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# A qualitative evaluation of professionals' experiences of conducting Beardslee's family intervention in families with parental psychosis

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**ABSTRACT**

After Sweden passed new health care legislation in 2010, Beardslee's preventive family intervention (FI) was implemented to meet children's rights to information and support. No studies have yet evaluated perceived effectiveness of FI in families with parental psychosis or its reception by families or professionals. This study focused on professionals' experiences of offering FI to parents with psychosis, their partners, and their children. We conducted 11 semi-structured interviews with FI-educated professionals at open care psychosis service units. Both authors applied thematic analysis to the interview data. The main reported benefit of FI was more open communication in the family; discussing the parent's illness was thought to be helpful for all family members. Psychoeducation was described as particularly useful because family members generally seemed to lack sufficient information about psychosis. The FI manual also made professionals more confident about asking about patients' parenting capacity and their children's wellbeing. Despite positive descriptions, participants had conducted few FI interventions because of heavy workloads, organizational problems, and patients' resistance to talking about their children. These barriers need to be addressed because children of parents with psychosis are a vulnerable group in great need of information and support.

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## Introduction

Many people with psychosis have dependent children at high risk of developing mental illness themselves (Gottesman, Laursen, Bertelsen, & Mortensen, 2010; Rasic, Hajek, Alda, & Uher, 2014). About 63% of women with psychosis in the U.K. (Howard, Kumar, & Thornicroft, 2001) and 56% in Australia (Campbell et al., 2012) are mothers. Parenting with psychosis is challenging; an Australian national survey showed that up to 50% of fathers and 36% of mothers with psychosis had severe parenting impairments (Campbell et al., 2012).

Parents with psychosis often have a limited social network and poor economic circumstances, both of which hinder the child's practical and social needs (Campbell et al., 2012).

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Delusions, hallucinations, cognitive dysfunction, and fatigue can also affect the parent's attention and abilities to communicate and satisfy the child's emotional needs (Healy, Lewin, Butler, Vaillancourt, & Seth-Smith, 2016; Kahl & Jungbauer, 2014). These parents also rarely know how their illness, often surrounded by silence in the family (Pihkala, Sandlund, & Cederström, 2011), affects their child's wellbeing and development (Pihkala, Cederström, & Sandlund, 2010). It is crucial that psychiatry offer effective interventions to support these parents and their children in facing the risks and challenges of parental psychosis.

In Sweden, two sets of legislation regulate the rights of children of parents with mental illness. One, formulated by the Department of Health (SFS, 2001), obliges all health care professionals to be alert to the child's situation and to report promptly if the child's wellbeing is at risk. The other (SFS, 2010) requires all health care staff to pay special attention to children's needs for information, advice, and support when a parent or other adult in the home has a mental illness. After the health care legislation of 2010, Beardslee's preventive family intervention (FI; Beardslee, Gladstone, Wright, & Cooper, 2003) and the 'Let's Talk about the Children' intervention (LTC; Solantaus & Toikka, 2006) were implemented to meet children's rights to information and support. No studies have yet evaluated the perceived effectiveness of FI in families with parental psychosis or its reception by families or professionals. This study focused on professionals' experiences of offering FI to parents with psychosis, their partners, and their children.

### *Beardslee's family intervention*

Beardslee's FI is a manualized secondary prevention program aimed to (1) provide information about the parent's mental illness, (2) reduce the child's feelings of guilt, and (3) support the child's relationships within and outside the family. Communication and openness leading to some understanding of the parent's illness are thought to improve the child's situation (Beardslee & Podorefsky, 1988; Beardslee, Wright, Gladstone, & Forbes, 2007), promote protective factors, and strengthen the parent's role. The theoretical foundation of the FI is eclectic, including narrative, cognitive, psychoeducational, and dialogical elements (Pihkala et al., 2010). The intervention is conducted by two trained professionals working as a pair in six different meetings with family members (Pihkala et al., 2010). In the first two sessions, both parents are given an opportunity to talk about the illness and its consequences for the family. Psychoeducational material and the protective factors for the children are discussed and linked to the family's own experiences. Each child's situation is discussed, along with the parents' concerns about the child and any questions parents want to ask him/her. In the third session, the child is interviewed and the focus is experience of the parent's illness and exploration of protective and risk factors. In the fourth step, parents are given feedback from the interview and information about how they can promote the protective factors and talk about the illness with them. Then parents and professionals together plan for a family meeting based on the children's experiences and questions. Follow-up is offered after one and six months (Pihkala et al., 2010).

Because, to our knowledge, FI has not been evaluated for its effectiveness in families with parental psychosis, we present results from other clinical groups that may inform our results. A randomized trial compared the effects of FI with the effects of a psychoeducational intervention in families with parental mood disorder (Beardslee et al., 2007). Both interventions had sustained effects after 4.5 years; however, FI had significantly more gains in parents'

child-related behaviors and attitudes, and the children reported better understanding of the parent's disorder. Another randomized study evaluating the effectiveness of FI in parents with mood disorders (Solantaus, Paavonen, Toikka, & Punamäki, 2010) found that FI was effective in decreasing children's emotional symptoms and in improving children's prosocial behavior. A Swedish study in parents with various mental health problems (67% with a diagnosis of depression/anxiety) found that parents and children generally found the FI positive, with only a few negative responses (Pihkala et al., 2010). The parents' experiences were somewhat more positive than those of the children. Most parents reported reduced guilt and shame and improved relationships within their family; about half the children felt better understood by their parents and had less guilt and concern about their parents. In evaluations of interventions, children are rarely heard by themselves. However, in one rare study 14 children of parents with mental illness were interviewed about their experience of the FI (Pihkala et al., 2011). A central finding was the children's increased knowledge of their parent's illness, coupled with a sense of relief from excessive responsibility and worries gained through greater openness in the family.

Because of the specific symptoms that characterize parents with psychosis, it is important to understand whether and to what extent professionals think FI is suitable for this group. The aim of this study was to gain an understanding of professionals' experiences of using FI in families with parents with psychosis, focusing on their descriptions of both its advantages and its disadvantages.

## Method

This study is part of a larger research project called *Evaluating Parent-Based Interventions Targeting Children of Parents with Psychosis* that aims to investigate the possible effects of Beardslee's FI on parental capacity, children's wellbeing, and family climate and communication. The research project also investigates mental health professionals' experiences of supporting parenthood and integrating children's perspectives in adult psychiatric care. The design of the research project was approved by the Regional Ethic Review Board, University of Gothenburg (Ref. nr. 599–15).

### *Setting*

The study was carried out at eight open care psychosis units in one of the larger cities in Sweden and one in a mid-sized city in the south of Sweden. The units were in diverse areas representing socioeconomic statuses ranging from low to high. All units were organized in multidisciplinary teams including nurses, occupational therapists, physiotherapists, psychologists, psychiatrists, administrative workers, and social workers. In each unit, about five professionals educated in LTC had delivered that intervention for three to four years, and two educated in FI had delivered that for two to three years.

### *Participants*

Eleven women, aged 32–57 years, participated in the study. All participants worked at psychiatric open care units specialized in working with adult patients with psychosis. The participants' working experience ranged from 3 to 26 years ($m = 13.09$). Six were social workers,

four mental health workers, and one was a nurse. All participants had received training in FI in the previous two to four years and two had also received training six years earlier. All participants had conducted an average of three FI with their patients; two participants had conducted 20 interventions each.

### Procedure

An invitation with information about the study was sent by email to all professionals ($N = 20$) educated in FI and working at the units included in the research project. Information included the aim of the study, the voluntary nature of participation, and the guarantee of anonymity. Initially, seven professionals agreed to participate. After one month, a reminding email was sent to those who had not replied to the first email and another three professionals accepted. A last invitation was sent after another month and one more professional agreed to participate.

Appointments for interviews were made within two weeks of participants' agreement to participate. One interview was conducted at the Department of Psychology, University of Gothenburg, and all others were carried out at the professionals' psychiatric units.

### Interviews

The semi-structured interview covered three areas: families' needs and resources, experiences supporting families with parental psychosis, and experiences of working with FI. The analysis in this study was based on respondents' reported experiences of offering FI to families with parent(s) with psychosis and of conducting FI with those families. Questions also concerned how respondents perceived working with a manual-based intervention, whether there was anything missing in the intervention, what was perceived as helpful when working with FI, and whether there were any obstacles to offering or conducting FI with families with parental psychosis. All questions were open-ended to invite professionals' own thoughts and experiences. Participants were asked to speak partly out of their general understanding and partly from their experience of specific families. Follow-up questions were asked to ensure our better comprehension of the participants' experiences and thoughts. The number of follow-up questions varied depending upon how forthcoming and detailed the participants was.

The interviews took approximately one hour. The first author carried out six interviews and the second author, five. All interviews were audio-recorded and transcribed verbatim. To gain familiarity with all interviews, the first author transcribed the second author's interviews and the second author transcribed the first author's interviews.

### Analysis

We analyzed the transcripts using inductive thematic analysis (Braun & Clarke, 2006). Both authors read the transcripts first to extract all data relevant to the research question, and then each coded the data-set, making no attempt to fit the data into a pre-existing framework and noting ideas for a possible structure. We discussed all the codes and ideas and re-coded the data, and first categorizing extracts as positive or negative experiences. We then reorganized the coded extracts to investigate whether the original themes captured the

respondents' thoughts about the advantages and disadvantages of FI for patients, children, and professionals and reorganized them under two main themes: 'an intervention with benefits for all parties' and 'a demanding intervention for all parties'. We created subthemes to structure the material and reviewed all data extracts to find quotations that best captured the essence of each theme and subtheme.

## Results

### *An intervention with benefits for all parties*

All participants said that FI had benefits for parents, children, and the professionals themselves. The main positive effect of FI was in opening the families' communications and helping parents inform their children about the illness. 'Letting the secret out' reduced stigma and fear for both parents and children, and the manual-based intervention offered professionals clarity and security and made them more comfortable in asking about patients' experiences of parenting and their children's situation and wellbeing (Table 1).

### *FI helps inform and support the child*

The main reported benefit of FI for children was in informing them about their parents' illness. Families seemed not to talk about the illness, leaving the child alone with worries and questions.

> You know that your mom is ill, but you don't know for how long, and 'What is this illness?' Kids want to know, of course they do. And they don't talk about it enough, not even in relatively well-functioning families. (Claire)

All participants stressed the children's need to be informed about their parents' illness, but often described the parents as incapable of discussing it adequately and age-appropriately. Helping parents talk with their children alleviated some of the children's emotional burdens and misunderstandings about psychosis. Some parents were helped to assure their children that parents, not children, were responsible for ensuring medications were taken as prescribed; other parents were helped to explain that their illness was not contagious.

> I think that the most important thing has been that we helped put words on the illness, and helped to talk about it. I have told them that it's not contagious, talked about that, that [the children] will not get sick just because they have a mother who is ill. I have told them that it's okay to hug each other. (Jenna)

Encouraging communication was seen to help children to share their worries about their parent's condition. Many participants also spoke about the need to include information about the early signs of psychosis in the intervention to give children the ability to notice their parents becoming ill and the opportunity to ask for help. Knowing that their parent

**Table 1.** Main themes and subthemes

| Main theme | Subtheme |
|---|---|
| An intervention with benefits for all parties | FI helps inform and support the child |
| | FI strengthens the parent |
| | FI offers support and guidance for the professional |
| A demanding intervention for all parties | FI requires cooperative families and patients with high levels of function |
| | FI needs to be adjusted for the specific patient group and complemented with other types of support |

was receiving help from professionals at a psychiatric unit also seemed to make children feel supported and more secure.

> That can make them feel more secure … to know that Mom or Dad visits this psychiatric care unit and that [the children] can come here and meet us, see what it looks like instead of the parent saying something else at home, like 'Mom is going to the district health care center now.' (Eva)

Participants felt that FI made it possible for children to express their experiences and needs and find security and validation by being listened to. Many participants expressed that taking the children's perspective was one of the most important strengths of the intervention.

> One thing is that you acknowledge the children. Kind of like, 'Now I'm talking to you and only you' and 'What do you think, what you feel, what do you do?' It seems as if the children appreciate that. To acknowledge them, make them feel that they are important. (Claire)

### *FI strengthens the parent*

Participants perceived educating parents with psychosis, and especially their partners, as beneficial. They spoke about psychoeducation as a key step in making the parent more aware and opening communications in the family. Psychoeducation was also described as a key step in reducing stigma.

> To get help to help to talk to an outsider about what kind of illness they have, what kind of treatment they receive, what symptoms there are, well, to explain that their symptoms are their illness, that has been very helpful. (Julie)

Although almost every parent in the intervention was described as satisfied afterward, participants also spoke about parent's hesitation to accept FI. Some parents were reported to have been afraid that the aim of the intervention was to show them that they were not good enough parents. After the intervention, however, parents seemed to feel strengthened and more competent in their parenting role.

> And she was so happy and grateful that last meeting, and she talked about how she had been given just the opposite of what she expected: been told that she was a good parent. She had not expected that, so she'd carried a lot of guilt, which her husband surely also had been thinking about. (Karen)

All participants spoke about the need to help parents feel 'normal' rather than defined by their illness. Participants expressed that the intervention, through reducing stigma and guilt, seemed to make it easier for parents to accept other types of support.

> I mean, the patient becomes more at ease and then you're able to work on other areas of life. Perhaps start another type of treatment; they are not fully occupied by this anymore. Perhaps they have spent a lot time worrying and it has taken time and made them anxious. (Jennie)

### *FI offers support and guidance for the professional*

One of the main benefits of the intervention for participants was working with a manual that offered support and guidance for them as professionals. The manual made them feel more comfortable in asking sensitive questions about parenting capacity, family functioning, and the child's wellbeing. The manual also allowed participants to reassure parents that the questions were asked of everyone in the intervention, making the parents feel less identified as a 'bad parent'.

> I feel more secure, and it makes it easier. Even if the questions are loaded, they become less dramatic, because this question is asked to everyone who takes part in the intervention. (Eva)

The participants also spoke about the feelings of security and support that came with offering the intervention with a partner. Although the intervention was manual-based, many found it flexible enough to allow them to adjust, change, and add content according to a family's specific needs. All participants described FI as effective and helpful. Although none described it as a solution to all of the parents' problems and all felt that more parental support was needed, the participants felt that by offering FI they were making a difference, they were needed, and they could bring change for the better. This insight seemed to lift a burden from the participants themselves.

> It is so positive, it really is. Because in the long run, I would be surprised if a daughter would throw herself on the phone and tell us that now there's a crisis and disaster, but it feels good to me to know that she can do that. (Ellie)



### *A demanding intervention for all parties*

Although the participants stressed the benefits of working with FI, they also described difficulties in motivating parents and children to participate. One reason for the difficulties was the many meetings FI requires. Participants had to be flexible in setting up and changing their work schedules to adapt to those of the patients. The intervention was not always seen to be well adjusted for this specific group of patients, sometimes making it difficult or impossible for those most in need to participate. No participants had been able to conduct as many interventions as they wished, and all stressed the need for more follow-up and for complementary types of parental and child support.

#### *FI requires cooperative families and patients with high levels of function*

The participants described how much time and work FI required from all parties. It could be difficult to motivate parents and children to prioritize time for all meetings. Also, for families with working parents and children in school and leisure activities, FI often required care providers to work outside their own scheduled work days. Because of these scheduling difficulties, some parents wanted to conduct FI with fewer meetings, although participants felt that more rather than fewer meetings would be most effective.

> If they, the parents … well it's not an entire intervention but instead … kind of … well, sometimes they won't agree to that many meetings. (Fiona)

The participants also described parents who might be interested in participating, but whose children refused out of lack of interest, unwillingness to spare the time, or fear that the intervention could result in their parents' losing custody. Some children who took part were also resistant, unwilling, or afraid to talk to the professional.

> One of the children didn't want to go with us [to the meeting room] at first, but when he got to know that the mother was waiting just outside the room, he came with us. But during the meeting he regressed and talked like a little baby. And he didn't want to talk about that his mother was ill at all, he didn't want to hear about it. (Monica)

Many participants reported that parents' willingness to take part in the intervention sometimes depended on their level of functioning. Parents with feelings of guilt or paranoia were especially reluctant to take part in FI. Some parents seemed to be afraid that talking to the child about their illness would do more harm than good, and some low-functioning parents had difficulties talking to their children at a level appropriate to the child's age, sometimes making the parent over-inform and scare the child.

> … delusions about her, how it was, and I thought 'Now you have to be quiet!' But I couldn't say anything when this little kid was sitting next to us. But I had to try to ease it up and get the kid to go outside and play so that I could talk to the mother about the symptoms and treatment, and about how to talk to her child. Well, to be five years old and to hear, to live in that way. She could not see that her child was five years old, and that he shouldn't have to listen to that. (Julie)

Participants said that some parents with lower-functioning had difficulty understanding how their illness affected their children. Although acknowledging that low-functioning parents and their children were those most in need of the intervention, all participants said it was easier to conduct FI with higher-functioning parents who were not as troubled by guilt and were more able to describe their illness to their children in an age-appropriate way.

> But I think it's easier to find collaboration with a well-functioning parent … where a certain amount of the fear is not there. (Ruth)

FI needs to be adjusted for the specific patient group and complemented with other types of support. All participants spoke about of a great need for psychoeducation for the parents and their partners. Many spoke of patients who had poor knowledge and misconceptions about psychosis: its origin, manifestations, and effect on their children. The FI-manual, not specifically designed for this patient group, was sometimes described as not leaving enough space for psychoeducation.

> Well, for example, when we provide information about the parents' illness, that part takes a lot more time than you would think. And now I can't quite remember, but in that part there is a lot to do. During that meeting, you are expected to do a lot, and usually there's not enough time for all of that, so you have to schedule two meetings. There's not enough time. (Sylvia)

Participants often had to schedule additional meetings to allow time for psychoeducation with parent with psychosis and their partners, which could obstruct the intervention though the additional time demands. All participants spoke of the importance of offering complementary supports to FI, such as groups for patients and for their children to share experiences and advice with those in similar situations. Some wished that their psychiatric unit could set up family groups to offer this type of support.

> You share experiences and ideas. It's like you're not alone in your thoughts and concerns; the children get to meet other children, patients get to meet other patients, and families, and extended networks. They get to meet each other. I think that's our next challenge, but we're not there yet. (Ellie)

Participants emphasized the importance of having FI-educated professionals at the psychiatric unit to minimize the risk of the child's perspective getting lost in the administration of the patient's treatment. Many described it as their personal responsibility to make sure that the child was acknowledged and offered support. They stressed the intervention as needing continuous work and many talked about a need for more follow-up meetings after conducting the intervention. At the same time, many described how they had failed, mainly due to a lack of time.

> If you were to say that I would want another follow-up [meeting], then I would be alone to do that, and that's not always easy. Because with these kinds of things … there are a lot of things [the patient] needs to be reminded about, a lot of work that needs to continue. (Jennie)

Although they felt FI helped families, participants remained unsure about whether the intervention had made a real change. For many, the lack of time and structure around follow-ups was a source of frustration.

I: Do you feel that the intervention made a change?

R: No, I cannot say that, because I haven't met them after the intervention. I haven't been allowed to see them! (Monica)

## Discussion

Consistent with the aim of FI and results from studies exploring the experiences of parents' in general psychiatric services (Pihkala et al., 2011), the professionals in the present study described the main benefit of FI was its opening of communications in the family. Talking about the parent's illness was perceived as helpful to both parents and their children, especially as it allowed children to ask questions and share their worries and concerns about their parent's illness. These findings are supported by a study in parents with mental illness, in which both parents and their children said that FI had increased the children's knowledge and opened up communication about the parental illness (Pihkala et al., 2011). Few professionals in the current study had conducted follow-ups and they had limited information about whether the familial communication continued beyond the schedule meetings. This aspect should be stressed, especially because FI has been neither developed nor evaluated in families with parents who suffer from a severe mental illness. However, a study conducted 4.5 years after enrolment showed that FI had positive long-term effects on children's understanding of their parents' depression (Beardslee et al., 2007). Further studies are needed to confirm whether FI has positive long-term effects on communication in families with parental psychosis.

### *Parents with psychosis are in need of psychoeducation and guidance when talking to their children about their illness*

Our participants thought psychoeducation was beneficial for all parties and FI provided them an opportunity to educate families about the early signs, symptoms, medications, heredity, and other factors involved in psychosis. Participants reported that before the intervention patients often had little knowledge about how their psychosis could affect their children's wellbeing, partners lacked information about psychosis symptoms and medication, and children had important misconceptions about their parent's illness. Professionals felt they had to increase the number of family meetings to accommodate the families' needs for information, which raises the question of whether psychoeducation should take place in an extended family intervention or if it should be offered as a routine part of psychosis treatment.

Another important finding related to both psychoeducation and communication was the apparent inability of some parents to discuss their illness with their children without overwhelming them with information beyond their developmental capacities. Difficulty in taking the child's perspective might be specific to this patient group and related lack of insight into their illness (Nair, Palmer, Aleman, & David, 2014). This finding suggests that psychosis service has an important role in guiding parents to talk to their children about their illness in a way that does not frighten them or cause them harm. However, more knowledge is needed to assure that information about parental psychosis neither increases children's burdens nor leads them to become even more self-sacrificing in an effort to help their ill parents.

### *FI might not be sufficient for parents with low functioning*

A troubling finding was the professionals' difficulties in reaching families with a parent with severe symptoms, including paranoia, or low functioning. Parents with lower functioning had difficulty understanding how their illness might affect their children, and those with symptoms of paranoia were prone to overprotect the child in inappropriate ways. This finding suggests that children in the greatest need of help and information remain unsupported as a result of their parent's legal rights to decide on behalf of their children.

Although all professionals thought the intervention was valuable and strengthened both parents and children, they were clear that FI was not near to sufficient for some parents and children. Many suggested that groups for parents, children, and families to share their experiences would help to sustain and support the results of FI. The need for parents with psychosis to meet and talk with parents in a similar situation has been reported in previous studies (Dolman, Jones, & Howard, 2013). There are also several examples of effective group interventions that include participants exchanging experiences, training in parenting skills, and learning about the impact of their illness on parenting (Schrank, Moran, Borghi, & Priebe, 2015).

### *Parents with psychosis need to be motivated to participate in FI*

Despite the professionals' positive responses to FI, their average number of interventions (only about 3 each over 2–4 years) was quite low. This could be attributed to general difficulties in motivating this specific group of patients or to an organizational failure. Many parents were described as resistant to taking part in FI because they feared losing custody of their children. Possible solutions could include providing parents with information about laws and legislations and asking routine questions about their parenting capacity and the child's wellbeing. These steps could help prevent parents feeling judged when offered support and help professionals to overcome any hesitation in offering the intervention.

### *Limitations*

The fact that some professionals had conducted only a few interventions is a limitation of this study. The two professionals who had conducted more interventions had a longer experience of conducting FI. Those participants were also located at the same open care psychosis service unit where the child perspective was more integrated in the service, in comparison to the other professionals. Future studies would benefit from including participants with more experience in the intervention to gather more detailed and nuanced information. It is also important to keep in mind that all information presented about the parents and children is based on the professionals' perceptions and should not be understood to accurately describe any actual family situations.

## Conclusion

The low number of interventions conducted by the participants in this study could reflect a heavy work load for professionals in psychosis service, but if the child's perspective is to be taken seriously (SFS, 2010), organizations must provide scheduled time for staff to conduct

the interventions they are trained in. The many parents with psychosis who have severe impairments in their parenting ability (Campbell et al., 2012) and the high percentage of their children who will develop mental illness themselves (Gottesman et al., 2010; Rasic et al., 2014) mean this area must be a priority in mental health care.

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