

The SMILES Program: A Group Program for Children With Mentally Ill Parents or Siblings

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The Simplifying Mental Illness + Life Enhancement Skills program, for children with a mentally ill parent or sibling, is a 3-day program that aims to increase children's knowledge of mental illness and to better equip them with life skills considered beneficial for coping in their family. Self-report data from 25 children who attended 3 of these programs, in Canada and Australia, indicate that these aims were achieved. Their parents also report benefits for their children.

The lifetime prevalence of mental disorders in adults has been estimated to be somewhere between 50% and 60% (cf. Mordach & Hall, 2002), and about half of all adults with a mental illness care for a child (Gopfert, Webster, & Seeman, 1996). In Sweden, up to about a third of adults admitted to a psychiatric hospital have children under the age of 18 (Ostman & Hansson, 2002). In Australia, Cowling, McGorry, and Hay (1995) have estimated that there may be 27,000 children who have a parent with a serious mental illness.

The needs, however, of children with parents who have a serious mental illness (e.g., psychosis) have for a long time been underrecognized. Mordach and Hall (2002) considered that current research has failed to focus on issues from the child's perspective. Understanding the child's perspective is important, given that research has shown that, often, such children manage to hide their feelings and have misconceptions about their parent's illness (Marsh & Dickens, 1997). These children have been shown to have worries specific to their family situation—concerns

such as whether they, too, will develop the same illness as their parent, whether their parent will need to be in hospital permanently, and whether they are the cause of their parent's mental health problems (Gerace, Camilleri, & Ayres, 1993; Marsh, Appleby, Dickens, Owens, & Young, 1993). Despite such specific concerns, there is evidence that the psychological needs of children of mentally ill adults are often not met. Caton, Cournos, Felix, and Wyatt (1998) found that only half of their sample of 39 offspring (aged between 13 and 48) of psychiatrically ill parents had ever spoken with a health professional about their parent's illness, whereas Ostman and Hansson (2002) found that just over half of the well spouses in their sample considered that their child needed further professional support related to the other parent's mental illness.

The issue of support for these children is therefore paramount. As with many ongoing stressors, individuals are reluctant to disclose their family situation to others for fear of the attached stigma. This results in a sense of isolation for the child, and the burden of responsibility for dealing with the day-to-day difficulties of having a mentally ill parent can often rest solely with the child or his or her siblings. The argument for supportive services to help these children, and their families, has understandably therefore been raised. Byrne et al. (2001), in a Canadian study of families with a parent with an affective disorder, found that many of the participants wanted their whole family involved in the treatment, not just the adult with the illness.

In a review of services and studies provided for this population, the Australian Infant, Child, Adolescent and Family Mental Health Association (2001; AICAFMHA) summarized the recommendations of previous reports. These recommendations include providing the child with education regarding mental

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We thank Mental Illness Education—Australia (New South Wales) Inc. for their administrative support over many years, Fairchild Australia Proprietary Ltd. for their generous donations, and the following services who were involved in the delivery of the SMILES program in their areas: Fairfield Mental Health Service, New South Wales; Orange Community Health Service, New South Wales; CLSC Lac-Saint-Louis (Montreal, Quebec, Canada).

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illness and helping children develop resilience and coping skills. Similar practice guidelines are given by the Royal College of Psychiatrists (2002).

Luntz (1995); Cowling (1999); Hinden, Biebel, Nicholson, Henry, and Stier (2002); and the British Columbia Schizophrenia Society (2003; BCSS) have reviewed programs that include such aims for children of mentally ill parents. These programs aim to provide support to the child, act as his or her advocate, increase the child's knowledge of the parent's mental illness, and improve the parent-child relationship. Some programs have specific components for separate members of the family, whereas others are focused just on the children. Hinden et al. described five programs in the United States, such as the Invisible Children's Program in Orange County, New York, whereas Cowling (1999) described several Australian programs, such as the Children and Mentally Ill Parents Project (CHAMPS) camp (Cuff & Pietsch, 1997). BCSS (2003) briefly described over 20 programs in Canada, the United States, and Australia. Various positive outcomes have been reported for such programs, including reduced hospitalization of parents, reduced denial of family problems by the children, an increased capacity for the child to share his or her concerns with the group, an increase in the child's knowledge about mental illness, and improved social skills. The outcome details of most programs, however, are only reported in in-house documents rather than in peer-reviewed journals, which can therefore make it difficult for clinicians to access the information. Hinden et al. also discussed the lack of an empirically supported evidence base for many of these services—thus, although most programs may report beneficial outcomes, few have empirical evidence to support their claims. We hope that the information reported in this article, therefore, will supplement that from others and provide empirical evidence that clinicians and the community can use when deciding what is current good practice in helping children with a parent with a mental illness.

Method

Participants

A total of 25 children between the ages of 5 and 15 ($M = 10.8$, $SD = 2.0$), from 18 families, participated in three separate programs conducted in Australia (two programs; $n = 19$) and Canada (one program; $n = 6$). Two thirds of the children were girls, and 11 came from English-speaking backgrounds, with the remainder having a variety of cultural backgrounds (e.g., Vietnamese, Cambodian,

Greek, Sri Lankan). All the children had sufficient command of English to participate in the program, although some required assistance with completing the evaluation measures.

The diagnoses given to the parents by the referring health workers included affective disorders ($n = 17$; a mixture of major depression with or without anxiety disorders or bipolar disorder) and schizophrenia ($n = 8$). For 17 of these parents, the diagnosed disorder had been present for more than 5 years. In addition, 4 children had a sibling with a diagnosed disorder; these were autism ($n = 1$), obsessive-compulsive disorder ($n = 1$), eating disorder ($n = 1$), and one not specified. All these sibling disorders were reported to be for less than 5 years.

Fifteen of the children were living with both their parents, 7 lived with just the parent with the mental illness, 2 lived with their nonmentally ill parent, and 1 lived with relatives.

Program

The Simplifying Mental Illness + Life Enhancement Skills (SMILES) program, designed by Erica Pitman, is for children aged 8 to 16 who have a parent or sibling experiencing a mental health problem (i.e., schizophrenia, bipolar disorder, or depression). If there are sufficient numbers of children, it can be run separately for two age groups (8–12 and 13–16). In the data to be reported, one 5-year-old child participated in the program because her family had two older siblings enrolled in the program and wanted their youngest to be included.

The SMILES program is conducted over 3 consecutive days, from 9 AM to 3 PM, usually during school holidays. The program aims to provide age-appropriate education about mental illness, teach life skills to improve the children's capacity to cope more effectively and increase their resilience, improve the children's self-expression and creativity, increase their self-esteem, and reduce their feelings of isolation. The aims are achieved through education about mental illness, communication exercises, problem solving, artwork, music, interactive and relaxation exercises, and peer support. On the 1st day the activities include family drawings and communication exercises (e.g., the use of pie charts, inner-view exercises), education about mental illness, and exercises to help relax during times of stress. In addition, there are games and singing to add some fun and further avenues for self-expression. On the 2nd day, there is continued education on mental health and illness, together with more communication exercises, stress-reducing exercises, and problem-solving games. On the 3rd day, the activities of the previous 2 days are repeated (with variations), as well as a feelings story to help the children identify and communicate emotions, and information about referral sources in the community. On all 3 days the activities are broken up with age-appropriate games and activities that ensure it is an enjoyable group for the children. For the three programs to be reported, transport was provided for the children to attend. Lunch and refreshments were also

Table 1
Mean Scores on the Knowledge and Skills Measures: Pre- and Postprogram Ratings

Questions	Preprogram		Postprogram		<i>t(df)</i>	<i>r_{pb}</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Knowledge measure						
What is mental illness?	3.7	2.4	7.8	2.1	-7.92 (18)***	.88
What causes mental illness?	2.5	2.4	5.9	2.8	-6.47 (16)***	.85
What is schizophrenia?	2.3	1.9	6.8	4.2	-2.71 (3)†	.84
Signs of schizophrenia	1.6	1.5	5.7	3.1	-4.31 (6)**	.86
What is depression?	4.8	3.3	7.1	3.6	-2.2 (11)*	.55
Signs of depression	4.3	3.6	7.5	3.4	-3.73 (16)**	.68
What is bipolar disorder?	1.8	1.9	6.6	3.7	-4.24 (8)**	.83
Signs of bipolar disorder	1.3	2.5	5.5	3.6	-4.16 (9)**	.81
What treatments help?	3.6	3.0	7.1	3.1	-4.83 (15)***	.78
Life skills measure						
Ability to talk with people	6.6	2.9	8.3	2.1	-3.70 (17)**	.67
Ability to listen to other people	7.2	2.7	8.9	1.7	-3.05 (17)**	.59
Ability to express good feelings	7.7	2.5	9.4	1.2	-3.90 (17)**	.69
Ability to express bad feelings	4.0	3.0	6.1	3.4	-2.85 (17)*	.57
Ability to recognize my strengths	6.7	2.5	8.4	1.6	-2.99 (17)**	.59
Ability to be creative	7.9	2.7	9.2	1.7	-2.03 (17)†	.44
Ability to solve problems	5.4	2.7	7.4	2.7	-3.77 (17)**	.67
Ability to relax	6.2	3.1	7.8	2.4	-3.50 (17)**	.65
Ability to feel good about myself	6.8	2.8	8.4	2.3	-3.34 (17)**	.63
Ability to have fun	9.2	1.5	9.9	0.6	-2.40 (17)*	.50

Note. Ratings range from 1 to 10. On the knowledge measure, scores ranged from 1 = *I know nothing at all* to 10 = *I know everything there is to know*. On the life skills measure, scores ranged from 1 = *I find it very hard to do* to 10 = *I find it really easy to do*. *r_{pb}* values of 0.3–0.49 indicate a moderate association, values of 0.5–0.69 indicate a substantial association, and values of 0.7 or more indicate a very strong association.

† *p* < .10. * *p* < .05. ** *p* < .01. *** *p* < .001.

provided each day. The program was provided free to the participants.

For the program conducted in Canada, the parent with a mental illness also participated in a parent program at the same venue. On the 3rd day, the children and parents combined for lunch and discussion.

Measures

A measure of the children's knowledge of mental illness was constructed for this program (the *knowledge measure*). This consisted of nine questions (e.g., "What causes mental illness?"; see Table 1), in response to which each child rated the amount he or she felt confident of the answer to the question on a 10-point scale (from 1 = *I know nothing at all* to 10 = *I know everything there is to know*).

A similar set of 10 questions was also constructed for this program, which asked about the child's ability to use various life skills (the *life skills measure*; e.g., "My ability to solve problems," "My ability to feel good about myself"; see Table 1). They also rated these on a 10-point scale (from 1 = *I find it very hard to do* to 10 = *I find it really easy to do*).

A daily child's feedback form also asked about what the children liked or did not like about the program and about

what they felt they had learned. At the end of Day 3, the form also included the following: "What else would have helped you?" and "Sometime later you may feel you want to talk with someone. If you feel the need to do this, list some people you know you could contact to help you."

There was also a parent's feedback form, with open-ended questions about benefits, changes, concerns, or additional comments they had regarding their children attending the program.

Procedure

Erica Pitman facilitated each program, with one or two cofacilitators from the different services participating on a train-the-trainer basis. Children were referred to the program by their parent's caseworker.

The knowledge and life skills measures were completed by the children at the start of the 1st day (preratings) and again at the completion of the program (postratings). Facilitators gave assistance in completing these by reading out the questions and explaining the 1–10 scoring system. They did this to ensure the validity of the responses for those children who might otherwise have had difficulty understanding how to complete these instruments. In addition, the postscores were made on the same sheet as the prescores.

We deliberately chose this method, even though a more usual procedure in program evaluation is to ask respondents to make postintervention ratings blind to their preintervention ratings. We chose this method for two reasons: (a) The short pre-post time interval of 3 days would not be long enough to be confident that the children had forgotten what their preratings had been; therefore, if a separate form had been used for the postratings, this would incorrectly assume that the respondents were blind to their pre-ratings. (b) We considered it important that the children make their postrating knowing what their preratings had been, so that if they felt they now knew more, or less, they could ensure their rating truly reflected this situation. This reduces the problem that could be caused by not knowing what the reliabilities of the two measures are (knowledge measure and life skills measure)—a difference score between the pre- and postratings can therefore be interpreted more confidently as a real difference and not a random fluctuation around the true score.

The child's feedback form was completed by the children at the end of Days 1 and 2 and again at the end of Day 3 with the additional two questions. The parent's feedback form was mailed to the parents approximately 2 weeks after the end of the program.

Results

Of the 25 children, 17 attended all 3 days of the program, with the remainder attending 2 days. Reasons for missing a day included illness, previous commitments, and parental illness that required the child to help run the family business or look after the parent.

Related *t* tests were used to assess any changes from preratings to postratings on the knowledge and life skills measures, and the results from these are shown in Table 1.

On eight of the nine self-report questions concerning the child's knowledge of mental illness there was a significant improvement by the end of the 3-day program. On all of the questions regarding life skills there was also significant improvement in children's self-ratings. The point-biserial correlation coefficient (r_{pb}) values indicate that these changes were not only statistically significant but also clinically significant (Matthey, 1998). Inspection of Table 1 also shows that for some questions there were considerable missing data. This was primarily due to the children not attending either Day 1 or Day 3 and occasionally due to a participant failing to answer that question.

The children's feedback form indicated that all the participants felt the program was helpful. Some of the comments written by the children in response to the question about what they liked most or what were the things they had learnt were as follows: "I know a lot

more because Erica [the facilitator] has explained lots of things I was worried about"; "It was really fun and everyone was enveloped [sic]"; "I am not the only one who has a family member who is sick. It's not Dad's fault"; "It was fun doing the card and drawing [sic]"; "I liked the games and meeting new people"; "I learnt that mental illness can't be caught like a cold. And people with schizophrenia [sic] can hear things and see things that aren't real and they have delusions [sic] and hallucinations [sic]"; "I learnt that friends are very important to us and some people with mental illness can lose or get weight"; "I have told other children who don't know what they are talking about what depression really means"; "I learned a lot of problem solving at home"; "I learnt that it's [mental illness] not our fault"; "It was good cause now I can express my feelings [sic] more—thanks!"; "I learnt that illegal drugs don't help"; and "I learnt that you can call Kidhelp Phone instead of talking to your parents, if your [sic] shy."

The majority of children indicated that there wasn't anything they didn't like about the program. There was the occasional comment about not liking the food, singing, writing, meditating, or the hot weather (at the Australian site). The few additional comments about things children disliked were as follows: "Rest time in the afternoon and having to leave"; "Filling in sheets"; "The fact that I'm the eldest"; "Embarrassed when I first arrived, cause [sic] there weren't any little people" (from the 5 year old); "Sitting to [sic] long"; and "When we have to listen to people talk about their mother." The majority of children indicated that either there wasn't anything else that would have helped them or they didn't know. Some of them indicated that they would have liked a 4-day or even longer program. The additional comments about further things that would help were "How to deal with death [sic: death]" and "To get more attached to my dad."

Only 7 of the 18 families returned their feedback forms (10 forms returned—three couples completed a form each). All of these felt the program had been helpful for their child. Their comments about benefits, learning, and changes included the following: "The program gave the children a real insight into the hows and whys of depression at a level they could understand"; "[My son] has adopted a caring attitude that notices when I am feeling worse. He knows when to advise me what to do sometimes"; "The program was excellent and met [my son] where his understanding was"; "[My son] has a less frustrated attitude at what I can't do"; "The student, through this education program, is able to become more tol-

erant and open-minded and less judgemental. Through guidelines learnt, [my daughter] has the ability to listen, observe and recognise symptoms associated with mental illness. By recognising symptoms she has helped others"; "The program has also given to this family, a sense of belonging without pre-judgement"; "This is the first time we've been able to discuss mental illness as a family"; "[My daughter learnt] how to deal with her emotions/feelings more effectively"; "Great benefits. He is aware now of what mental illness is, what side effects the medications have and knowing that mental illness is like any other illness and not terminal—I think he feels quite relieved"; "We started understanding each other in many different ways"; "More understanding of her sister's difficulties and how normal it is to become frustrated at her and our life"; "[My daughter] seems to be calmer"; and "He also understood that he should express his feelings and thoughts more openly."

Additional comments from the parents included "Would like to share the experience with other children in the family"; "Both parents and children should participate. Really should not be optional for parents. Would be good to have lunch with the children and more for the parents in the afternoon" (Canadian program); and "We missed a day of the program because we didn't know about it. This would have been good for them to attend."

This study has several limitations that need to be recognized in an interpretation of the data. The knowledge and life skills measures were constructed for this program, and the psychometric properties of the instruments are not known. However, the positive comments by the children correspond to the improvement in their ratings and indicate that the measures have, therefore, a reasonable degree of validity. Another limitation is the lack of a control group—thus, the changes observed could be due to factors other than the participation in the program or could be due to nonspecific factors inherent in attending any program or service. There is also the consideration of demand characteristics intrinsic to any evaluation of a service provision—the children may have felt the need to report improvement on the items at the end of 3 days, regardless of how they actually felt. If such a demand characteristic is operating, it is obviously made easier because the participants are allowed to see their ratings to each question from the start of the program. However, as stated, without knowing the reliabilities of the instruments and given the shortness of the pre-post interval (3 days), we considered it better to adopt this procedure than presume blind

ratings. We accept, however, that this methodology is open to debate.

As with all programs, there are also issues to do with the representativeness of the sample—the children who attended the groups may be different from those who do not wish to attend such programs or who have families who do not want them to attend. Thus, we cannot say whether the SMILES program is suitable for all children with a parent with a mental illness. Also, the low response rate to the parent's feedback form means caution should be applied to these findings. We have no way of knowing whether those who did not respond felt as positively about the program as those who did respond.

Discussion

Given the caveats stated above, however, we believe that the positive comments by the children, together with supporting comments from their parents, are strong indicators of the benefits of the program. These comments also confirm that the positive changes on the knowledge and life skills measures are likely to be due to the content of the program and not to changes occurring naturally over 3 days, nor to demand characteristics.

Of interest are the longer term benefits of such a program. Given that for many children their parents will continue to experience the mental illness, future investigations should examine the resilience-building effects of children attending such a program as this. A longitudinal study that investigates whether attendance at such programs helps the children in the long-term would need to be funded if we are to truly tease out the best possible service that we, as health professionals, can give these children and their parents. Luntz (1995), in her review of various programs in America, described some that are of a long duration (e.g., some Michigan programs run for 2 years) and others of much shorter duration (e.g., programs in Ohio run for between 8 and 20 weeks). The comparative effectiveness of programs of differing lengths needs to be investigated—it may be that each type of program provides different kinds of benefits to the children and parents. It is clear that a lot more empirical work needs to be done, and reported, if we are to make informed decisions about what services to provide these families.

We hope that this information is a platform for others to evaluate their work in this field. We consider such evaluation attempts to be important for several reasons: (a) the preassessments provide clinically useful information that can improve the work

done during the program (e.g., focus on areas on which participants report low knowledge rather than stick to a prescribed format that may not be suitable for all groups), (b) understanding of the quantitative and qualitative evaluation components allows adjustments to be made to the program for future participants, (c) it provides potential future participants with information about the history of the effectiveness of the program, which should help them in deciding which service is most likely to provide them with benefit. This latter point is rarely made in mental health services, but we feel it is important if members of the community are to make an informed choice as to whether to avail themselves of services presumed to be helpful. And, finally, the importance of the data reported for this SMILES program should be seen in the context of the paucity of published empirical evidence from other programs. Although the AICAF-MHA (2001) scoping report states that 30 of 44 programs in Australia included some form of evaluation, there is no information as to what such evaluations showed for the different programs. This message about the need for empirical evidence for the benefits of local programs is also clearly given in the review of American programs by Hinden et al. (2002), whereas the overview of American, Canadian, and Australian programs given by the BCSS (2003) shows how difficult it can be for clinicians to access empirical data to help them decide on the comparative effectiveness of programs currently being run. Given that few such programs have been published for public access, it is therefore difficult for workers to use an evidence-based approach when trying to meet the needs of these children unless this information is described.

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Received July 30, 2002

Revision received April 18, 2003

Accepted April 23, 2003 ■