Parents with psychosis: a pilot study examining self-report measures related to family functioning.

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ABSTRACT

The aims of this study were to examine the utility of various self-report instruments related to family functioning in families where a parent has a psychotic disorder, and to explore associations between these instruments and symptoms in the parent. Twenty-one parents with a psychotic disorders participated in the study. All participants were able to complete the questionnaires and the majority of parents reported levels of parental competence in the average range. Most parents (90%) perceived themselves to be effective parents, however 30% reported low levels of satisfaction with the parenting role. There were significant associations between objective measures of negative symptoms and self-report scores related to problems in ways of coping, and problems with parent-child interactions. Many individuals with psychosis were able to report areas of perceived need related to their role as parents and to the functioning of their families, however there are several limitations in the use of these instruments in this setting.

INTRODUCTION

The interaction between psychosis and family functioning has been an area of considerable interest to researchers (Gopfert et al., 1995). Apart from the familial properties of schizophrenia and affective psychoses (Gottesman & Shields, 1976), having a family member with a mental illness places considerable stress on the family system (Dickstein et al., 1998; Friedman et al., 1997).

Compared to the amount of research about the impact of psychotic disorders on a person’s family of origin, there is relatively little information on the impact of psychosis on a person’s family of procreation. We know little about how psychosis impacts on the parental role and on general family functioning. There is a sizeable literature that has examined aspects of mother-child interactions where the mothers have severe depression or schizophrenia (Goodman, 1984; Riordan et al., 1999; Snellen et al., 1999), however, psychosis impacts on a broad range of family functioning that is less reported in the literature (Davenport et al., 1984). An acute episode of psychosis is often associated with reduced parental competency. At times this can lead to parent-child separation as a result of hospitalisation of the ill parent (Bebbington et al., 1985; Dohrenwend & Dohrenwend, 1984). Mental illness in a parent may result in significant family disruptions and crises such as children being placed in care (Rice et al., 1971).

Optimising the function of families in which a parent has a psychotic disorder may have long-term benefits. There is a growing body of evidence (some based on adoption studies) that suggests the offspring of parents with serious mental illness, who are already at increased genetic risk of themselves developing mental illness as adults, may be at added risk of developing an illness if raised in highly dysfunctional families (Rutter & Quinton, 1984; Wahlberg et al., 1997).
Therefore, the provision of services to these families could have medium and long-term implications related to prevention of mental illness in the at-risk child. However, our previous research (Hearle et al., 1999) indicates that parents with a history of psychosis believe they face a number of barriers when seeking assistance with supporting their children (e.g. fear of losing custody of their child, lack of available services etc). Interventions need to be developed and systematically evaluated in order to determine their feasibility and efficacy. Before interventions can be successfully developed to target the needs of families where a parent has a serious mental illness, it is necessary to determine the strengths of these families, and the social and community factors that may buffer a family from potential negative consequences (Kisthardt et al., 1992).

We were unable to identify existing instruments designed to specifically measure aspects of family functioning in families with a mentally ill parent. In order to address this issue, we decided to examine the broad utility of several self-report measures of family functioning that have been widely used in general family assessment. We were interested in issues such as: (a) Could the forms be completed without interviewer assistance? (b) Were the questions relevant for this population? and (c) If time was limited, which instrument(s) provide the most clinically useful information? The nature of the evaluation was limited by available resources, and we were not able to assess detailed psychometric properties of the instruments.

In addition, we were curious whether particular types of symptoms associated with psychosis differentially impacted on the self-report measure of family functioning. For example, would prominent negative symptoms (such as blunted affect, reduced motivation) be associated with a particular profile of self-reported family functioning, in contrast to positive symptoms (such as hallucination and delusions)?

**METHODS AND MATERIALS**

**Participants**

Parents included in the study required a DSM-III-R diagnosis of psychotic disorder (schizophrenia, schizoaffective disorder, delusional disorder, schizo-affective disorders, bipolar affective disorder, depression with psychotic features or atypical psychosis) (APA, 1994). Participants had one or more children under the age of 16 years living in their care for at least 50% of the week. Subjects were recruited via consumer newsletters, Community Mental Health clinics and through direct contact with individuals involved in prior research at the Queensland Centre for Schizophrenia Research. The study was approved by the local Institutional Ethics Committee, and all subjects gave written informed consent.

**Diagnosis and measures of symptoms**

All participants were assessed with a modified Schedule for the Assessment of Clinical Neuropsychiatry (SCAN)(Wing et al., 1990) and had their diagnosis confirmed with the Operational Criteria for Psychosis (OPCRIT)(McGuffin et al., 1991).

Prior to the completion of the self-report measures, the Positive and Negative Syndrome Scale (PANSS)(Kay et al., 1986) was conducted by a Masters level psychologist with extensive experience in schizophrenia research. The psychologist explained how each of the self-report instruments was to be completed, and was available for clarification and encouragement to complete the instruments. Testing sessions typically took between two and four hours. In some instances assessment was performed over two sessions if the participant found it too
difficult to complete all assessments in one session.

**Assessment of past family support and experiences**

We also administered a questionnaire used in our previous studies (Hearle et al., 1999), which assessed the needs of parents with serious mental illness (available from the authors). It involves both qualitative and quantitative information relating to a person’s socio-demography, illness-related factors, reproductive variables, family and offspring histories, service utilisation, and future need areas.

**Measures of family functioning**

The selection of the instruments was influenced by: (1) self report format, (2) the content of the items (e.g. more relevant to families with a psychotic parent rather than a disruptive child etc), (3) ease of completion (e.g. format, length etc), and (4) favorable psychometric properties in general family assessment settings. We selected seven measures for inclusion in this study.

1. **Family Assessment Measure (FAM-III)**
   The Family Assessment Measure provides quantitative indices of family strengths and weaknesses (Skinner et al., 1995). Basic concepts assessed by the FAM include: (a) Task Accomplishment; (b) Role Performance; (c) Communication; (d) Affective Expression; (e) Involvement; (f) Control; and (g) Values and Norms. Reliability estimates for internal consistency of the scale are generally high (Skinner et al., 1995).

2. **Parenting Stress Index (short form)**
   The Parenting Stress Index (PSI) was developed as an instrument to aid in early identification of stressful parent-child systems (Abidin, 1997). The PSI short form was derived from the PSI in order to provide a valid measure of stress in the parent-child system in less than 10 minutes. Test-retest reliability and internal consistency of the short-form has been found to be adequate (Abidin, 1997).

3. **Parenting Sense of Competency Scale (PSOC)**
   The Parenting Sense of Competency Scale (PSOC) (Johnston & Mash, 1989) is a 16 item scale that assesses two dimensions of parenting self-esteem: (1) “Efficacy” which is an instrumental dimension reflecting competence, problem-solving ability, and capability in the parenting role; and (2) “Satisfaction” which is an affective dimension reflecting parenting frustration, anxiety and motivation.

4. **Ways of Coping Questionnaire**
   The Ways of Coping Questionnaire is an instrument designed to identify the thoughts and actions an individual has used to cope with specific stressful events (Folkman & Lazarus, 1988).

5. **Coping Resources Inventory (CRI)**
   The CRI was developed in order to identify resources currently available to an individual for managing stress (Hammer & Marting, 1988). It is a 60-item instrument that measures resources in five domains: cognitive, social, emotional, spiritual/philosophical, and physical.

6. **Perceived Social Support Inventory (PSSI)**
   The Perceived Social Support Inventory - Friends and Family (Procidano & Heller, 1983) is comprised of 20 items for both the friends and family dimension, regarding the extent to which perceived needs of support, information and feedback are being met.

7. **Parenting Scale**
   The Parenting Scale, a scale designed to measure dysfunctional discipline practices in parents of young children, has three subscales related to verbosity, over-reactivity and laxness (Arnold et al., 1993). The Parenting Scale has been found to have adequate internal consistency and test-retest reliability.
RESULTS

Clinical and Demographic Variables
The sample included 21 participants (16 mothers and 5 fathers). Ages of the participants ranged from 23 to 48 years with a mean of 36.8 years. Fourteen of the parents were married or in de facto relationships, five were divorced or separated and two had never been married. To the best of our knowledge, none of the co-parents had a psychotic illness. Ten families were living in their own home, seven were in rented accommodation, and four were residing in public housing. In terms of diagnosis, thirteen of the parents had schizophrenia and eight had bipolar disorder. Age at diagnosis of mental illness ranged from 16 to 39 years with a mean age of diagnosis of 27.7 years. The 21 families had a total of 53 dependent children.

Assessment of Past Family Support and Experiences
Most of the parents (60%) required additional assistance in order to complete the battery of tests (help in interpreting the scoring rules etc.). Depending on their mental states (especially attention span/distractibility), the instruments took between one 60-minute session to three 40-minute sessions.

Parents provided information regarding who assisted with childcare when they became unwell. Most parents (95%) reported that they relied on relatives. Seven of the parents (33%) relied upon friends. Other forms of childcare included family day care (9.5%), crèche (9.5%) and emergency respite (5%). Parents were asked if there were factors which had impeded access to child care assistance (prespecified by the authors). The most frequently endorsed responses were that the parents preferred to manage alone (57%) and that they were unable to pay for services (57%). Over half of the parents (52%) reported that they feared that their children would be removed if they asked for assistance. Two parents had experienced child-protection interventions against their will. Other factors included not knowing where to access help (52%), a lack of services in their area (43%), and having asked for but not received assistance (23%).

Self-report Measures Related to Family Functioning
In order to cope with stress parents reported using strategies such as: a reliance on social supports, the comfort of spiritual/religious values, and cognitive techniques related to positive re-framing. Dealing with stress by using effective expression of emotions, and by engaging in health-promoting physical behaviors (e.g. diet, exercise) were used less frequently.

One third (30%) of parents reported low levels of social support from their immediate and extended families. These tended to be sole-parent families. Comparatively, 95% reported average or above average social support from friends.

Concerning measures related to parenting, 86% of parents reported levels of competence within the average range. Only three parents (14%) perceive that they have poor overall parenting skills. Most parents reported that they were effective parents (90%), however 30% reported low levels of satisfaction in their parenting role.

Almost half of the participants (45%) reported high levels of parenting stress. In their parenting style, participants reported that they were often lax and had difficulty in following through with consequences if their children misbehaved.
Correlation Between Objective Measures of Symptoms and Subjective Measures of Family Functioning

There were a number of areas of family functioning related to symptoms as measured by the Positive and Negative Syndrome Scale. This was particularly true for negative symptoms and aspects related to emotional expressiveness (FAM-III Affective expression $r = 0.44$, $p = 0.04$) and coping strategies (Ways of Coping “Distancing” $r = 0.50$, $p = 0.02$; Escape-avoidance strategies $r = 0.83$, $p < 0.000$). Negative symptoms were also associated with Dysfunctional Interaction between parent and child on the PSI ($r = 0.48$, $p = 0.03$); and Parental Distress on PSI ($r = 0.50$, $p = 0.02$). Parents with negative symptoms were also more likely to respond in a defensive manner (PSI Defensive responding $r = 0.47$, $p = 0.03$).

Positive symptoms were related to General Task Accomplishment ($r = 0.45$, $p = 0.04$) and Control ($r = 0.54$, $p = 0.01$) indicating more positive symptoms lead to more chaotic styles of parenting.

Qualitative observations

The parents themselves noted several problems with the measures. For example, parents were able to state that their current responses to certain items would have been different on past occasions when their illness was more active. Some of the instruments required the selection of one child only and could not adequately capture the complexity of families with two or more children. Based on observations during the session and informal feedback from case managers, the psychologist who supervised the completion of the forms was aware of discrepancies between what some parents were reporting and the behaviours related to parenting skills that were observed during the home visits. In addition, reports of child behaviour and the perceptions of whether the support they received was helpful or not were not entirely consistent with informal observations by the psychologist.

DISCUSSION

Parents with psychoses were able to complete self-report questionnaires related to family functioning, and the results of these assessments have heuristic value for future research. In terms of general utility, clinicians should be aware that parents with psychotic disorders may need more time and support in order to complete the instruments. In order to ensure valid results, the assessments should ideally be undertaken when psychosis is in remission.

None of the instruments was ideally suited to the needs of these families – a finding that should not come as a surprise when one considers that they were designed for families with a different range of issues. For example, many parents with psychotic disorders reported fluctuations in their abilities to manage the family related to exacerbations with their illness, and as result of the adverse effects of medication (eg. sedation). Clinicians and researchers should be aware that scales that assess “present state” only may not provide representative information. However, if “present state” instruments can measure change over time, then they would be of benefit in intervention studies.

As with all self-report instruments, subjective assessment may not always be congruent with objective ratings. This may be a particular issue for parents with psychotic disorders, who fear that asking for help with their families may result in the loss of their children (Hearle et al., 1999). In addition, people with psychosis may have cognitive impairment and/or lack of insight into their conditions, features that will impact on their ability to assess the functioning of their families (Pantelis et al., 1996). In spite of these issues, the participants in this study were able to disclose a range of issues that
suggest sub-optimal family functioning. Nearly a half of the participants in this study reported high levels of parenting stress, and a third reported low levels of satisfaction in their role. Fourteen percent rated their own parenting skills as “poor”. The first key finding of this study is a simple one with immediate clinical relevance – providing parents with psychosis the opportunity to discuss their perceptions about their families may provide valuable information to guide case management. Clinicians need to be aware that if parents are asked in a trusting and respectful manner, they may disclose difficulties within their family.

Based on our general observations during the assessment process, it seems likely that some parents underestimate certain aspects of their family functioning (e.g. in parenting skills). Once again, it may be that parents are reluctant to admit that they have difficulties in aspects of parenting for fear of child protection interventions. This mismatch between subjective and objective assessment of parenting skills is a central issue in the area of child protection, and is not unique to families with a parent with a psychotic illness. If parents are aware of some of their limitations (as this study suggests), then this awareness can provide an opportunity to build support services and, if needed, to negotiate interim placements for dependent children. While much can be done to effectively support families with a parent with psychosis, it must be also be acknowledged that serious child protection issues can arise and involuntary interventions may be necessary on occasions.

Parents with psychotic disorders rely heavily upon friends and family for support. Sixty percent of the parents reported high levels of family support and over ninety percent reported that they relied upon family members for childcare assistance when they become unwell. Friends also play an important role in supporting these families. Previous research (Hearle et al., 1999) has found similar results. There may be considerable benefits gained in providing services not only to the unwell parent, but also to the extended family in times of stress to optimize support for the family unit. On the other hand, not all families have suitable support networks, and agencies involved with these families must carefully consider placement options for the children.

The associations between positive and negative syndromes and certain sub-scores of the family functioning instruments warrant further investigation. For example, it is not unexpected that individuals with prominent negative symptoms such as blunted affect would also report impairments related to emotional expressiveness and coping strategies. It would be of interest to assess this issue more systematically, as interventions designed to optimize family functioning for parents with psychotic disorders could be “tailored” to a certain extent depending on symptom types.

However, regardless of symptom profile, there are many general needs that warrant attention. We have detailed how services could better met these needs elsewhere (Hearle and McGrath, 2000).

This study has a number of important limitations. The participants in this study may not be representative of all parents with psychosis. They had to provide informed consent, and some parents may have been disinclined to participate in a study that examined features relating to their parental abilities. The sample size is small, and the results of this study should be interpreted as preliminary. In order to provide a more complete understanding of family functioning, we would have liked to interview partners and key informants. In addition, objective measures of family functioning based on direct observation of
video-taped scenarios would have allowed us to assess “gaps” between self-report and other more objective sources.

In conclusion, parents with psychotic disorders can use self-report instruments related to family functioning. There is a need to build an evidence-base that can guide the management of these families. The refinement of these measures may assist researchers to evaluate potential interventions and guide clinicians in service planning.
REFERENCES


