Survivalkid(s): Online support for adolescents and young adults with a mentally ill family member

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Developing a shared research agenda for working with families where a parent has a mental illness

Abstract

The purpose of this paper is to identify a shared, international and inter-disciplinary research agenda amongst practitioners, researchers and administrators, in relation to families where a parent has a mental illness. Fifty-seven participants, identified as key informants were asked to respond to the following query: ‘What key research question(s) do you want answered that if answered would help to significantly improve services to families where a parent has a mental illness?’ 144 responses were qualitatively analyzed independently by three members of the research team. In order of frequency, the resulting research agendas were (i) service re-orientation, (ii) interventions (iii) risk and protective factors, (iv) parent, child and family feedback and involvement, (v) stigma and (vi) reach and access. Overall, this study provides an indication of priority research areas, which according to stakeholders, are most in need of investigation.

Introduction

The mental health and wellbeing of parents and children are intimately related. Given the prevalence of parenting amongst those with a mental illness, along with the potentially adverse impact of parental psychopathology on families, it is imperative that we understand the needs of such families, and provide effective and acceptable services and supports. This study seeks to identify the research areas that stakeholders consider to be important in the way they work with families. Establishing a shared research agenda has the potential to inform future research, service and program development.

Parental psychopathology is a well-established risk factor for children. Compared to other children, these children are at a greater risk of acquiring their own mental health difficulties (Reupert & Maybery, 2007). Other potential problems for these children include school failure (Farahati, Marcotte, & Wilcox-Gők, 2003), being taken into care (Leschied, Chiodo, Whitehead, & Hurley, 2005) and acquiring a substance abuse disorder (Mowbray & Oyserman, 2003). Families where a parent is experiencing mental health challenges are not uncommon. One study found that between 21-23% of children have at least one parent with a mental illness (Maybery, Reupert, Goodyear, & Crase, 2009).

In these families, children, parents, and the family have their own individual and interrelated needs. Some children assume caring responsibilities for their parent and/or...
siblings, which on the one hand may be negative to the young person if limiting to their educational and recreational opportunities, or on the other hand, beneficial for developing closer family ties and encouraging independence (Aldridge, 2003). Children may acquire maladaptive coping strategies. This may be due to social learning where for example, a depressed parent may model rumination as a coping strategy (Berg-Nielsen, Vikan, & Dahl, 2002). Parents have their own needs as they manage the same parenting challenges all parents face within the context of their illness. Finally, families where a parent has a mental illness have been characterised by low family cohesion and poor communication (Warner, Mufson, & Weissman, 1995). Thus, given the prevalence and risk associated with such families, it is critical that there are appropriate systems in place to identify the parenting status of clients and provide appropriate support to children, parents, and the family.

However, it is important to point out that not all families will be adversely impacted. There are a number of mechanisms that explain the link between parent psychopathology and children’s outcomes including genetic factors, the impact of the mental illness on parenting behaviours, type and severity of the parent’s illness, and the presence of environmental factors often associated with psychopathology such as isolation and poverty (for a review see Reupert, Maybery, & Nicholson, 2015). This means that not all children and families will be affected, nor will each child in the one family be affected in the same way. Accordingly, Steer, Reupert, and Maybery (2011) argue that a ‘one size fits all’ model of intervention is inappropriate for the complex lives of these families.

There have been a number of interventions developed for families. Bee et al., (2014) synthesized the clinical effectiveness and acceptability of interventions for improving quality of life in children in these families. They found evidence of effect in 18 programs, though these predominately targeted maternal depression, rather than parenting skills or children’s outcomes. There are few programs for families where parents have disorders other than depression. Data regarding acceptability (defined as intervention uptake, adherence and client satisfaction) were inconsistently reported across trials. Major methodological problems precluded the authors from making conclusive statements about the evidence base of interventions for families. As Reupert and Maybery (2015) summarise, we need to know more about appropriate intervention targets (child, parent, the parent-child relationship, and/or family) and content (e.g., psychotherapeutic and/or psychoeducation) when designing interventions for these families. Coupled with a lack of knowledge about effective interventions are the general workforce deficits in working with these children and parents (Maybery & Reupert, 2009).

Targeted research may assist in formulating future interventions (determining what works, with whom and when), as well as policies and organisational services. Research that focuses on implementation can assist in ascertaining how acceptable any given intervention is to clinicians, parents, and children, the settings in which an intervention is best delivered, the best time to deliver an intervention, and issues pertaining to reach (who receives an intervention and, just as importantly, who does not). Setting a research agenda is important to establish priorities and may be used to guide the allocation of scarce resources, personnel and funding. Identifying research priorities may also highlight the need for research collaborations across professional disciplines and settings.

One way to develop a research agenda is to ask stakeholders what research would be most useful to the way they work. Involving stakeholders such as practitioners ensures that the resulting agenda is accessible and pertinent. Given the problems with research translations where some interventions ‘languish’ for 15-20 years before being implemented into clinical practice (Proctor, et al., 2009), it is essential that research is timely, and has an impact on practice and workplaces.

This article is premised by an appreciation of the intersection between science and service, and where the contributions of scientific enquiry and clinician experience are equally valued. Shonkoff (2000, p. 182, italics in the original) argues that ‘science is focused on what we do not know. Social policy and the delivery of health and human services are focused on what we should do’. He concludes by urging for an effective ‘cross cultural’ relationship between science and service as a viable strategy for generating research and for applying knowledge that has the potential to make a difference to the lives of children and families. The present study is positioned within this cross cultural exchange.

This study sought to identify a research agenda for families where a parent has a mental illness, shared amongst researchers, practitioners, policy makers, and administrators who work with families where a parent has mental health challenges. It is hoped that the results of the study will assist in the development and/or strengthening of research collaborations between researchers, practitioners, and policy makers.

**Methodology**

A qualitative design was employed using a self-constructed survey. Ethics approval was provided by the Monash University Human Research Ethics Committee (Australia).
### Procedure

The site for data collection was at the Fourth International Conference on Families with Parents with Mental Health Challenges, in Berkeley, California, in April 2014. The conference aimed to bring together practitioners, researchers, policy-makers, and those with lived experience to share knowledge and experience. The conference was intended as a forum to discuss common experiences, effective and evidence informed support and advocacy strategies, and contemporary, cutting edge research.

One of the research team disseminated an explanatory statement about the study and invited conference participants to complete a hard copy, single item questionnaire. After the conference, an email was sent to all conference participants with a reminder about the study, with an invitation to complete an anonymous online version of the questionnaire.

### Materials

After participants recorded gender, country, profession and discipline, they were asked to respond to the following single question: ‘What key research question(s) do you want answered that if answered would help to significantly improve services to families where a parent has a mental illness?’

A similar question has been used in other jurisdictions, for example, Charles, Charlesworth, and Kober (2013) used a comparable question in their work developing a shared research agenda for the British Columbia Ministry of Children and Family Development in Canada.

### Participants

The sample was purposive, where key informants were targeted. As a result of their position and/or experience, Marshall (1996) contends that key informants are able to provide information and deep insight into the topic at hand. Given the conference topic, it was assumed that conference delegates would have pre-existing knowledge about the topic and/or be working in the field. Of the 189 conference delegates, 57 participants completed the questionnaire (return rate of 30%). As can be seen in table 1, most participants were female (80%) and came from North America (just over 54%). Just over 45% identified as practitioners, while 40.4% were researchers; most (35.1%) were psychologists, while nearly 30% came from a social work background. These demographic details are representative of all conference participants.

### Table 1. Participant demographics

<table>
<thead>
<tr>
<th>n = 57</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
<td>19.4</td>
</tr>
<tr>
<td>Female</td>
<td>46</td>
<td>80.7</td>
</tr>
<tr>
<td><strong>Country</strong></td>
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<td></td>
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<tr>
<td>USA</td>
<td>16</td>
<td>28.1</td>
</tr>
<tr>
<td>Canada</td>
<td>15</td>
<td>26.3</td>
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<tr>
<td>Australia</td>
<td>7</td>
<td>12.3</td>
</tr>
<tr>
<td>Netherlands</td>
<td>6</td>
<td>10.5</td>
</tr>
<tr>
<td>Norway</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>Italy</td>
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<td>3.5</td>
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<tr>
<td>UK</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Sweden</td>
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<td>1.8</td>
</tr>
<tr>
<td>Ireland</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Mexico</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>New Zealand</td>
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<td>1.8</td>
</tr>
<tr>
<td>Unknown</td>
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<td>1.8</td>
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<tr>
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<tr>
<td>Practitioner</td>
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<tr>
<td>Researcher</td>
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<td>Student</td>
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<td>17.5</td>
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<tr>
<td>Administrator</td>
<td>7</td>
<td>12.3</td>
</tr>
<tr>
<td>Policy maker/ Government</td>
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<td>7.0</td>
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<tr>
<td>Consumer/Family advocate</td>
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<td>5.3</td>
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<tr>
<td>Program coordinator</td>
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<td>1.8</td>
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<tr>
<td><strong>Discipline</strong></td>
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<tr>
<td>Psychology</td>
<td>20</td>
<td>35.1</td>
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<td>Social work</td>
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<tr>
<td>Medicine</td>
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<td>19.3</td>
</tr>
<tr>
<td>Education</td>
<td>7</td>
<td>12.3</td>
</tr>
<tr>
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<td>10.5</td>
</tr>
<tr>
<td>Nursing</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Law</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>9.5</td>
</tr>
</tbody>
</table>

*Numbers do not add up to 100% because of multiple responses.*
Data analysis

Data were analyzed using thematic analysis, a flexible qualitative analytic method for identifying, analyzing, and reporting themes within data (Braun & Clarke, 2006). Data were first tabulated after which initial codes generated and primary themes were identified. Two members of the research team independently generated themes through a cyclic process of refining codes, which grouped sections of text according to concrete similarities, and then built descriptions of more abstract themes across multiple responses (Bazeley, 2013). A third member of the research team then considered both sets of codes, and identified similarities and differences. These were then returned to the original two researchers who re-analysed their codes in the light of this consolidation. Rather than a numerical index of agreement, consensus was reached by reviewing respective themes in relation to participants’ initial responses. Resulting themes were then defined and named with key extracts identified. Responses were also considered in terms of participants’ country, profession, and discipline, and representative extracts are tagged according to these key demographics.

Results

While there were 57 participants, many provided more than one research area with a total of 144 research agenda items identified, as presented in order of frequency in table 2. Most responses came from participants located in the USA (34%), with 19.4% from Canada, 15.3% from the Netherlands, and 13.2% from Australia.

Service re-orientation

Many responses (48 of 144) were concerned with reorienting services to the needs of families. Thirteen responses were around policy in terms of either changing policy, ‘How to impact policy?’ (USA, administrator, social work) or seeking to ascertain how policy might make an impact ‘How can policymakers help to advance the issue?’ (Canada, policy maker, medicine). Another group of responses involved reorienting services to becoming more family focused, ‘What are the effective strategies that change an individual focus e.g. person centered to family focused practice?’ (Australia, practitioner, medicine). Some responses in this subtheme wanted to know how family focused practice might be operationalized within adult mental health settings, hospital and jails. Training was another research issue for example, ‘what is the most effective way to train professionals’.
Risk and protective factors

A medical researcher and practitioner from Italy wrote generally, ‘Why [do] some children become ill and some others do not?’ Seven items related to risk factors involved with the child, the parent-child relationship or the family’s socio-economic context. Five responses focused on parental risk factors, ‘examine if there are differences in risk when comparing fathers and mothers with mental health issues’ (Netherlands, researcher, psychology), and in terms of diagnosis ‘examine risk levels in different parental mental health issues’ (Netherlands, researcher, psychology). There were four items that sought to ‘focus on protective factors’ (Netherlands, researcher, psychology), with three relating specifically to children for example, ‘What factors determine positive coping for children with a parent with a mental illness?’ (USA, researcher & policy maker, psychology) and ‘what key factors are effective in preventing mental problems for children?’ (Norway, researcher, medicine).

Parent, child and family involvement and feedback

There were 16 items concerning the need to have greater input from family members about what they wanted, for example, ‘ask parents and children and youth themselves (what is helping them most etc)’ (Netherlands, researcher, psychology) and ‘How do children of parents with mental illness want to be supported by mental health professionals?’ (Ireland, researcher, nursing). The need to obtain the views of all family members was also indicated ‘Interviewing/hearing from all the members of a family (e.g. parent(s), children, others) rather than just perspectives from one member’ (USA, researcher & administrator, medicine) with two including fathers in particular. Other responses sought to investigate how consumer input might ‘add value’ (USA, researcher, psychology) and ‘How does parent and youth involvement in organised youth and family activities affect overall outcome’ (USA, practitioner, social work).

Stigma

Nine responses were around how stigma impacts on families and help seeking behaviour for example, ‘Does stigma impact on services for mothers with serious mental illness?’ (USA, researcher & policy maker, psychology). Two also focused on strategies to reduce stigma while one made reference to culture ‘Does culture have a significant impact on stigma? If so, what is the impact?’ (Canada, practitioner, social work).
Reach and access

Six responses related to intervention and service outreach for example, ‘how to reach more children with our preventative strategies and programs’ (Netherlands, researcher & practitioner, psychology) while three pertained to access issues for families. One access item was written as a direct question to the family:

What are some of the barriers that keep you from accessing services? If you have any reluctance to become involved with family services, what are they and what would help to alleviate them? (Canada, practitioner, psychology).

Discussion

While survey responses indicted many different research possibilities, several common themes were found. Perhaps not surprisingly, the practitioners, researchers and other participants surveyed here wanted more research in two critical areas; ways to reorient services and family interventions. No clear patterns in the data in relation to participants’ country, discipline or profession were found, which suggests that international projects may be established, where researchers, practitioners, and policy makers might work together on similar agendas.

As can be seen below, there is already research on some of the agendas identified by the participants; on risk factors, how stigma impacts help seeking, and reach and access issues for vulnerable families. Accordingly, participants’ request for further research in these areas suggests a need for more detailed knowledge, but perhaps also a problem with research translation and dissemination. Research translation as a discipline is still in its infancy but there are some innovative approaches that may be trialled. Engaging stakeholders in the developing and executing of dissemination plans, using knowledge brokers, interactive educational sessions and explicitly linking result findings to practice and service development are some strategies that may be employed (see Mitton, Adair, McKenzie, Patten, & Perry, 2007 for a review).

Service reorientation

Most participants wanted to know more about ways to re-orient services from focusing on specific individuals who have a mental illness to assuming a family focus stance that included a consideration of a client’s parenting role and a client’s children. An individual, deficit approach is still the service paradigm in many countries (Maybery & Reupert, 2009), even though repeated research has shown that providing services to individuals without supporting the family as a whole decreases the likelihood of successful outcomes for all relevant stakeholders (Glynn, Cohen Dixon, & Niv, 2006; Miklowitz, George, Richards, Simoneau, & Suddath, 2003). Tellingly, participants identified potential strategies for promoting a family focus, via policy, legislation, funding, professional development and collaborative practice, though still wanted to know how to leverage these strategies to re-orient the ways in which services currently operate. Most available research focuses on the many barriers related to the uptake of family focused practice, which highlight a lack of policy, practice guidelines and procedures for working with families along with practitioner skill and knowledge deficits (for a review see Maybery & Reupert, 2009). Conversely, we still do not know enough about the enablers for family focused practice and interventions. Implementation is a relatively new discipline in mental health, and while evidence is emerging, as a science it has been described as ‘embryonic’ (Proctor, et al., 2009, p. 11). Proctor et al., (2009) continue by suggesting that implementation models may differ between different sectors and organisational platforms; we would suggest that processes may also differ for implementing different paradigms such as a family focus stance. Thus, future research might identify existing organisational enablers and those practitioners that assume a family sensitive stance (perhaps on the basis of clients’ feedback) in order to shed light on how to initiate and sustain family focused practice across services.

Interventions

The second group of responses might be considered in terms of what needs to be implemented, namely family interventions. Within this theme there were calls for evidence of intervention outcomes and the long term impact of available interventions. As outlined earlier, evidence for program effectiveness in this area is largely lacking. Much of the available evidence comes from interventions directed to families affected by parental depression, with implications for other family types still unclear (Reupert et al., 2012). This point was also picked up by participants who identified a need for greater specificity of interventions for different family types. Further research is needed to determine what works, for whom and under what conditions and circumstances.

One way to appreciate how and why interventions work approach is to investigate the change processes that occur within families. This may occur by examining mediators and moderators of the effect of interventions for different family types, circumstances and
families with children of different ages. Such investigations will also need to consider universal, low threshold interventions as well as relatively more intensive, focused interventions. While there is an emerging evidence base for interventions, there is also a need, clearly expressed by participants, for further development and research to meet the needs of families.

**Risk and protective factors**

Although participants recognised the risks associated with families where a parent has a mental illness, they wanted greater specificity for the types of risks and protective factors impacting on families. There are several conceptual frameworks that identify and explain the mechanism by which risk is transmitted or mitigated in families (Falkov, 2012; Goodman & Gotlib, 1999; Hosman, van Doesum, & van Santvoort, 2009; Nicholson & Henry, 2003). While the frameworks have slightly different foci (e.g., Goodman & Gotlib, 1999; focus only on parental depression), they have been developed on the basis of research and clinical experience and provide a comprehensive summary of the various risk and protective factors involved in the generational transfer of mental illness from parents to children. Reupert, Maybery, and Nicholson (2015) reviewed these frameworks to identify commonalities, including those within the child (developmental stage, temperament, social skills, intelligence), the parent (severity and chronicity of the illness, insight, parenting competence), the relationship between the parent and child, and the contextual factors associated with mental illness including poverty, social support and housing. It was also noted that the relationship between a parent’s psychopathology and children’s outcomes is not linear as the child’s behaviour and wellbeing impacts the parent’s health. The mechanisms that explain the risk associated with parental psychopathology are complex and it is not always clear whether children’s adverse outcomes arise as a result of exposure to the parent’s mental illness, or are present independent of the parental disorder and subsequently function as a moderator of the impact of the parent’s illness on the child. Moreover, different paradigms (e.g., genetic, developmental, interpersonal, medical, and sociological) will influence how families and their problems and strengths are conceptualised, identified and subsequently supported. Thus, there is already a wealth of research in this area though the field is complex, with many factors involved, and where simple cause and effect relationships cannot be easily ascertained.

Past research has predominately focused on risk processes rather than specific and comparative sources of resilience in children. While it is important to investigate strategies to reduce risk, it is equally important to identify protective factors such as resilience.

Resilience is a dynamic process between the individual and the environment (Ungar, 2012), but we know little about that process. While parental mental illness may compromise parenting, there is very little, if at all, research on what aspects of parenting and family life remain functional and in what situations.

**Parent, child, and family involvement and feedback**

Participants highlighted the need to involve parents, children and other family members when developing supports and interventions and obtaining feedback. Our reading of available research confirms that there is a dearth of research that takes into account parent and in particular, children’s perspectives when developing family supports and programs. Gladstone, Boydell, Seeman, and McKeever (2011) reviewed studies that documented children’s experiences of parental mental illness, including their preferred supports. Although 20 studies were identified, only ten focused exclusively on children’s views, while the remainder elicited adult’s perspectives on what they thought children might need. Bee et al. (2014) also found that children’s views of community based lacking.

Maybery, Ling, Szakacs, and Reupert (2005) sought to ascertain what parents, practitioners and children themselves considered important for children whose parents have a mental illness. Parents and practitioners stressed the importance of having a counsellor to talk to, while the children preferred to talk to their peers. Given these diverse views, participants are correct in seeking the views of different family members and the need to obtain their input when designing services and interventions.

Participants in the present study also wanted to ascertain how family involvement might ‘add value’ or impact on overall family outcomes. There is already available research which demonstrates that consumer and carer participation improves both the quality and the outcomes of service delivery, and this applies also to families where parent has a mental illness (Trowse, Cook, & Clooney, 2012). Thus, it may be important to understand the barriers to knowledge distribution in different parts of the world and find pathways to disseminate available research, to ensure that consumers and carers are sought their feedback and actively involved in all levels of service development and delivery.

**Stigma**

Similarly, while some participants wanted to know more about how stigma
impacts families, there is available research on this. Corrigan (2004) found that because of public negative views about mental illness, many feel ashamed about their illness, and are reluctant to ask for help, or begin treatment. This means that parents may be ashamed to ask for help, making their illness worse; this in turn may limit their capacity to care for children (Larson & Corrigan, 2008). Similarly, children may be ashamed about their parent’s mental illness or be worried about the reaction of others and so not seek assistance (Larson & Corrigan, 2008). When others know about a family’s circumstance, children may be pitied, avoided or teased (Corrigan & Miller, 2004). As some members of the public believe that those with a mental illness are dangerous and/or are incompetent parents, the parent may be referred to child protective services (Corrigan, 2004).

As well, some participants highlighted the need for anti-stigma approaches. Although there are several anti-stigma approaches available (see Corrigan & Miller, 2004) how these might apply or need to be adapted to families living with parental mental illness is not clear and accordingly might be the target of future research.

Reach and access

Ways in which to reach out to families and promote access to services was the final identified research agenda. We already know why parents and children from vulnerable families do not regularly access services, including their sometimes negative attitudes to help seeking, access to information and daily stressors and complexities (Cortis, Katz, & Patulny, 2009) and the cost involved in accessing services. Additionally, parents may not believe that services can help them; similarly, the sometimes stigmatising attitudes of mental health professionals towards parents with a mental illness may also impede parents from seeking hope for their family (Corrigan & Miller, 2004). Some parents fear discussing their parenting role and children’s needs because of the possible involvement of child protection services (Reupert & Maybery, 2007); in some countries such as the United States, a psychiatric disorder is a legally accepted reason for custody loss (Kaplan, Kottsieper, Scott, Salzer, & Solomon, 2009). We also know that parents do not discuss their parenting role, because they do not get asked about it (Maybery & Reupert, 2009); relatedly, parenting status is typically not a standard intake question or followed up in treatment plans, though there is some evidence that this situation is slowly changing (Maybery, Goodyear, Reupert, & Harkness, 2012). Thus while we know a lot about why families might not access services, we are less clear as to how to promote reach. Online supports may be useful to reach out to families in that they provide easy access at all times of the day, and provide the option of remaining anonymous (Drost, Cuijpers, & Schippers, 2011).

However, in terms of regular service delivery, we still do not know enough about effective strategies to reach out to family members and promote access to services.

Limitations and future studies

One limitation of the present study is the relatively small number of participants. While representative of conference attendees, we cannot claim that participants are representative of the larger research, policy maker and practitioner community. It is not clear whether non participants would have similar or different views on possible future research priorities. Moreover, the participants were primarily from four countries (United States, Canada, Netherlands and Australia) and results should be read with these limitations in mind. In particular, the perspectives of those from developing countries are missing. Given that only 7% of participants were policy makers, their views are underrepresented. The views of consumers and family members (including the parent with the mental illness, the well parent, the children and other extended family members) were also not elicited. Their respective and potentially differing views are invaluable in establishing future research agendas. A final limitation is around the methodology of analysing responses to a single item question, which does not allow for further elaboration or clarification.

There are several steps that could be undertaken in developing a research agenda in this area, with a particular focus on engaging those who did not attend the California conference. Country specific studies might be conducted, by key researchers within their respective countries disseminating the questionnaire across their various professional, community and agency networks. These could then be compared to other country specific studies, to identify country specific issues as well as priorities shared internationally. Leaders practicing in mental health from developing countries need to be identified (perhaps through mental health and/or international aid agencies) and invited to facilitate similar studies in their own communities. It is essential that carer and consumer groups are identified and invited to participate in studies that aim to identify research priorities in this area. Finally, semi-structured individual and/or focus group interviews might be employed to further extend the methodology employed here.

Conclusion

This project was a beginning attempt at identifying key research questions to drive the development of policy and program initiatives to improve the lives of families affected by parental mental illness. However, it is only the beginning. It is hoped that the format
used for the development of this shared research agenda will be repeated in local jurisdictions to identify gaps in our knowledge which if answered, will improve the quality of the lives of families. We also see it as foundation or ‘beta test’ for a much larger initiative which will survey the informed opinions of a significantly larger number of consumers, researchers, policy makers, and practitioners from around the world.

The work reported here is the first attempt to systematically develop a research agenda that can be used locally, nationally and internationally. While the number of participants was relatively small, they appear to be a reasonable cross-section of the people who work in various sectors. The priorities identified in this project have the potential to inform future research, for establishing collaborations and advising policy and program development as well as service improvements.