Children of a parent with a mental illness: perspectives on need

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Abstract

Being a child of a parent who has a mental illness involves considerable risk to the child’s secure attachment and long-term mental health. Parental mental health concerns place children at a significantly greater risk of lower social, psychological and physical health than children in families not affected by mental illness. In this paper, previous research is extended by examining the needs of these children from the perspectives of children, parents and mental health and welfare professionals. The study involved qualitative and quantitative data collection from focus groups with children and parents, and a comparison of quantitative findings with mental health professionals. Similar responses from the children and parents included problems with major episodes (e.g. parent hospitalisation), issues regarding coping and the importance of sibling support. Parents also identified a number of different issues (e.g. external support) compared with children (e.g. the importance of friendships). A final component of the research undertook a quantitative comparison of seven core ‘things that might help’ children in the circumstance of their parent being hospitalised. The findings showed differences between parents and mental professionals but most significantly with children. The findings overall are discussed in relation to the needs of children whose parent has a mental illness and recommendations are made regarding policy and service provision.

Keywords
attachment, mental illness, children whose parents have a mental illness, connectedness, focus groups, resilience

Introduction

In Australia, it is estimated that during their lifetime one in five people will experience serious disruption to their mental well being (Commonwealth Department of Health & Aged Care, 1999) and more than one million people will have a psychiatric disorder (Commonwealth Department of Health & Aged Care, 2000). In any 12-month period, up to 4.7 million Australians are thought to be affected by at least one mental disorder (Commonwealth Department of Health & Aged Care, 1999), with 12.6% of the population suffering an anxiety disorder, 9.5% an affective disorder, 9.5% substance abuse and 0.5% schizophrenia (Stedman, Yellowlees, Mellsop et al., 1997). People with a mental illness and their families are among the most vulnerable in our community. Such families are more likely to experience social isolation, financial hardship

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and marital discord, which, together with the direct impact of the parent’s emotional illness (such as emotional blunting or delusional behaviour), involves increased risk to the child of a parent with a mental illness (COPMI), genetically, psychologically and environmentally (Rutter, 1986). Current research consistently shows a higher rate of behavioural, developmental and emotional problems in such children compared with those in the general community (Beardslee, Versage & Gladstone, 1998; Brotman Band & Weisz, 1988; Cicchetti, Rogosch & Toth, 1998; Compas, 1987; Klimes-Dougan, Free, Ronsaville, et al., 1999; Lazarus & Folkman, 1984). In addition, it is thought that between 25-50% of these children will experience some level of psychiatric disorder compared with 10-20% of children whose parents are not affected by mental illness (Worland, Weeks & Janes, 1987).

Furthermore, the core attachment needs of love, security, physical and emotional nurturing that are essential to the emotional and physical development and appropriate socialisation of children (Bowlby, 1969, 1980; Karen, 1998) may be at risk within families where there is a parental mental illness. Bowlby (1980) described attachment behaviours as actions engaged in by all humans to attain or maintain closeness to another. Attachment theory is based on the premise that an infant’s first attachment experience (usually with his or her mother) profoundly shapes the child’s cognitive and emotional development (Bowlby, 1969) and later relationships (Ainsworth & Marvin, 1995; Karen, 1998). A parent, who responds sensitively and consistently to a child’s needs, sends messages that build an ultimate sense of security and self identity (Chase-Lansdale & Wakschlag, 1995; Howes, 1999; van Ijzendoorn, Sagi & Lambermon, 1992).

Sometimes, however, because of a parent’s mental illness (or for other reasons, including addiction or death), instead of sensitive, responsive nurturing an infant may face inconsistency and/or neglect. Such parental cues often lead to what has been referred to as avoidant, anxious or insecure/disorganised attachment, which in turn, have been linked to a variety of adverse outcomes (Erwin, 1998; Rutter, 1986). In addition, children whose parents have a mental illness may experience the trauma of family disruption and out-of-home placement due to the parent’s hospitalisation or inability to care for them on a day-to-day basis. As parental mental health problems are thought to impact negatively on parent-child attachment (Erwin, 1998; Rutter, 1986) it is, therefore, extremely important to examine the needs of children in such circumstances in order to enhance ongoing parent-child connectedness for the long term normal development of the child.

While there are considerable psychological risks associated with being a child of a parent with a mental illness, this group has frequently been referred to as ‘hidden children’ (Fudge & Mason, 2004) because adult mental health services and other professionals are often unaware that their clients are parents. In addition, there has been very little research in Australia that has examined the needs of children who have a parent with a mental illness (Fudge & Mason, 2004).

A focus group study with parents, undertaken by Cowling (1999), highlighted various issues for children whose parents have a mental illness, including continuity of care when the parent goes to hospital, educating children about their parent’s illness, a need for a support person for the children to talk to, as well as programs where children can meet other children in a similar situation. Aiming to develop Australia wide service guidelines for COPMI, Fudge and Mason (2004) undertook several focus groups with children and adolescents whose parent has a mental illness and found similar results, by highlighting the issues of parent hospitalisation, support, respite, communication and an ongoing need for community education to reduce stigma. Together, both studies (Cowling, 1999; Fudge & Mason, 2004) highlight important issues for COPMI in Australia.

An initial aim of the current research was to replicate the findings of Cowling (1999) and Fudge and Mason (2004). Another aim was to extend current research by examining different viewpoints regarding issues facing children whose parents have a mental illness. While it is important to understand a phenomenon from the consumers’ perspective (Rapp, Kisthardt, Gowdy & Hanson, 1994) a parent’s mental illness affects many members of a family and
consequently, there exist several different consumers, including children. Previous research has shown that need may vary according to the perspective from which it is viewed (Jorm, Korten, Jacomb, Christensen & Henderson, 1999; Jorm, Korten, Jacomb, Rodgers et al., 1999). Consequently, this study sought to determine differences in perspective on the issues facing children whose parents have a mental illness, by undertaking separate child and parent focus group interviews.

In addition, and with reference to the specific issue of parental hospitalisation (Cowling, 1999; Fudge & Mason, 2004), a final quantitative research component of this study sought to quantify and compare child, parent and professional perspectives of the activities that would best alleviate needs of children at such times (i.e. ‘things that might help’). While previous research has outlined a number of activities and supports that might help children when their parent is sick (or hospitalised) (i.e. Cowling, 1999; Fudge & Mason, 2004), this study sought to establish and highlight similarity and disparity of perceptions from the various key stakeholders. Comparing the perspectives of the various consumers, including children, with mental health practitioners is important as practitioners may assess and support families through their own cultural and class filters (Azar, Lauretti & Loding, 1998; Watzlawick, 1976). When identifying the needs of children whose parents have a mental illness there are multiple perceptions, interests, motivations and interpretations which might be highlighted. Identifying these various perspectives is seen as important in highlighting possible intervention and supports for those affected by parental mental illness.

Method

There were two components to this study. The first involved focus groups with parents and children from families where one parent had a mental illness. This aspect of the study was undertaken within the interpretative research paradigm and sought to describe events and situations within a specific context. The second component involved a brief questionnaire to quantify the impact of various strategies which might be helpful for children when their parent was hospitalised (e.g. how helpful is it to have other children who are in a similar situation to talk to?). The questionnaire was completed by the parents and children at the end of their focus group sessions and by mental health professionals as described below. Ethics approval was granted for this project by La Trobe University Human Research Ethics committee (A020/02).

Parent and child focus group participants

Participants were recruited from North East Victoria. The 12 parents included ten with a mental health diagnosis and two partners of a parent with a mental illness. Using self report, five parents had a mood disorder, three an anxiety disorder, three a personality disorder and one had a psychotic disorder (there was a high level of dual diagnosis). Fifty five per cent were single parents and their ages ranged from 29 to 46 years, with a mean age of 39 years. Initially, there were 17 participants in the children's group, but after approximately 10 minutes, five of the younger participants indicated that they were bored and withdrew. The remaining 12 children ranged in age from six to 16 years; unfortunately more detailed information about the children (e.g. gender, age, mental health status) was not collected. However, it was estimated that the mean age was approximately eight years of age with a modal age of ten years.

Procedure

The focus group questions were prepared by the authors of this paper and the Steering Committee members (see acknowledgements), and guided by the results of Cowling’s (1999) previous study. Focus group questions are presented in Appendix 1. Initial questions were designed to facilitate a discussion of positive information as it has been found that recall of positive information can be hindered if negative information is presented first (Maybery, Maybery, Bresnan et al., 2001). As an overarching aim of this study was to establish and distinguish the issues for children whose parents have a mental illness from different perspectives, focus questions aimed to avoid leading participants to identify specific issues. The questions were developed to allow open responses according to participant experience. Questions were structured to suit the developmental age of the children.
The focus group facilitators were recruited from the Steering Committee and were selected on the basis of their experience in mental health and research. Two clinicians from the local child and adolescent mental health services facilitated the children’s group. The parent focus group was facilitated by the Supporting Kids project worker and an experienced adult mental health clinician. The focus groups ran concurrently for approximately 45 minutes. The questions for each group were in the same order to allow a comparison of child and parent perceptions of need. Participant responses were recorded on audiocassette tapes and subsequently transcribed.

The items on the quantitative questionnaire (‘things that might help’, see Table 2) were developed from the literature (e.g. Cowling, 1999) and from consultation with the Supporting Kids Steering Committee. The seven questions focused on key issues of support for children when a parent is hospitalised and required participants to rate how helpful such strategies were, on a zero (not helpful) to four (very helpful) Likert scale.

Mental health professionals

The mental health professionals’ responses to the seven ‘things that might help’ questions were taken from a larger ‘mental health worker’ study (reported in Maybery, Ling & Szacaks, 2002). The 62 participants were from the North East of Victoria and worked in community health centres, mental health services and from one inpatient facility (from Albury, NSW). The 16 males and 46 females included 12 mental health nurses, 12 general practitioners, 11 social workers, six psychologists, four occupational therapists, two youth workers, one psychiatrist, one support worker and 13 with unspecified mental health or welfare occupations. The length of experience working in mental health varied from no direct experience to forty years. The professionals completed questionnaires that had been distributed by Supporting Kids Steering Committee members or by mail with a reply paid envelope.

Results

Major themes for families experiencing parental mental illness were identified from audiotapes and hand written notes using frequency of mention and importance to participants. The seven core parent group themes and the five themes from the child group are presented in Table 1.

Parent focus groups

Issues around major mental health episodes or hospitalisation. Participants spoke of the difficulties associated with hospitalisation and major episodes. One parent suggested that a strategic plan be developed for each family for when a parent is hospitalised as this would help alleviate some of the difficulties associated with this process. Another commented that police need to be more sensitive to the needs of children when they are involved in the involuntary admission of the parent. A number of parents felt that children need to be debriefed following hospital admission of their parent by a mental health professional.

Importance of siblings. The majority of parents saw siblings as being a great support to one another and particularly as someone to rely on when the parent is unwell. One mother commented that it doesn’t matter how much her two children are arguing or disagreeing - when she is sick they put their differences aside. She indicated ‘mum’s sick and we have got to get in there and help’.

| Table 1. Issues for children of parents with a mental illness (COPMI): Parent and child focus group themes |
|---------------------------------------------------------|---------------------------------------------------------|
| **Parent focus group**                                  | **Child focus group**                                    |
| Major episodes (e.g. parent hospitalisation)            | Major episodes (e.g. parent hospitalisation)             |
| Importance of siblings                                  | Importance of siblings                                    |
| Coping strategies employed by COPMI                     | Coping strategies employed by COPMI                       |
| External support for COPMI                              | Importance of friendships                                  |
| Education for COPMI                                     | Extra roles assumed when parent unwell                    |
| Community education                                     |                                                         |
| Respite for parents and COPMI                           |                                                         |
**Children’s coping mechanisms.** In terms of coping strategies that children employ when the family is experiencing difficult times, some parents spoke of how their children would withdraw or not leave the house. There was talk of children taking extra roles, for example one parent stated that her child took on the mother role, while another parent said that their children ‘try and normalise, they make order out of chaos’.

**External support for children with a parent that has a mental illness.** When asked what would improve things for their children the majority of parent participants commented on the need for more support for the children, particularly from professionals. Statements like ‘someone to talk things through with’, ‘a qualified person to vent to’, ‘someone to ask the children what’s happening to you when mum or dad’s like this’ reflect the notion that parents felt it was important for the children to have more support.

**Education for children who have a parent with a mental illness.** When asked how much their children know about their illness most parents commented that while their children knew something about mental illness, they could benefit from more education. There was an agreement that the age of the child played a big part in education, influencing both what and how much to tell the child. Some parents commented that their children didn’t want to know what was wrong with them or didn’t believe anything was wrong with them. One parent wanted to know who should explain to children about mental illness; they made the comment that ‘workers don’t’. Other parents were curious as to how they should educate not only their children about the mental illness, but also their partners.

**Community education.** Parents thought that the community in general required more education around mental illness and issues involved for children who have a parent with a mental illness. A number of parents commented that within the community there was a lack of awareness regarding children with a parent that has a mental illness, in particular in schools. One parent made the comment ‘AIDS gets more publicity than we do.’

**Respite.** Participants considered respite to be important and helpful both for children and themselves. They also suggested that respite was necessary on a regular basis and should be both in and out of home.

**Child focus groups**

**Issues around major mental health episodes of the parent’s illness.** The majority of children said that the most difficult time for them was when their parent went into hospital, with the exception of one boy who made the comment that ‘it’s no different because mum doesn’t do anything anyway’. He went on to talk about how when his mother is in hospital it just puts more pressure on his father. Another participant said when her parent is in hospital she gets lethargic and depressed and finds it difficult to go to school. While some of the children in the focus group had a well parent or another relative to look after them while their parent was in hospital, some children (in the older age bracket) were required to find their own accommodation, which often resulted in a separation from their sibling/s. These children spoke of the difficulty in accessing transport when visiting their parent in hospital, having limited finances and feeling guilty if they continually asked friends to take them to visit their parent. The children also felt that a more family friendly environment within a hospital setting would be appropriate. Children also spoke of issues around the effects of medication on their parents. One boy described his parent as being unavailable because she was ‘doped up to the hilt’.

**Importance of siblings.** Participants frequently identified sibling relationships as a positive experience in their life. Several children said they felt their brother and/or sister were very supportive and that they could rely on them when things were not going well. The two facilitators of the child focus group commented on the closeness of the siblings that were in the group.

**Children’s coping strategies.** Some children described behaviours or coping mechanisms that might put them at risk for later maladjustment. For example, a few children spoke of withdrawing when the parent was unwell, including not going to school when their parent was in hospital. One child spoke
of not coping when her mother was unwell saying ‘my dog is the closest thing I have to human contact for days when mum is in hospital’.

**Importance of friendships.** Friendships were of great importance to the child participants. Most of the children said that their relationships with friends were positive and supportive. Some children also said that they went to a friend’s house as a way of coping when their parent is unwell.

**Taking on extra roles when the parent is unwell.** Some of the children identified taking on extra roles or jobs to help out when the parent is unwell. One child reported having to look after his parent. Other children spoke of the need to be quiet when their parent was unwell. Cooking and cleaning were other jobs that children mentioned they did when mum or dad was unwell.

**Comparing parent, child and professional ratings for ‘things that might help’**

In addition to the focus group interviews, children and parents completed a five point Likert scale (from zero: not helpful, to four: very helpful) to identify how helpful they felt various activities would be for children whose parent was hospitalised due to their mental illness. Results are shown in Table 2 along with data from the mental health professionals.

The table shows that the mental health professionals scored many items higher than did the parents. Also, apart from item number four (having a friend at school that you can talk to), the children scored all items considerably lower (over 1 point) than parents or mental health professionals. The children scored six of the items between 1.33 to 1.84 points lower than parents or mental health professionals. One way analyses of variance were undertaken to examine if there were differences in group scores for each of these items. Table 2 shows the summary statistics from those analyses including Student-Newman-Keuls post hoc analyses to determine specific group differences.

The statistical analyses showed that the children scored significantly lower on items 2, 3, 5, 6 and 7 compared to the workers and that both the children and parents scored significantly lower than the workers on item 1.

<table>
<thead>
<tr>
<th>‘Things that might help’ children whose parent has a mental illness when the parent is hospitalised</th>
<th>Parents (n=12)</th>
<th>Children (n=12)</th>
<th>Workers (n=62)</th>
<th>df</th>
<th>F-ratio</th>
<th>p</th>
<th>Post hoc test</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having more support from another person in your family who lives at your house? a</td>
<td>2.25 (1.54)</td>
<td>1.64 (1.12)</td>
<td>3.48 (0.79)</td>
<td>2.81</td>
<td>21.68</td>
<td>&lt;0.001</td>
<td>Child and parent group lower</td>
</tr>
<tr>
<td>2. Being able to see/get together more often with someone from your family who does not live at your house?</td>
<td>3.42 (0.79)</td>
<td>2.00 (1.41)</td>
<td>3.36 (0.66)</td>
<td>2.82</td>
<td>14.44</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
<tr>
<td>3. Being able to see/get together more often with another adult who is not from your family?</td>
<td>3.45 (0.82)</td>
<td>2.09 (1.30)</td>
<td>3.15 (0.84)</td>
<td>2.79</td>
<td>7.57</td>
<td>&lt;0.01</td>
<td>Child group lower</td>
</tr>
<tr>
<td>4. Having a friend at school that you can talk to?</td>
<td>3.08 (1.24)</td>
<td>3.00 (1.28)</td>
<td>3.41 (0.78)</td>
<td>2.84</td>
<td>1.36</td>
<td>n.s.</td>
<td>No difference</td>
</tr>
<tr>
<td>5. Having other children who are in a similar situation to you to talk to?</td>
<td>3.33 (1.56)</td>
<td>1.75 (1.29)</td>
<td>3.37 (0.73)</td>
<td>2.83</td>
<td>14.45</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
<tr>
<td>6. Having time out from your situation?</td>
<td>3.00 (1.65)</td>
<td>2.13 (1.68)</td>
<td>3.46 (0.70)</td>
<td>2.82</td>
<td>8.38</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
<tr>
<td>7. Learning more about what’s wrong with your mum or dad?</td>
<td>3.50 (1.24)</td>
<td>2.25 (1.66)</td>
<td>3.66 (0.57)</td>
<td>2.83</td>
<td>12.41</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
</tbody>
</table>

a. In response to the importance of siblings from the focus groups, this question was specifically targeted as such in the worker questionnaire. It read ‘Having support from their brother or sister?’ in the mental health professional study.
Also of note, there were no differences between groups on the question, ‘Having a friend at school that you can talk to’. However, statistical analyses are problematic where there are large differences in the size of samples (see Tabachnick & Fidell, 2001, for details). The sample size from which the worker data emanated was much larger (n=62) than the parent (n=12) and child (n=12) groups. Consequently, some caution should be taken with the interpretation of this finding.

**Discussion**

In the discussion, an overview of the issues for children whose parents have a mental illness, from the perspectives of parents and children is outlined, followed by the various ‘things that might help’ such children (when a parent is hospitalised), according to children, parents, and mental health practitioners. Seven core themes for families experiencing parental mental illness were identified by parents in the focus group, and five themes were identified by children. Most of these core issues are generally consistent with previous research (i.e. Cowling, 1999, Fudge & Mason, 2004). The three themes that were common to the parent and child groups were: the problems associated with the parent having a major mental health episode (e.g. hospitalisations); the importance of other siblings as supports in times of crisis; and the development of various (often inadequate) coping mechanisms.

The findings confirm that a major time of risk for children is when their parent has a major mental illness episode (Cowling, 1999, Fudge & Mason, 2004). This suggests that the disruption to the family unit when a major mental health episode occurs has considerable ramifications for children. Responses indicate that such times put considerable added pressure on the whole family and may lead to mental health concerns for the children themselves. Consequently, future programs and services need to focus on assisting families to better manage at such times.

A second finding, from both parents and children, was that the way children coped with their parent having a mental illness might be a potential risk factor for the child’s future mental wellbeing. Withdrawing, avoiding and distancing were identified (by both parents and the children themselves) as coping strategies employed by children whose parents have a mental illness. In the coping literature, these strategies are commonly referred to as emotion-focused (Folkman & Lazarus, 1988) and are regularly labeled as ‘unhealthy’ if maintained as long term strategies (McCrae & Costa, 1986).

From a useful coping perspective, both groups identified the support of other children within the family as especially important. The children’s focus group identified the relationship with their brother/sister as positive generally and both parents and children highlighted the importance of sibling support when things were not going well in the family. Others have suggested that taking care of siblings leads to ‘…self confidence and a healthy sense of power’ (Brenner, 1997:160) leading to resilience in the face of difficult situations (Werner & Smith, 1982; Widmer & Weiss, 2000). The importance of sibling support is also consonant with Fudge and Mason’s (2004) study, which highlighted the family as an important source of support. Consequently, sibling support should be encouraged and not underestimated for its value as a coping mechanism that may encourage adaptive behaviour. While Cowling (1999) clearly identifies support from outside the family as important (e.g. meeting other children in similar circumstances, someone for children to learn to trust) the findings in the present study indicate that sibling support is considered essential for children when a parent has a mental illness and opportunities to encourage this needs to be incorporated in future programs.

Overall, parents and children identified two different sources of support. The parent group identified external support, education regarding the illness, and respite as being important. While parents considered it important for children to have someone professional to talk to, the children themselves identified friends as being very important in their lives generally and as people upon whom they could rely for support. Similar to previous research findings (Cowling, 1999; Fudge & Mason, 2004), the children also identified having to undertake extra roles when the parent was sick as being an important issue. Together these are important concerns for children and should be considered in future...
programs aiming to address the needs of children whose parents have a mental illness.

The quantitative findings regarding the ‘things that might help’ children whose parents have a mental illness (when their parent is hospitalised) also highlight similarities and differences between the perspectives of parents, children and mental health professionals. While interpretative caution should be observed due to the statistical analyses employed, the most startling finding was that the children scored all but one of the seven items significantly lower than the mental health professionals and all but two items lower than their parents. Professionals might have identified supports as more helpful than other key stakeholders, because of their role in having to identify and employ appropriate supports for numerous families. Another interpretation might be that mental health professionals have a vested interest in being able to provide various services, such as the providing respite and educating others about mental illness (items six and seven). Parents on the other hand might have inflated and overemphasised their scores to encourage more resources and actions to be made available to their children. Equally, the children may not realise the gravity of their circumstance and have underestimated their need for assistance at such times. Regardless of these explanations the surprising finding is that the group of children scored significantly lower than the other groups on almost all items – this suggests that the view of the problem may be quite different depending on the perspective taken. Policy makers and program deliverers should heed the variety of points of view in their decision making regarding children whose parents have a mental illness. In addition, future research should be undertaken with equal size respondent groups to verify the current response differences.

A statistically non-significant between groups difference was noteworthy. The children rated ‘having a friend at school that you can talk to’ when their ill parent was being hospitalised at an equivalent level to parents and mental health professionals (i.e. between helpful and very helpful). This was notable because the child rating was one point more helpful than their ratings for the other strategies. Erwin (1998) also highlighted the importance of maintaining friendships in times of stress: ‘Unfortunately, many stressful situations may simultaneously disrupt friendships and hence remove them as a potential source of support’ (Erwin, 1998:9). This finding lends further support to the differences highlighted in the focus group data and indicates that maintaining and developing friendships for children whose parents have a mental illness is very important. Overall however, the remaining six strategies were not considered to be particularly helpful for children at the time of parental hospitalisation.

Given that the parent-child connection is at risk in families where a parent has a mental illness, it is important for such children to have the opportunity to develop other social connections, both within and outside of the family. Social connectedness emphasises the independent self in relation to others (Lee, Draper & Lee, 2001) and it is thought that family and peer connectedness are important for promoting resilience in young people generally (Fuller, McGraw & Goodyear, 1999; Resnick, Harris & Blum, 1993). Consequently, even if the parent-child attachment is broken or dysfunctional, a child’s resilience may be fostered through connectedness to another source. The children involved in the present study suggest their current sibling and friend relationships as important sources of connectedness. While future policy and programs should continue to develop external supports for these children, programs should also encourage and develop children’s existing support networks. Improving and developing such family and friendship connections may buffer some of the adverse effects that the parental mental illness has on adult-child attachment (Erwin, 1998).

**Summary and conclusions**

Although this study is limited in its generalisability due to the small sample size and need for replication across different samples (e.g. according to location, type of illness), three general areas of recommendations can be drawn from the findings. In conjunction with previous research findings (Cowling, 1999; Fudge & Mason, 2004), a central issue is the welfare of the children when the parent suffers a major mental illness episode and/or is hospitalised. The findings suggest that this is a key crisis period for the family that needs to be better managed. In addition, intervention for such children should
also focus on developing and improving support and coping mechanisms (e.g. problem focused coping, developing adaptive cognitive styles, fostering social skills with peers and siblings, encouraging the use of other support during times of crisis) and on education (e.g. about their parents mental illness and support services in their community such as respite, mental health services).

Finally, according to the children themselves, rather than emphasise external support, intervention needs to focus on enhancing and supporting existing sibling and friendship groups for children whose parents have a mental illness. Although this research was from a relatively small sample, the findings highlight the different perspectives on what might be helpful for children whose parents have a mental illness. Future research might consider the needs of different children, for example, across gender, ages and socio-economic groups. In general however, program developers, funding bodies and researchers should be cognisant of ‘whose perspective on the problem’ is underpinning decision making for COPMI families. In particular, the child or adolescent’s point of view should be regularly sought so that young people are empowered in their own lives, rather than being made reliant on supports outside themselves, which may not always be accessible or available. We need to ensure that programs do not exacerbate or reinforce young people’s needs, based on someone else’s perception, without making an effort to uncover the young person’s perception of their own needs and potential supports.

Note
Parts of this paper are adapted from a more extensive report by Maybery, Ling and Szakacs (2002) that was published privately for limited distribution, and from a paper presented at the VICSERV Conference 2002.

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Appendix 1: Focus Group Questions

Focus group questions for children

1. What are the good things about your family?
   - What are the fun, enjoyable things that happen in your family?
   - Who do you have the most fun with?
   - What sorts of things make it fun?
   - Who can you rely on the most in your family?
   - When you think back over the last few years what have been the three (get them to write these things down) most enjoyable things that you have done?
   - Do you sometimes think about or dream about things that you have done in your family that make you happy? What are they (get them to write them down)?
   - What are the things about your family that make it better than anyone else’s?

2. What are the not so good things about your family?
   - What sorts of things make it not so enjoyable?
   - Who do you have the least fun with?
   - Who are you not able to rely on the most in your family?

3. Does the fact that someone in your family is not well have an effect on you and your family?

4. Do you think that people treat your family differently than other families?

5. How do you cope and what works well for you when there are problems in the family?
   - What things do you do?
   - Do you rely on someone outside of the family at such times?

6. What would help you most when you are not able to cope very well?

7. When do you feel like you need help the most?

8. When there are problems in your family do you receive help from people outside the family? What sorts of things do these people do? Who are they? Are there factors that might stop you from seeking outside help?

9. Do you have any suggestions as to how we might be able to help you and your family?

Focus group questions for parents

1. What are the good things about your family?
   - What activities do your children do that are the most fun for your family?
   - Do your children rely on other individuals/groups?
   - When you think back over the last few years what have been the three (get them to write these things down) most enjoyable things that you have done?
   - Do you sometimes think about or dream about things that you have done in your family that make you happy? What are they (get them to write them down)?
   - What are the things about your family that make it better than anyone else’s?

2. What are the not so good things about your family?
   - What sorts of things make it not so enjoyable?
   - Who do you have the least fun with?
   - Who are you not able to rely on the most in your family?

3. Does the fact that you or someone in your family suffers from a mental illness have an effect on your family?

4. Do you feel that your family is treated differently to other families?

5. How do you cope and what works well for you when there are problems in the family?

6. What would help you the most when you are not able to cope very well?

7. When do you feel that you need help the most?

8. When there are problems in your family do you receive help from people outside the family? What sorts of things do these people do? Who are they? Are there factors that might stop you from seeking outside help?

9. Do you have any suggestions as to how we might be able to help you and your family?