

Experiences of Peer Support for Children and Adolescents Whose Parents and Siblings Have Mental Illness

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PROBLEM: There is minimal published literature on experiences of peer support programs for children/adolescents in families affected by mental illness. This study aimed to explore children's and adolescents' perspectives of the ON FIRE peer support program.

METHODS: An exploratory qualitative study with 14 children/adolescents 9–17 years of age who participated in semi-structured interviews. Thematic analysis resulted in three themes of experience.

FINDINGS: Participants made connections with others in the program, developed personal strengths, and learned how to contribute to others' well-being.

CONCLUSION: Participants derived substantial personal benefit from peer support. Use of social media and the Internet may facilitate future program delivery.

Prevalence estimates indicate that up to one in five children/adolescents live with a parent with mental illness (Maybery, Reupert, Patrick, & Goodyear, 2009). International research has identified a range of risk and protective factors for these children. Risk factors include genetic predisposition to mental illness, parents' compromised parenting ability, relational difficulties, socioeconomic strain, emotional unavailability, and uncertain family life (Fudge, Falkov, Kowalenko, & Robinson, 2004). Further, mental illness from any family member can impact children, including sibling mental illness. Children with siblings with mental illness have reported experiencing stigma, burden and stress, and feelings of guilt and embarrassment in relation to their unwell brothers and sisters (Greenberg, Kim, & Greenley, 1997; Sin, Moone, Harris, Scully, & Wellman, 2012).

Relative to their peers, children in families with mental illness can experience a range of psychosocial outcomes, including poorer academic and social functioning and development of their own mental illness (Reupert, Maybery, & Kowalenko, 2012). Adverse outcomes can be reduced, and children's resilience strengthened, with protective factors such as adequate parenting and warm parent/child relationships, strong family communication, adequate finances, housing and education, social connection and support, and proactive intervention by the mental health workforce, including nurses (Foster, O'Brien, & Korhonen, 2012).

Social and community support, such as peer support, play a key protective role in ameliorating adverse outcomes for children (Reupert, Maybery, & Kowalenko, 2012). Peer support programs are prevention interventions that use a peer setting to promote personal growth where individuals learn by interacting with, observing, and listening to peers in similar circumstances (Dennis, 2003). There is an emerging international body of evidence on the impact of peer support programs for children of parents with mental illness (Reupert, Cuff, et al., 2012), although extremely limited published literature (e.g., Pitman & Matthey, 2004) on programs for children with both parents and siblings with mental illness. A review of 26 Australian peer support programs for this group of children (Reupert & Maybery, 2009) reported that these programs commonly took a strength-based approach, aiming to develop participants' understanding of mental health and illness, peer support network, and life and coping skills. Program structures were found to vary from school holiday programs and camps to after-school programs. Age groups targeted by programs also tended to vary, including 6–9, 9–12, and 13–18 years. Investigation of these programs (e.g., Fraser & Pakenham, 2008; Goodyear, Cuff, Maybery, & Reupert, 2009) has focused primarily on children's outcomes such as strengths and difficulties and coping. There is little reported evidence on the subjective experiences of children who receive peer support, and their voices and

perspectives on peer support are largely absent from the literature.

Orel, Groves, and Shannon (2003) reported brief comments from 11 children (8–13 years) made in journals and open-ended survey questions during a peer support program in the United States. These were not analyzed but descriptively reported. Comments included learning about mental illness, having fun, and learning how to manage their feelings. Children reported they enjoyed playing games in a group, that they had learned mental illness was not their fault and was not contagious, and that the person with mental illness could not control his actions. Children found talking to peers in a group to be helpful. Hargreaves, Bond, O'Brien, Forer, and Davies (2008) also reported descriptive comments/reflections made by adolescents (12–18 years) in an Australian peer support program. Adolescents reported learning about mental illness, realized they were not alone, had fun, and made new friends. However, these comments were limited in scope and represented only a few adolescents in the program. Pitman and Matthey (2004) reported young people's (8–16 years) written responses to open-ended feedback questions about the SMILES peer support program in Canada and Australia for children with parents and siblings with mental illness. All participants found the program helpful. They identified that increased knowledge of mental illness had empowered them at home and at school, the fun they had during the program, and skills learned (e.g., problem solving) and applied outside the program. These comments again represented a small number of program participants.

The international evidence base for the impact and experience of peer support for children in families with mental illness is still developing (Reupert, Cuff, et al., 2012). The evidence base can be expanded by understanding participants' subjective experiences of peer support. Given the limited knowledge on children/adolescents' subjective experiences of peer support where parents and/or siblings have mental illness, this study aimed to provide valuable insights into children/adolescents' perspectives on the ON FIRE program.

Peer Support Program Description

ON FIRE is offered by the Schizophrenia Fellowship of New South Wales Inc. (SFNSW) Australia, and is designed for young people aged 8–17 years in families affected by mental illness. The aim of the program is to cultivate hope, resilience, and well-being in children and adolescents by focusing and building on individual strengths. ON FIRE is underpinned by the positive psychology philosophy of "Epicorma" (Yu, 2011), a coaching program designed to cultivate happiness and success for individuals, groups, and communities. The Epicorma vision is that people live flourishing lives where they are at their optimal functioning, including having a sense of mastery and purpose, personal growth, self-acceptance,

autonomy, positive relationships, and making a difference to those around them (Yu, 2011). Program objectives include increasing positive emotions; enhancing social belonging; strengthening social-emotional life skills such as hope, positivity, resilience, and positive coping; improving well-being literacy; and building social capital (Yu, 2011). The program is manualized and offered across several sites in NSW. Each program is led by a program facilitator, supported by trained volunteers to assist with program activities. Core program activities include fun days (regular day-long social outings) and camps (over two to three nights per day). Camps included fun and leisure activities in combination with group work that focused on developing peer support networks, mental health literacy, and life skills. The program is not time limited and is offered continuously through the year. Children/adolescents can join the program at any point. This article reports the findings from a qualitative study that aimed to explore children and adolescents' experiences and perspectives of the program.

Method

This study was part of a larger study investigating the impact and outcomes of the ON FIRE program (see Foster, McPhee, Fethney, & McCloughen, 2014). The present study employed an exploratory qualitative design. Fourteen children/adolescents participated in a semi-structured interview on their experience of the program. In order to include a wide range of participant perspectives, maximum variation sampling, a form of purposive sampling, was used (Patton, 2002). Participant characteristics included a range of ages, site of program, and gender.

Ethics and Procedure

Ethics approval for the study was gained from the University of Sydney Human Research Ethics Committee, and the ON FIRE Program Steering Committee, SFNSW. Prior to the overall study commencement, parental written informed consent was gained for children under 16 years of age. Written or verbal consent was also obtained from children. Adolescents 16 years or over provided their own written informed consent. Face-to-face semi-structured audio-taped interviews were conducted with 14 participants toward the end of a program camp. Initially, the site facilitator asked the child/adolescent, who had already provided consent to the overall study, if they were willing to be interviewed. If willing, the researcher was then introduced to the child/adolescent. Participants were interviewed by same-sex interviewers and informed they did not have to answer questions if they did not want to, and could stop the interview at any time. Interviews were approximately half an hour in length and held in a quiet, private location. A range of topic areas were explored,

including program activities in which the children and adolescents had participated, what they had learned in the program, what they considered the best and not so good things about the program, and what, if anything, they thought could be improved.

Data Analysis

Audio-taped interviews were de-identified, transcribed verbatim, and managed using NVivo 8 software. We conducted a thematic analysis in order to identify the range of participant experiences. Two researchers independently familiarized themselves with the transcripts, and all data were initially coded. In an iterative process, initial codes were collated to form emergent themes, which were reviewed and checked (Braun & Clarke, 2006). To ensure trustworthiness and credibility of the process (Shenton, 2004), the research team met regularly to discuss codes and themes, which were refined until consensus was reached (Braun & Clarke, 2006).

Findings

There were 14 participants from three program sites; five boys and nine girls aged 9–17 years (mean age 12.36 years). They had participated in one to four fun days and one to two camps. Family members' mental illnesses included depression ($n = 8$) and anxiety, including obsessive–compulsive disorder and panic disorder ($n = 4$). Some family members had more than one mental illness, most commonly comorbid depression and anxiety ($n = 4$).

Three themes describing participants' experience of the ON FIRE program emerged from analysis: "I'm not alone"—connecting with others in ON FIRE; "I feel a lot braver and stronger in myself"—developing personal strengths; "I can help"—being able to contribute to others' well-being.

"I'm not Alone": Connecting With Others in ON FIRE

All participants spoke of developing a sense of connection with other program members (children/adolescents). "Connecting" included making new acquaintances within the program, some of whom became friends. For several participants, these connections continued outside the program and into their everyday lives. Participants also spoke about bonding with volunteers and program staff. Fun days and camps provided formal and informal opportunities to connect with each other and with program workers. Formal opportunities included planned, supervised camp activities that incorporated games and recreational pursuits and encouraged members to work together to accomplish tasks. Boys especially liked outdoor activities such as archery and rock climbing that involved some physical exertion and com-

petition, ". . . I'm still not that much of an active person, but I participate and I have fun, which is what it's all about" (Boy, 14 years).

Girls appreciated the informal opportunities including "free time," which they used to talk about themselves and their family situations.

We all have one thing in common, that's a relative with a mental health issue or a disability. We can sit down and talk about things and we get to go out and have fun as well as getting help with the issues. And it's really helpful and I think we appreciate it a lot, because our home lives can be tough and when we come here, we can express our feelings and, you know, we can say it in such a way where people actually understand. (Girl, 14 years)

Girls valued the opportunity to mix with other girls of different ages. One older participant (17 years), for example, liked "being seen as a mentor" by the younger girls and was mindful of her position as a role model within the program. This led to her modifying her behavior, for instance, by self-censoring answers in order not to "scare the younger kids."

Participants of all ages and both genders spoke frequently about feeling unconditionally accepted and supported, ". . . the other kids, they have the exact same problems, we get along so well, and there is no dramas, no fights, there is no judging. It's really good" (Boy, 13 years). Participants had a sense that other program members and workers understood them in a way that was caring and nonjudgmental. They felt that ON FIRE provided a safe physical and emotional space within which they found support and understanding, and reported a sense of belonging that alleviated loneliness for some. This feeling of a "safe space" was enhanced when participants compared the support and understanding they received within the program with the lack of support they sometimes perceived from others in their daily lives. This included being bullied, and more commonly, feeling stigmatized by other children because of their family members' mental illnesses.

There are a few people that walk around school and they just look at you funny and you just think, you shouldn't be judging me . . . because people know that my parents and my siblings have disabilities and, like mental issues and all these different things, and they are probably going, you know, she is probably one of them. In primary school it'd be like, "Your mum's crazy. Your mum's insane." "Your dad's weird." (Girl, 14 years)

Participants of all ages and both genders reported that they had formed new friendships through participating in the program. These friendships were significant, "I've made like a new best friend" (Girl, 13 years), and sustained by maintaining frequent, informal contact outside the program. Some visited their new friends' homes, and older members (13–17

years) arranged meetings in parks or other convenient locations. Although friendships usually developed among members of similar age, participants also commented that the age range of ON FIRE members was “good” because “it adds to the variety” of experience while engaged in ON FIRE activities. These meetings were possible because they had learned through the program that other young people in their local area had family members with a mental illness. Encounters were spontaneous or planned in advance through social networking such as text messaging and Facebook. Facebook contact was more prevalent among older participants.

. . . me and some of the other girls, like we will meet down at the shops and have lunch together and talk about stuff or you know sometimes like I go down to the park and I will call up a few of the boys and I will be like, “Hey come down and we will play soccer.” And, you know, we just sit and have a good time. (Girl, 15 years)

“I Feel a Lot Braver and Stronger in Myself”: Developing Personal Strengths

ON FIRE camps included activities such as archery, canoeing, rock climbing, and the “Big Swing.” These activities aimed to promote self-confidence and cooperation between members and this was borne out in participants’ experiences. They spoke of finding the confidence to try these new pursuits and, in the process, were delighted at discovering personal strengths and courage that they did not necessarily experience in their usual daily lives.

I learnt to face fears and stuff ‘cause with the giant swing I get really nervous when I’m going up ‘cause you look down it’s like ‘oh I don’t want to pull the string, I don’t want to go down’ but then I pulled it and then it was just fun and then the rock climbing I got higher and higher every time I got up there so it was really good, and how to trust people ‘cause with the belay team they have to – they pull you up and if you fall you’re not going to fall anywhere if they’re doing it properly and I had to trust them. (Boy, 13 years)

In being encouraged to tackle challenges within the context of individual and team fun recreational activities, participants learned to believe in themselves and their capacity to be proactive and make choices. Program staff emphasized this when supporting members to step out of their “comfort zone” and into their “courage zone.” One participant illustrated this when explaining the lesson he had learned from trying some of the more challenging camp activities: . . . *trust yourself, trust your parents and if you’re going to do something don’t say “I can’t do it” say “I’ll try”* (Boy, 13 years).

Some participants acknowledged that through their involvement in ON FIRE, they learned they had the capacity

to overcome the loneliness and isolation they experienced at school and at home. One boy illustrated his change in perspective by using metaphors:

. . . [I’ve learnt] you’re not always alone and that you can – you will find your way out of it, like it’s a big dark cave and there’s two roads. There’s one road to hide your feelings but another road leads to an opening and that’s what I’ve learnt here. . . . it practically tells you what path to choose. It’s not saying “oh choose the one on the right” it’s just saying “that way leads to a better ending but on the left one you’ll just live in a deep dark house.” (Boy, 11 years)

As a result of learning how to develop and recognize their own strength and capacity, and in accessing resources and support, participants acknowledged that they felt better equipped to cope with difficult situations that resulted from their family member’s mental illness.

We learn how to cope with things and what to do if one of your relatives goes off the wall, a little bit haywire, like they have given out helpline numbers . . . and you know you have always got somebody to call or talk to if there is anything that you need help with. (Girl, 14 years)

Some of the older participants (13–17 years) identified that their family members’ mental illnesses were not their fault. In turn, they now better understood how to distance themselves from family members’ behaviors and to modify their own responses to behaviors. This greater understanding was a relief for some; they had been liberated by the realization that they were not to blame for their family member’s mental illness.

. . . sometimes you’ve just got to know that it’s not you personally, and not take [your parent’s behaviour] personally, kind of just swallow your pride a bit and just say, “Okay I know that it’s not me.” (Girl, 13 years)

“I Can Help”: Being Able to Contribute to Others’ Well-Being

This final theme was not as prominent in participants’ conversations; however, those who reported developing personal strengths also spoke about how these strengths manifested in their lives. They spoke of no longer feeling *helpless* and had identified ways in which they could be more *helpful* to others. They talked about learning how they could contribute to the physical and emotional needs of their parents, siblings, and other program members. Some participants developed a sense of themselves as being more helpful in their daily lives. This group realized they had the capacity to help other people and the ability to act on their capabilities. However, the emphasis on each function was experienced differently by younger participants (9–12 years old) compared to older participants (13–17 years old).

Younger participants spoke about learning *how* to help their family member(s) with a mental illness; they learned skills of helpfulness: “[I learnt] that you can help the parent that’s got a mental illness, you can help them, you can try and make sure that they’re happy and have a good lifestyle” (Girl, 10 years). Older participants learned that they had the *power* to help. This meant that they had a new understanding they could exercise their personal agency in social situations. An older girl (16 years), for instance, identified that she could help her mother, who had a mental illness, by not fighting with her sister.

Some participants also spoke of helping children in the program to talk about their problems. Others spoke of helping each other to engage in program activities they found challenging.

In archery there was this one girl that was next to me trying to do the bow and every time she tried to pull it up her arrow would come off and she got really agitated with that so I thought I’d help. I helped her and she finally got it so I was happy about that and [camp volunteer] complimented me on that one for helping her so that felt good as well. (Boy, 13 years)

Discussion

This study on the experience of 14 young people in the ON FIRE peer support program found that participation in the program affected them in three main ways. First, they felt a sense of better social connection because they mixed with young people in similar situations to their own. Second, they developed personal characteristics of strength and courage by participating in challenging ON FIRE program activities. Third, they learned skills that they could use to help other people both within the ON FIRE program and at home. Consistent with previous qualitative literature on peer support programs (Hargreaves et al., 2008; Orel et al., 2003), the children and adolescents in ON FIRE reported that they had made new friends, realized they were not alone, had fun, and learned more about how to contribute to the well-being of others. These findings are also consistent with the common aims of peer support programs for this group of children (Reupert & Maybery, 2010), with the findings of the SMILES program for children with parents and siblings with mental illnesses (Pitman & Matthey, 2004), and with ON FIRE program objectives (Yu, 2011).

Making new friends was a major aspect of children’s/adolescents’ conversations. They identified that life with a family member with a mental illness could be unpredictable, stigmatizing, and potentially isolating. Participating in program activities and meeting other young people in similar circumstances played a vital role in reducing their sense of isolation, promoting universality and a sense of belonging.

Interactions between program members occurred in a space specifically designed to be supportive, and that was removed from the pressures or distractions of their daily lives. This had a positive impact on participants who clearly articulated that having a temporary “safe space,” where they experienced understanding and support, helped combat feelings of isolation and loneliness experienced at other times.

The development of close relationships usually requires time and repeated contact to enable interpersonal interactions to broaden and deepen, and this was possible to only a limited extent during program activities. While friendships among ON FIRE members might be an anticipated outcome of the program (Hargreaves et al., 2008; Orel et al., 2003), the finding that some older members (13–17 years) were establishing their own informal peer support networks outside the program through face-to-face connection and web-based social networking is consistent with other similar adolescent peer support programs (Hargreaves et al., 2008; Woolderink et al., 2010), and illustrates the potential of the Internet and social networking in providing future peer support (Drost, Sytema, & Schippers, 2011; Woolderink et al., 2010). This can be particularly useful for adolescents who are unwilling, or unable through geographic distance, to engage in face-to-face peer support. However, as Hargreaves et al. (2008) have similarly cautioned, it is important that program staff be aware of the risk that young people may forge a subculture where they see themselves as different from others. Their ON FIRE relationships, face-to-face or online, could occur at the expense of establishing peer connections beyond the program. Given the range of developmental stages of young people in the program, consideration could be given to implementing age-specific program activities tailored to particular groups (e.g., 8–12 and 13–17 years). Consideration could also be given to construction of a virtual meeting place for 13- to 17-year-olds—a website facilitated by program staff which includes regular blogs or chat rooms to discuss issues relating to mental health and illness and to connect outside the program.

“Feeling braver and stronger” was another key finding. Participating in activities enabled some members to develop a new sense of their strengths and capabilities, which had the potential to translate into confident interactions with others. Participants acknowledged that activities were deliberately designed to promote these feelings of increased self-worth and capacity. Recognizing one’s own strengths and capabilities is empowering and promotes resilience (Foster et al., 2012), and young people’s capacity for self-reliance when dealing with their family members with a mental illness. This finding indicated the resilience-building potential of the program.

Being able to contribute to others’ well-being is a related finding that reflects the ON FIRE program philosophy of “paying it forward” “. . . which is about giving young people opportunities to make a positive difference in their commu-

nities” (Yu, 2011, p. 8). Yet being able to contribute by caring for others, particularly parents or siblings, can carry both benefits and risks for young people (Gladstone, Boydell, & McKeever, 2006). The risks include that they may put others’ needs before their own, or become parentified and have role reversal, taking on adult or parenting roles with their parents. There is evidence that parentification and caregiving roles can hold potential risk for this group of children over the longer term (Foster, 2010); however, Ungar (2012) contends that parentification can also have benefits and be protective in providing opportunity for young people to maintain a positive sense of self-worth and see themselves as competent. In learning to “pay it forward,” therefore, there is potential for children/adolescents in ON FIRE to develop these characteristics of resilience. If they are supported to maintain their personal boundaries, their contributions to others will not strain their capacities or be at the expense of their physical and psychosocial well-being.

Study Limitations

This was a small purposive sample and due to the context-specific nature of the program the views of the participants may not necessarily be transferable to other program contexts. To minimize participant burden, we did not use member checking. Our focus on program activities may have limited our understanding of how those experiences affect young people’s daily lives. Given the interview context, it is also possible that participants may have emphasized positive aspects and minimized any negatives of the program.

Conclusion

Participants in this study derived substantial personal benefit from participating in ON FIRE. Connections with peers fostered resilience and helped alleviate feelings of stigma, isolation, and loneliness. Participants reported pursuing new friendships with other ON FIRE members which they valued. They spoke about the opportunities provided by the program to develop their strengths and capabilities, and how program activities enabled them to face their fears, find personal courage, and develop abilities and achieve tasks that they had not achieved before. Activities enabled them to learn cooperation with each other and what it means to help other people. These findings indicate that young people’s abilities and perspectives of themselves and their situations have potential to be transformed by participating in peer support and to build resilience. The addition of family fun days and support for parenting could strengthen relationships between the family members.

Peer support programs such as ON FIRE are key interventions that health services can implement to support children/adolescents in families with mental illness. These programs

are important referral services for nurses and other health professionals in schools or inpatient and community health settings, who are working with mental health consumers who are parents of dependent children, and/or working with children/adolescents in families with mental illness. There is a lack of evidence on the ongoing effects of peer support. Longitudinal research that follows up peer support participants, and investigates the long-term impact of peer support in young people’s lives, is recommended. Further research into the impact of social networking in peer support, the specific resilience characteristics enhanced by peer support, and the effects of peer support on other family members (e.g., parents and siblings) would add to the emerging evidence base on peer support programs.

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