, one of the authors of the National Academies report, has spent more than 25 years studying how some kids of depressed parents avoid the illness, and he has found that resilience is key. The kids who don't develop depression are "activists and doers," Beardslee says. Even growing up in the darkness of a depressed home, they muster the capacity to engage deeply in relationships. They also are likelier than other kids to understand that they aren't to blame for their parents' disorder — and that they are free to chart their own course.

How do you foster resilience in order to prevent depression? Over the past 17 years, Beardslee's team has developed an early intervention that targets kids from families in which at least one parent is depressed. Like McFarlane, he uses a family-based approach because a bad home environment tends to be more predictive of adolescent mental illness than dysfunctional peer relationships are. Beardslee's Family Talk Intervention includes both separate meetings with parents and kids as well as family meetings with social workers or psychologists that focus in part on demystifying depression — explaining that it is a treatable illness, not a beast that will necessarily crush a family. In a randomized trial, Beardslee found that just seven sessions of this intervention decreased pre-depression symptoms among the kids and improved the parents' behavior and attitudes. All this makes kids more resilient.

Tackling Schizophrenia

McFarlane hadn't gotten far with the New York City schools in the 1980s, and his prevention work waned for a few years as he taught at Columbia University and wrote articles on his Multi-Family Group approach to treating psychosis. Eventually, he moved to Portland, Maine, where he had been offered the chairmanship of Maine Medical Center's psychiatry department. There, he settled into quieter, less paradigm-changing work.

It wasn't until 1996 that his prevention work resumed. That year, a team of researchers in Norway — one that included Dr. Thomas McGlashan of Yale — approached McFarlane about training therapists to use the Multi-Family Group approach with patients who had just suffered a first psychotic episode. These patients already had the illness, so it was too late for prevention. But the Norwegians had succeeded where McFarlane had failed in New York: they had connected with schools and other local institutions to identify the first signs of psychosis and refer patients to the team immediately.

In October 1998, the picture grew still more promising when NATO sponsored a major psychotic-disorders conference in Prague, where McFarlane learned that several groups around the world, including one in Australia, had also been trying to prevent first episodes of psychosis. He returned from Prague and tried again to set up an early-detection system with schools, this time in Portland. By now, the stigma against mental illness had eased a bit;

schools had seen a dramatic rise in emotional and behavioral problems during the '90s. Unlike their New York counterparts, Portland school superintendents welcomed McFarlane.

At about the same time, McGlashan's team at Yale was working on a screening interview that might distinguish kids who would become psychotic from those who wouldn't. McGlashan tested his questions at various sites in North America, including with teens who sought treatment in McFarlane's department in Portland. By 2001, McGlashan and his team had completed their "Structured Interview for Prodromal [pre-disease] Symptoms" (SIPS) — a two-hour assessment involving various oral tests and a family history. Those who meet SIPS criteria for risk are about 30 times as likely as the general population to develop a diagnosable psychotic disorder. SIPS allows for the careful scoring of warning signs, some of which are obvious (hearing mumbling that isn't there) and some of which are less so (changing your behavior because of a superstition).

McFarlane and his team connected with most of Portland's principals and pediatricians. The message was simple: If you encounter kids who seem slightly off — prone to jumbled thoughts, maybe even hearing voices — send them our way. Among those referred to him, McFarlane found that 80% of those who met SIPS criteria for prodromal psychosis would receive a diagnosis of schizophrenia within 30 months. He put kids who met a certain SIPS threshold into Multi-Family Group psychoeducation. At first, he intended not to use drugs with these prediagnosis kids, particularly since the meds can cause side effects like weight gain, acne and uncontrollably shaky legs. But McFarlane found that once symptoms like auditory hallucinations started, he couldn't correct them with only psychosocial interventions. (Today, virtually everyone enrolled in his Portland Identification and Early Referral prevention program is prescribed psychiatric medication.)

The combination of the family approach and drug support seems to be working well. The National Institute of Mental Health is funding a trial of McFarlane's work, and while he is still writing up his data for publication, his anecdotal results are promising: most of the kids are so far avoiding a first psychotic episode. Even those who have heard voices and nearly dropped out of high school are going to college and getting jobs.

But this approach doesn't come cheap. The kids who are enrolled are bombarded with care: social workers help them at school or work; therapists guide them and their families in individual and group sessions; a psychiatrist or nurse practitioner carefully calibrates their medication based on response rates and side effects.

When members of McFarlane's clinical team gather each day to discuss cases, they know virtually everything about their kids: they know about boyfriends, girlfriends and summer plans. They know the kids' grades in English class, how much pot they smoke, what they did on a recent trip to Disneyland. They know whether Dad just lost his job and if Mom's grandmother killed herself. This is what prevention of mental illness looks like: unwavering, sweeping, complicated. But it works.

One Family at a Time

The Robert Wood Johnson foundation is so impressed with McFarlane's program that it has devoted \$15 million to its national expansion. It is the foundation's single largest mental-health initiative. McFarlane's approach costs about \$3,500 per patient per year, but compare that with the \$150,000 a year to care for a hospitalized schizophrenic or severely bipolar patient.

Still, not all the kids McFarlane sees can be helped. Patti White is a plainspoken 47-year-old Mainer who works for McFarlane as an administrative coordinator. She has a son who began experiencing psychotic symptoms a few years ago, and he might have seemed like a perfect fit for her boss's program. He wasn't; prevention isn't that easy. Instead, White's son Tyler, who turns 20 this month, was too far along in his illness — eventually diagnosed as schizoaffective disorder, a relative of schizophrenia — to benefit from prevention therapy. A social worker on McFarlane's team helped Tyler get into treatment, and he is doing better and holding down a job in food service.

But White has another son, Jacob, who causes her to worry. A few months ago, Jacob, 10, started to withdraw. He was getting paranoid. At school, he started seeing complicated machinations where none existed. And even though White works for one of the world's leading prevention experts, she at first resisted having Jacob take the SIPS test. "If his brother had had diabetes, I wouldn't have thought twice about having Jacob screened for diabetes," she says. "But I just couldn't deal with the idea that another one of my kids would have" — she pauses — "this enormous thing."

Three weeks ago, Jacob took SIPS. The good news: he showed no red flags for psychosis. He does have depressive symptoms and is now taking a low dose of Prozac to help prevent a full-blown depression. But for Jacob — and millions of other Americans with all manner of mental ills — intervention can now come in time.

RESEARCH ARTICLE

Open Access



Challenges for group leaders working with families dealing with early psychosis: a qualitative study

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Abstract

Background: Family work is one of the best researched psychosocial interventions for patients with chronic psychosis. However, family work is less studied for patients with a first episode psychosis and the studies have revealed contradicting results. To our knowledge, no previous studies have examined qualitatively group leaders' experiences with family work. In the present study we wanted to explore challenges faced by mental health professionals working as group leaders for family interventions with first episode psychosis patients.

Method: A qualitative exploratory study was carried out based on digitally recorded in-depth interviews and a focus group interview with nine experienced mental health professionals. The interviews were transcribed in a slightly modified verbatim mode and analysed by systematic text condensation.

Results: Challenges faced by group leaders was classified into six categories: (1) Motivating patients to participate, encouraging potential participants was demanding and time-consuming; (2) Selecting participants by identifying those who can form a functional group and benefit from the intervention; (3) Choosing group format to determine whether a single or multi-family group is best for the participants; (4) Preserving patient independence, while also encouraging them to participate in the intervention; (5) Adherence to the protocol, while customizing adjustments as needed; (6) Fostering good problem-solving by creating a fertile learning environment and choosing the most appropriate problem to solve.

Conclusions: Group leaders face challenges related to recruitment and selection of participants for family work, as well as in conducting sessions. Awareness of these challenges could help health professionals more specifically to tailor the intervention to the specific needs of patients and their families.

Keywords: Early intervention, Family work, Psychosis, Qualitative research

Background

Onset of psychotic disorders typically occurs in late adolescence or early adulthood [1]. Although the course of psychosis may vary substantially among patients, many patients have poor long-term outcomes [2] resulting in personal suffering and costs to society. Over the past two decades the major focus has been on early intervention, with the primary aim of initiating treatment (e.g., antipsychotics, family work and individual psychotherapy) as early as possible to reduce the

severity of symptoms and increase psychosocial functioning. The effect of antipsychotic medication in reducing psychotic symptoms and the risk of relapse are well documented [3]. However, a large majority of patients require additional psychosocial intervention. The efficacy of family intervention for individuals experiencing psychotic symptoms for several years is well documented [4]. However, to our knowledge there are only five quantitative studies on first episode psychosis (FEP) and family interventions. The results are contradictory; two studies showed positive effect [5, 6], two studies showed negative effect [7, 8] and one study showed no effect [9].

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Regarding qualitative studies, in a descriptive review of studies between 1996 and 2008, Boydell and colleagues found no studies about family work from the mental health perspective [10]. To our knowledge no other studies have been published on this topic since 2008. Our group recently [11, 12] published two studies examining the perspective of patients and family members on participation in family intervention. The first study [11] examined the reported experiences of patients and family members with family intervention, which demonstrated that a good relationship with group leaders was important to avoid participant attrition. Furthermore, the study revealed that meeting other people in the same situation reduced feelings of shame and increased hope for the future. Narratives from real life were considered to be more important sources of knowledge about psychosis than lectures and workshops, but many patients experienced considerable anxiety and tension during meetings. The group format could be difficult for patients immediately after a psychotic episode, and for those still struggling with distressing psychotic symptoms. The second study [12] examined how patients and family members perceived the benefits of participating in family intervention. Family intervention benefits included gaining insight and acceptance of the illness. Moreover, it was important to recognize warning signs and take them into account, as well as to learn new ways to communicate. The patients also felt that they gained more independence and were able to take responsibility for their own lives.

Patients with a first episode psychosis and their families are best qualified to describe the family intervention experience. However, health professionals can probably offer important additional information. They may be experienced in aspects of interventions that are useful for assessing patient potential and aiding progress towards recovery. Challenges, experienced by health professionals conducting family work, could be to decide what kind of patients they should invite to participate, what kind of relatives, when in the illness process they should invite the participants to join family work, should patients and family members participate together, how strict must the group leaders follow the treatment manual and how could they best evaluate how much stress and anxiety the patients are able to tolerate? These difficulties and challenges, in conducting family work are, to our knowledge, never explored in earlier studies. As health professionals and researchers experienced in psychiatry and family work, we were interested in learning more about these challenges in order to improve the intervention for patients with a FEP and their families.

Aim of the study

This study aims to explore the challenges faced by mental health professionals as group leaders in family interventions for first episode psychosis patients.

Methods

This qualitative exploratory study, conducted in a natural setting, is based on data from in-depth single interviews and a focus group interview. As the goal was to explore challenges in conducting family work, a qualitative approach was chosen. The study was carried out at the Centre of Competence for Early Intervention in Psychosis (TIPS), and is part of the Thematic Research area Psychosis (TOP) study at the University of Oslo and Oslo University Hospital.

Participants

Mental health professionals trained in psychoeducational family work, based on the manual developed by McFarlane and colleagues [13, 14], were recruited from hospitals in southeast Norway. Fifteen health professionals were invited to a focus group interview. Six did not respond to the invitation and four were not able to participate. To achieve a more heterogeneous material we invited the four group leaders, who were not able to join the focus group interview, to individual in depth interviews. The sampling strategy aimed at achieving diversity of health professionals; the sample included psychiatric nurses, occupational therapists, psychologists and psychiatrists with group leader experience. A total of nine mental health professionals agreed to participate and provided informed consent. All but one had conducted sessions with one or two multi-family groups, while four had experience with 1 to 14 single-family groups. The length of intervention was one year for single-family groups and two years for multi-family groups. All participants were women with five to 15 years of experience in family work. The number of interviewees was small, but hopefully the participants' long and varied clinical experience compensates for that. During the interview process it became evident that the group leader experienced challenges in conducting family work. It was easily discussed, and the material revealed answers about their perceived challenges, especially during the recruitment phase. Their concerns were mainly about how they best could take care of the young patients in a difficult situation. In spite of the low numbers of participants, in the present study, we secured saturation by performing the analysis concurrently with the data collection and by continuously evaluating the interviews and the transcripts.

Data collection

An interview guide was developed in cooperation with patients, family members and health professionals familiar with the intervention. The guide was based on the manual and efforts were made to ensure coverage of all elements of the intervention (Table 1).

The first author conducted the interviews, which lasted between 30 and 110 min, between June and

Table 1 Interview guide

-
- How would you describe your experience as a group leader?
 - The treatment is divided into phases, could you describe your experiences with the different phases. Obstacles, challenges and positive experiences.
 - The joining in period
 - The survival skills work shop
 - The meetings
 - What are the most challenging subjects in conducting family work?
 - How do you differentiate between those who should be offered a single- or a multi-family intervention?
 - What benefits do you think the participants experienced by participating in the intervention?
 - Is there something within the intervention that makes it easy/difficult to participate?
 - What changes should be made to make the intervention more beneficial for patients experiencing a first episode psychosis?
 - How would you describe the patients who drop out?
-

November 2013. The second author (IN) participated as an assistant moderator in the focus group interview. The interviews were digitally recorded, and transcribed in a slightly modified verbatim mode [15] by the first author. Both LN and IN are psychoeducational multi-family group (PEMFG) leaders with experience conducting and supervising the intervention with patients suffering from various psychotic disorders. This may have influenced the results. However, all authors made a deliberate effort to bracket preconceptions by having an interdisciplinary dialogue throughout the research process.

The intervention

Psycho educational family work is a method for working with families who have a member suffering from mental illness. The goals are to improve outcome and quality of life as well as to reduce family stress and strain and has a multi-family or a single-family format [13, 16]. The method comprises three stages: the joining in period, survival skills workshop and the meetings. The meetings are usually biweekly and last for 90 min in a multi family approach and for 45 min in a single family intervention. The intervention is originally designed for patients suffering from long lasting mental disorders, but is also an intervention recommended for patients with a FEP [8, 17].

Ethical aspects

The study was approved by the Regional Committee for Medical and Health Research Ethics for southeast Norway (REC South East) (2011/566).

Analysis

Data were analysed according to the principles of systematic text condensation (STC) [18]. Analysis was

conducted in four steps, and steps two and three were analysed using NVivo 10. First we read through the interviews to achieve an overall impression, and to look for preliminary themes related to the challenges faced by mental health professionals working with patients and family members in psychoeducational family intervention. Second, we broke down the text into manageable meaning units and connected related meaning units into code groups. Third, we condensed the meaning under each code group. Fourth, we developed an analytic text about the six categories we found relevant for this study. The first and the last author read through all the interviews separately several times and identified meaning units. All authors were involved in the analysis, determining the categories and their content. Agreement was reached through group discussion.

Results

Health professionals reported six challenges (Table 2): (1) Motivating patients to participate in the intervention, because encouraging potential participants was both demanding and time-consuming; (2) Selecting participants by identifying those who can form a functional group and benefit from the intervention; (3) Choosing group format to determine whether a single or multi-family group is best for the patients and their families; (4) Preserving patient independence, while also encouraging them to participate in the intervention; (5) Adherence to protocol, while customising adjustments as needed; (6) Fostering good problem-solving by creating a fertile learning environment and choosing the most appropriate problem for patients to solve.

Motivating patients to participate

In the recruitment phase, health professionals faced challenges in motivating patients. Despite the heavy caseload of potential participants, motivating patients to participate in multi-family group intervention was experienced as time-consuming and intense. While most family members were motivated and willing to participate immediately, patients were anxious about the intervention, which frequently caused considerable delays before consent was given. Understanding these feelings was important in the recruitment process. Experience as a group leader could be a strength for motivating potential participants, since they could refer to their own confidence in the intervention, citing experiences from previous participants. The interviewees argued that group leaders should be involved in the recruitment phase from the start, in order to establish good alliance with participants. In their experience, participants who showed little or no interest during the bonding period were more likely to drop out of the intervention.

Table 2 Important challenges emphasised by mental health professionals conducting psychoeducational family interventions in early psychosis

Theme	Quotes from mental health professionals
Motivating patients to participate	<p>"The recruitment period starts very early and it is necessary to take small steps to avoid frightening the patients away."</p> <p>"I had to put my heart into the work; I had to say that I really believe this intervention is something worth trying...I know it has been useful for others in the same situation."</p> <p>"Patients get a lot of offers and you have to promote the intervention."</p> <p>"For some patients it took a year before they were ready to accept the invitation."</p> <p>"It was much more difficult to recruit patients into a group than I would have thought."</p>
Selecting participants	<p>"In the future I would have been much more responsive to patients who do not want to participate."</p> <p>"This type of family work is an important part of treatment for psychosis, and it feels like a loss when someone drops out. But it isn't right for everyone."</p> <p>"Looking back, I think we exposed some patients to too much pressure during the recruitment phase, the family members were motivated, but the situation caused substantial anxiety for the patient."</p> <p>"I think he [the patient] became traumatized and it hurts to think about it...In the future I will listen to my clinical experience."</p> <p>"I don't think it is right to bring people from different life situations and with different types of illness, symptoms and needs into the same group."</p>
Choosing group format	<p>"Those who are able to identify themselves as having an illness, and at the same time are able to distance themselves from feelings of loss and sorrow, gained more from participating in a group ...the ones caught up in their emotions became anxious."</p> <p>"In a single-family group, family secrets could have been revealed. This would give the family members opportunities to talk about issues they never have discussed before."</p> <p>"It was difficult to handle the group, especially when some family members talked too much or ignored the structure."</p>
Preserving patient independence	<p>"Patients often feel embarrassed participating in an intervention together with their family members; they hardly want their family to participate in an ordinary treatment session."</p> <p>"Patients prefer to keep up with their usual activities and to maintain their normal life."</p> <p>"If the patients' capacity is to be social twice a week, they prefer to be with friends rather than in a group."</p>
Adherence to protocol	<p>"...if you are unfamiliar with the method, the manual could be something to hold on to."</p> <p>"You have to be flexible and make use of your clinical experience, not strictly follow the manual."</p> <p>"You have to be yourself and communicate in a language and in words you feel comfortable with."</p> <p>"The ability to look above and beyond the manual makes you a good group leader."</p>
Fostering good problem-solving	<p>"Being able to explore together in the group and realising that they [the patients] were able to handle the problem"</p> <p>"I think a more optimistic view ... and talking about hope, achievements and resources, would have suited the participant better than talking about problems"</p> <p>"The opportunity to ask about what is going well is the brilliant part of this intervention, which improved conversations. Otherwise it could have been difficult to handle"</p>

Selecting participants

Health professionals emphasized that multi-family group interventions were not appropriate for all eligible participants. They found that patients often were reluctant to participate in such a long lasting intervention. They experienced that patients were eager to return to their ordinary lives and were not interested in further treatment. The health professionals felt that high-pressure persuasive techniques during recruitment could traumatize vulnerable patients. This became especially evident for patients with a short period of illness or with rapid remission. They were not interested in the intervention even though the families were eager to participate. For future purposes, health professionals concluded that they needed to be more responsive to the unwillingness of

some patients to participate, but found it challenging because they wanted to provide patients with a treatment they found beneficial for most patients. They concluded that there are many paths to recovery and that this particular intervention might not be suitable for all FEP patients and their families.

Choosing group format

Deciding whether to include participants in single or multi-family intervention could be challenging. The ability of participants to manage troublesome and difficult feelings was important. The health professionals realized that not all participants would tolerate being with others who were perhaps more ill, or with those in a more stable recovery phase. In such situations, single-family

intervention might be the best choice. Health professionals found that vulnerable patients who became anxious tended to drop out of the intervention. Those who accepted their mental disorder while managing to control their feelings of loss and sorrow gained more from participation. Some family members suffered from symptoms themselves or had such serious and difficult problems that participation in multi-family group intervention was unsuitable. Health professionals familiar with both single and multi-family group intervention felt that families were able to discuss more serious issues in a single-family group. The recruitment process usually helped to differentiate between participants who would benefit from single-family group intervention and those who would benefit from multi-family group intervention.

Preserving patient independence

Young people experiencing their first episode of psychosis are often at an age where fitting in with peers is important. They are often in a separation process and prefer to spend their time with friends rather than participate in family intervention. At the same time the family is struggling to let go of their offspring at a time when they perceive that something is wrong. Health professionals experienced this tension between the desire to be a “healthy normal” person and the difficulties caused by the illness to be a challenge. On the one hand they know that intervention could benefit both patient and family, while on the other hand they realize that participants must accept the need for treatment so they will participate in the intervention.

Adherence to protocol

Health professionals described the manual as a useful guide that enabled them to work systematically. One challenge was how to remain flexible within the set guidelines. They realised that to be a good clinicians they had to customise the intervention to the situation; otherwise the solution would not be a good fit. They were also concerned about adherence to the manual. They found it difficult to know when they were in line with the model and when they crossed that line.

Fostering good problem-solving

At each treatment session, health professionals choose a problem from one of the patients to solve. Participants usually suggested a number of answers for each specific problem. The health professionals found it difficult to narrow down the number of suggestions they received. However, when they broke the problems down into manageable pieces, participants learned new ways to solve their personal problems. The health professionals also noted the importance of the problem-solving

method in reducing tension and anxiety within the group. Patients often preferred to talk about what they had already accomplished, rather than about their remaining problems. Similarly, family members preferred to talk about issues that were going well. The ability to do so was considered to be a strength of the intervention and often succeeded in easing tense situations. Health professionals found it difficult to decide whether they should focus on patient problems or patient accomplishments during the session; clinical experience was considered to be of major importance in this regard.

Discussion

We found that the challenges faced by group leaders could be classified into six categories: Motivating patients to participate, selecting participants, choosing group format, preserving patient independence, adherence to protocol and fostering good problem-solving.

Motivating patients to participate

Our results suggest that participant motivation and the experience and skills of the health professional were essential during the recruitment phase. To communicate information in an easy and understandable way has been reported as important in a study concerning behavioural family therapy [19]. This is in line with the findings in the present study that included patients with a FEP. In a study investigating factors for engagement in the initial stages of treatment, Stewart [20] found several essential factors such as the ability of health professionals to provide education about the illness, to provide guidance through treatment, the ability to identify and support patients’ personal strengths as well as to present an optimistic view of the future with a focus on the individual rather than on the illness. Our findings are consistent with these results, suggesting that the quality of the relationship during the recruitment process is important for successful engagement into treatment for young persons with FEP. In our study, group leaders found that family members usually were motivated at an earlier stage than patients. Stewart found that the patient decision to remain in treatment was driven by accepting and engaging in relationships with health professionals [20]. Our findings underscore that relational competence is crucial for mental health professionals who embark on training programs to become group leaders for psychoeducational group work.

Selecting participants

Group leaders found that selecting participants could be a challenge, and we noted tension between the use of persuasion by group leaders and reluctance from the patient to participate. Patients experiencing FEP may not

be at a stage in their illness where they understand the need for treatment. A two-year intervention that involves sharing experiences with others may cause ambivalence and anxiety. Although most families were eager to participate, some were more reluctant. Interestingly, this finding is in line with well-known barriers to recruiting patients with FEP into research projects. Furimsky and colleagues [21] noted that patients in an early stage of illness need to develop insight and acceptance of their diagnosis before consenting to participate in research projects. Moreover, some family members work full-time and may be unable to take time off to participate. Gonzalez and Steinglass [22] showed that the intervention should be timed to coincide with the needs of participants, the demands of the situation and the different phases of the illness. They referred to conditions such as diabetes and cystic fibrosis as diseases that require about two years for patients to accept, and they state that it is likely that FEP patients and their families require the same length of time. Our study adds to previous knowledge by underscoring the conclusion that patients with a psychotic disorder need time to reach a state of acceptance.

Choosing group format

Group leaders reported challenges in choosing patients and family members that could work together in an optimal and meaningful way. Some of the patients were too vulnerable to participate in a multi-family group, and some family members suffered from symptoms that were too serious for them to participate. These families were more likely to benefit from a single-family intervention approach. The manual describing the intervention claims that single-family interventions have been found to be more effective for patients who respond positively to medication and whose families are emotionally resilient and have already adopted good coping skills. Multi-family groups are effective in patients and families with more severe disabilities [13]. This is consistent with the findings of our group [11] in a previous study: the decision on whether to participate in single or multi-family intervention should be individualised during the relationship-building phase, depending on social skills and intensity of distressing symptoms. This might describe an important difference between working with FEP and working with those suffering from chronic psychosis. This knowledge is important in order to offer the right treatment to the right person at the right time.

Preserving patient independence

We found that group leaders experience tension between preserving patient independence and encouraging patients to participate in family intervention. Patients often experience their first episode of psychosis at a time

when personality development and identity issues are likely to manifest and when the separation phase is underway. Nevertheless, they still depend on their families for housing, money and transportation. Moreover, families are an important part of the social network for young people who develop a psychosis [21]. In a study by Windell and colleagues [23], patients with FEP described that “hope-inspiring” health professionals could be enormously influential by reducing stigma and increasing acceptance of being ill and the need for treatment. This is in line with the findings of our study, where health professionals had to achieve balance between their knowledge about how helpful such an intervention might be and the struggles of participants to maintain their everyday life. Understanding this dilemma and how to manage it are important for optimal handling of these issues during the recruitment phase.

Adherence to protocol

Our results indicate that health professionals used the manual as a guide that enabled them to work systematically, but they had concerns about how to use the manual in a flexible way so as to accommodate the individual circumstances of participants. This is in line with previous studies that have included patients with chronic mental illnesses. Mental health professionals and families valued a clear structure, but they also wanted flexibility in conducting the intervention [19, 24]. The family intervention is evidence-based [25, 26], according to studies in research settings [27–29]. In those settings the treatment manual must be strictly followed. Our study suggests that group leaders should balance rigour and flexibility in their clinical approach, which is in line with the above mentioned studies [19, 24], and Nock *et al.*, who described the flexible use of evidence-based treatment [30]. Knowledge and clinical skills in how to individualise treatment within the guidelines of the manual are important in order to provide all participants with the best possible family treatment.

Fostering good problem-solving

Problem-solving was linked to challenges faced by group leaders in choosing the most appropriate problems for patients to solve while creating a good learning environment, characterised by an acceptable anxiety level, that stimulates improvement by solving problems in a constructive and meaningful way. Norman and colleagues [31] found that participants emphasised the value of health professionals who provide helpful information and remain hopeful, while customising their therapy to meet the particular needs of the situation. Helpful information should be provided within the context of enhancing and expanding the patients' level of choice. Relationships with others suffering from the

same illness provided participants with useful information about coping strategies allowing them to gain more control over their own situations. This is in line with health professionals in our study who emphasise the importance of a positive and optimistic view as essential for the recovery process. Pihet and colleagues [32] found that when participants experienced success, treatment motivation also increased. Our study indicates that a success factor for recovery might be the ability to handle problems in a meaningful way, and that the creation of an optimal treatment environment in the group is likely to be of major importance for patient improvement.

Limitations and strengths

The scope of the present study was to explore challenges related to family interventions from the perspective of group leaders. Although the study has a small sample size, we believe that the long and varied experience of participants compensates for this. Although several men were invited to participate in the study, our sample consists only of women, and our sample may therefore be associated with gender bias. Still, the challenges our participants report are not specifically related to the gender of the group leaders, and we believe that our findings reflect the experiences of both male and female group leaders. The first and the second author are experienced group leaders who have been conducting family work and have supervised group leaders for several years. They both share a theoretical approach that is consistent with McFarlane's manual. While this may have influenced the results, the research group made a deliberate effort to bracket preconceptions in all phases of the study. Still, it is possible that researchers working with a different theoretical framework might have identified and classified themes differently than what was done in the present study. The results may not be transferable to all participants with FEP; therefore knowledge about the results might be of importance to help group leaders to avoid some of the pitfalls in facilitating the intervention.

Conclusion

Group leaders face challenges related to recruitment and selection of participants for family work, as well as those related to conducting sessions. Awareness of these challenges and strategies to manage them could help professionals to successfully tailor interventions to patients and their families.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

LN, JCF, SF and JIR contributed to the development of the study, research design, analysing of data and drafting of the manuscript. IN participated in data collection, in the analysing process and drafting of the manuscript. All authors read and approved the final manuscript.

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