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## ***When your parent has a mental illness: children's experiences of a psycho-educational intervention***

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Psycho-education is a key component of interventions for young people who have a parent with a mental illness. *When your parent has a mental illness* is a psycho-educational booklet designed for young people, developed by the Australian Children of Parents with a Mental Illness (COPMI) national initiative. The booklet aims to promote young people's understanding of their parents' mental illness. This pilot study sought to ascertain possible differences in knowledge of mental illness after the young people viewed the booklet; another aim was to obtain young people's feedback on how they used the booklet. A mixed methods research design was employed. Nine participants between 12–15 years of age completed the Children's Knowledge Scale of Mental Illness questionnaire before and after reading the booklet. Five of these participants then took part in follow-up interviews. No significant change was recorded on the Knowledge Scale. In the interviews, young people indicated that the booklet helped them initiate conversations with their parent about the parent's illness. Results tentatively indicate the effectiveness of the booklet as a psycho-educational resource for young people whose parent has a mental illness. Implications for practice and future research in this area are discussed.

**Keywords:** children; parental mental illness; psycho-education; intervention; knowledge; education

### **Introduction**

Young people living in families where a parent has a mental illness are at higher risk of acquiring social, emotional and behavioural difficulties, compared to their peers (Leschied, Chiodo, Whitehead, & Hurley, 2005). At the same time, not all children will be adversely impacted by parental mental illness, nor will all children in the same family be affected in the same manner (Reupert, Maybery, & Kowalenko, 2012). Children vary in their ability to cope with their environment. Some children can cope well (Sheehan, 1997), and have the opportunity to access functional social supports (Edwards, Eiden, & Leonard, 2006), while others appear to cope less well (Mordoch & Hall, 2008). This pilot study explores the utility of a psycho-educational tool for these children, as a preliminary way of establishing some of the issues that may be involved in a full-scale evaluation study.

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There is much that can be done to prevent the intergenerational transmission of mental illness in families. Siegenthaler, Munder, and Egger (2012) systematically reviewed 13 randomised controlled trial studies of interventions for families with parents who have a mental illness. They found that interventions, which commonly include cognitive, behavioural and psycho-educational components, have the potential to decrease children's internalising behaviours and reduce the likelihood of young people acquiring their own mental illness by 40%. There are also additional interventions which target other impacts of living in a family where a parent has a mental illness such as family breakdown (Oram, Trevillion, Feder, & Howard, 2013), substance abuse problems (Reupert, Goodyear, & Maybery, 2012) and socio-economic disadvantage (Eaton, Muntaner, & Sapag, 2010; Murali & Oyeboode, 2004).

Notwithstanding the importance of these potential environmental targets for children in families where parents have mental illness, the interventions commonly offered to young people include peer support programmes, online supports and psycho-educational materials such as DVDs or books, each with varying levels of success (Reupert, Cuff, et al., 2012). A common component across these interventions is the provision of information or psycho-education to children about their parent's mental illness (Reupert, Maybery, et al., 2012). Lukens and McFarlane (2004) define psycho-education as psycho-therapeutic and educational information designed to support and empower individuals through a strength-based approach. Psycho-education typically presents biomedical information on the causes, symptoms and treatment of mental illness; it may also incorporate ways that individuals learn to adaptively cope with a mental illness (Lukens & McFarlane, 2004). However, psycho-education activities in reference to children whose parents have a mental illness take on a relatively more nuanced stance by emphasising the importance of talking with, rather than to young people. This means that psycho-educational discussions for this target group of youth are normally interactive and child-led. For example, Reupert and Maybery (2010) describe the manner in which support group facilitators deliver psycho-education through groups or one-to-one discussion, with consideration of the young person's family context and the questions and concerns he or she might have. Gladstone, Boydell, Seeman, and McKeever (2011) concur with these findings when they argue that psycho-education needs to commence with, and incorporate the child's perspective of, their parent's illness.

Alasuutari and Jarvi (2012) propose that children's understanding of their parent's illness is always developing and evolving over time. They argue that young people have prior knowledge or understanding of what is happening for their parent and that this needs to be acknowledged in any given intervention. Accordingly, each child will understand and want information differently; indeed, some may not want any or certain kinds of information about their parent's illness (Gladstone, McKeever, Seeman, & Boydell, 2014). Through the narratives of two young people, Gladstone et al. (2014) showed that the use of medical discourse as the only or primary source of information about parental mental health problems may not be helpful. Gladstone et al. (2014) concludes by questioning whether the information provided to young people in these families can or even should be standardised.

There have been some, albeit few, psycho-educational materials that have been developed for these young people and subsequently evaluated. Grove, Reupert, and Maybery (2013) examined the impact of a DVD, called 'Family Focus'. The DVD provided young people with information through stories of other families living with a parent who has depression and/or anxiety and encouraged them to seek help if required. A significant increase in young people's mental health knowledge was reported post-DVD viewing, though no changes were found in help seeking behaviours. In follow-up interviews, youth indicated that while they might talk about their parent's illness within the family they would be unlikely to share such information outside their family because 'it's not [about] me, it's my mum ... it's her personal life and [her] information to share' (p. 7).

Given that psycho-education is a common element across interventions for children of parents with a mental illness, it is critical to examine the utility of psycho-education as an intervention. The current study aims to establish, from the young person's perspective, how a psycho-educational intervention (booklet) for youth whose parents have a mental is experienced. A mixed methods sequential design was employed to determine young people's experience of a psycho-educational booklet, which provided different types of information about parental mental illness along with suggestions regarding coping strategies and help seeking. Specific research aims were to:

- (1) examine possible changes in knowledge acquisition pre and post-intervention and
- (2) elicit young people's feedback on how they used the booklet.

## Methodology

Ethical approval for this study was provided by the relevant university committee.

### Research design

A mixed methods sequential design was employed using a mental health knowledge questionnaire, before and after youth viewed the booklet, followed by in-depth individual telephone interviews. This method follows a sequential approach by collecting one type of data (e.g. quantitative) and then another data type (e.g. qualitative) (Creswell, 2009). The quantitative approach in this study provides pre- and post-data to examine any specific change (knowledge) after young people read the booklet. In contrast, the qualitative approach seeks to conceptualise young people's experience of the booklet, through the interpretation and construction of themes extracted by the researcher from interview data (Creswell, 2009). Both methods provided different though complementary perspectives of young people's experience of the booklet and the sequential design was thus considered an appropriate methodology to address the research aims.

### Intervention development

The booklet, *When your parent has a mental illness*, was developed by the Children of Parents with a Mental Illness (COPMI) national initiative. The development of the psycho-educational intervention commenced with a review by the COPMI national initiative of current information resources for families where a parent has a mental illness and the identification of a lack of available resources for young people in Australia and overseas. This initial review, undertaken in 2010/2011 was conducted online and found few English publications for children of parents with a mental illness. There were also some resources identified from Finland and others in North America that had not been released publically. These materials were then reviewed by the COPMI National Lived Experience Forum, a national reference group consisting of parents and young people (between 17–25 years). As well, five focus groups were facilitated in partnership with peer and carer programmes from rural and urban regions in Victoria and South Australia with 27 young people (11–21 years old) to further elicit key messages and content. The various groups reviewed the design and tone of existing resources and identified gaps in content. This review was followed by telephone interviews with an additional 11 young people to identify the important messages and information to include in the resource. The findings of this review and consultation were developed into online content presented on the child and youth section of the COPMI national initiative website ([www.copmi.net.au](http://www.copmi.net.au)). An advisory

group consisting of 12 family members assisted in refining the online content into the booklet, *When your parent has a mental illness*, with young people. Finally, two draft revisions were reviewed by the advisory group and mental health professionals from adult and child mental health services.

#### When your parent has a mental illness

*When your parent has a mental illness* is a 40-page booklet designed for young people (12–15 years) who have a parent with a mental illness. The booklet includes information about different types of mental illness, treatments and supports and ideas about how to talk with parents, other adults or services. The booklet also provides guidance and links to resources that can assist young people when they may be worried about their parent or when they have concerns about their own well-being and safety (websites, helplines and support services). The design of the booklet was informed by children and young people who indicated that they wanted information communicated through fast facts and advice, quotes from other young people, descriptive content and engaging graphics and photography. Space to write personal reflections and questions were also included.

#### Procedure

Various mental health agencies across Australia were asked to electronically disseminate an information flyer to parents and young people in families where a parent has a mental illness. The flyer was also posted in public spaces such as in hospitals, supermarkets, universities and libraries, advertised on a website designed for children of parents with a mental illness and via Facebook through ‘open’ groups relevant to parental mental health. Inclusion criteria were young people aged between 12–15 who had one or more parents who were currently in (or had just completed) treatment for a mental illness. Interested participants (either parents or young person) registered their interest through a web link with their preferred contact details. Both young people and their parents provided written consent to take part in this study. Researchers contacted interested participants by mailing a research information pack (this included an explanatory statement, consent forms, pre–post-questionnaire and the booklet) with pre-paid reply paid envelopes. A total of 17 children’s packs were mailed to prospective participants and 10 were returned to the researchers, a return rate of 58.8%. Children were instructed to wait a minimum of one week after reading the book before completing the post-questionnaires. The interval between doing the pre-survey and reading the booklet was not recorded or asked. One questionnaire was removed during data cleaning, due to several invalid questionnaire responses.

#### Participants

Nine young people between 12 and 15 years old completed the Children’s Knowledge of Mental Illness questionnaire before and after reading the booklet and of these, 5 completed telephone interviews. [Table 1](#) presents participant demographics.

#### Measures

The Children’s Knowledge of Mental Illness questionnaire was completed before and after young people read the booklet, along with a self-constructed, satisfaction questionnaire completed after young people viewed the resource.

Table 1. Demographics of participants who completed questionnaires and interviews.

Demographics	Questionnaire participants ( <i>n</i> = 9)	Interview participants ( <i>n</i> = 5)
Age		
Mean	13.2	13.0
Range (SD)	12–15 (1.09)	12–15 (1.22)
Gender		
Female	4 (44.4%)	3 (60.0%)
Male	5 (66.6%)	2 (40.0%)
Parental diagnosis <sup>a</sup>		
Post-traumatic stress disorder	0	1 (15%)
Major depressive disorder	0	1 (14%)
Depression	3 (33%)	1 (14%)
Anxiety	0	1 (14%)
No response	6 (67%)	
Maternal diagnosis		
Borderline personality disorder	1 (11%)	1 (13%)
Depression	3 (33%)	2 (25%)
Post-traumatic stress disorder	0	2 (25%)
Anxiety	1 (11%)	2 (25%)
Bipolar disorder	4 (45%)	1 (12%)
Previous support accessed		
Peer Support Group	2 (22.2%)	1 (20.0%)
DVD	1 (11.1%)	0 (00.0%)
Other support (leaflet about mental illness)	1 (11.1%)	1 (20.0%)
None	5 (66.6%)	3 (60.0%)

\*Diagnosis was self-reported by the parent.

### *Children's knowledge of mental illness*

The Children's Knowledge Scale of Mental Illness questionnaire was designed to identify children's knowledge and understanding of mental illness (Goodyear, Maybery, & Reupert, 2005). The scale contains seven items, for example, 'All people are affected with mental illness in the same way', with instructions inviting participants to circle whether each statement is true, false or don't know. High scores indicate greater knowledge and positive attitude about mental illness. Low scores are indicative of stereotypes or beliefs about people with a mental illness, for example circling true on the item 'Most people with a mental illness are dangerous' (Goodyear et al., 2005). While the measure can be used to assess children's understanding of mental health, it is not specific to children of parents with a mental illness. There is an absence of data within the literature regarding the scale's psychometric characteristics; nonetheless the author reports good face and content validity (personal communication, M. Goodyear, 6 November 2012). At the same time, it needs to be acknowledged that there are many different types of knowledge about mental illness (Gladstone et al., 2014), which may not necessarily be captured by the use of a single questionnaire.

### *Satisfaction questionnaire*

A satisfaction questionnaire was developed in consultation with staff from the national COPMI initiative. The questionnaire invited participants to provide ratings on a five-point scale on nine statements that aimed to gauge children's impressions of the booklet, for example, the booklet was interesting. See Table 2 for the nine statements asked in the booklet evaluation questionnaire.

Table 2. Frequency statistics for the booklet evaluation questionnaire.

Question	Yes, very interesting	A little interesting	Not interesting or boring	A little boring	Really boring
1. The booklet was interesting	5 (55.6%) Yes, totally agree	3 (33.3%) Agree a bit	1 (11.1%) Neither agree or disagree	0 Disagree a bit	0 Really disagree
2. The booklet helped me understand about mental illness	7 (77.8%)	2 (22.2%)	0	0	0
3. The booklet gave me some ideas about how to cope better	5 (55.6%)	2 (22.2%)	2 (22.2%)	0	0
4. I would consider talking to my parents about mental illness now	4 (44.4%)	3 (33.3%)	1 (11.1%)	1 (11.1%)	0
5. The booklet helped me understand my parent and their behaviour better	5 (55.6%)	3 (33.3%)	1 (11.1%)	0	0
6. The booklet made me feel better about my parent's mental illness	3 (33.3%)	6 (66.7%)	0	0	0
7. The booklet helped me realise that many young people have a parent with a mental illness	5 (55/6%)	3 (33.3%)	1 (11.1%)	0	0
8. I feel that I can talk to someone about my parent's mental illness now	3 (33.3%)	3 (33.3%)	2 (22.2%)	1 (11.1%)	0
9. It is okay to have positive and negative feelings about my parents	6 (66.7%)	3 (33.3%)	0	0	0

### *Semi-structured interviews*

Semi-structured interviews were used to broaden and explain the questionnaire data and further explore young people's experiences of the booklet. The interview schedule was developed by the researchers and was based on a literature review and the research aims. Questions were broad, such as 'how did you find the booklet?' and 'what did you do after reading the booklet?' Interviews were conducted over the phone at the main researcher's university. Each interview ranged between 30 and 40 minutes. With participant consent, all interviews were audio-recorded and subsequently transcribed.

### *Data analyses*

#### *Quantitative analyses*

The questionnaire data were analysed with the Statistical Package for Social Sciences (SPSS Inc, Released, 2009. PASW Statistics for Windows, Version 18.0. Chicago: SPSS Inc.). Paired sample *t*-test was utilised to identify changes in young people's knowledge of mental illness after using the booklet. Frequency statistics were used to analyse and explore young people's responses to the booklet satisfaction questionnaire.

#### *Qualitative analyses*

Data analysis of interview transcripts proceeded through a thematic analysis approach whereby the researchers searched the data for common threads that extended across each interview. The six-step approach advocated by Braun and Clarke (2006) was employed to identify, analyse and report patterns or themes within the data. Inherent within this approach is an acknowledgment that themes are subject to the researchers' interpretation of the phenomenon being studied

(Green et al., 2007). Sandelowski (2010) speaks further on this when she suggests that ‘data never speak for themselves’ and ‘that researchers make something of their data’ (p. 79). In this study, the first researcher used an electronic notebook to document analysis procedures, decisions and memos, and code definitions to increase the likelihood of consistent coding and analysis (as per Saldana, 2009).

## **Findings**

### ***Questionnaire results***

#### *Children’s knowledge of mental illness*

A paired sample *t*-test analysis was used to compare young people’s knowledge of mental health before and after young people used the intervention. The analysis showed that young people’s knowledge of mental illness did not improve after using the booklet (pre  $M = 10.88$ ,  $SD = 4.25$ ; post  $M = 12.88$ ,  $SD = 2.26$ ). There was not a significant increase in mental illness knowledge ( $t(8) = -1.37$ ,  $p > .05$ ).

#### *Satisfaction questionnaire*

Overall, a majority of the sample found the booklet to be interesting (88.9%) and informative about mental illness (100%) (see Table 2). The booklet provided most participants ideas for coping (77.8%), and helped them understand their own and their parents’ behaviour (88.9%). After reading the booklet, most participants felt they could talk to their parents or someone else about their parent’s mental illness (77.8% and 66.7%, respectively). All participants either ‘agreed’ or ‘totally agreed’ that the booklet helped them feel better about their parent’s mental illness (66.7% and 33.3%, respectively). Most realised that they were not the only one who has a parent with a mental illness (88.9%), and all participants felt it was okay to have positive and negative feelings about their parents.

### ***Interview findings***

The following themes and subthemes as summarised here related to young people’s experiences and outcomes of reading the booklet.

- Knowledge about parental mental illness;
  - feeling not alone;
  - understanding parental mental illness;
  - accepting the parent’s mental illness;
- Ways of seeking support;
  - coping;
  - talking with parents;
- Resource accessibility.

Each theme presents participant quotes using different pseudonyms (i.e. ‘Meg’ or ‘Tricia’).

### ***Knowledge about parental mental illness***

#### *Feeling not alone*

Four of the five young people interviewed indicated that the booklet showed that they were not the only young people living in these families, with Tricia reporting ‘other people go through it, it’s not just you’ and



Knowing that my family's not the only one going through the same thing ... I thought it was interesting because I was learning about what my mum and dad have; what other people have, other people's parents have ... [it] just shows kids that they're not alone, other people's families have it too. (Lois)

Feeling not alone was a result of being able to identify with the stories and families presented:

There was a lot of information telling you about everything and it gave you examples that other families are going through the same thing (Lois)

Also, Chris connected to the similar experiences of other children:

The best bits were probably the kid bits, kid's stuff ... I could understand that more and so it was – I thought fit in a bit more, so I could relate to it easier

### *Understanding parental mental illness*

All participants described learning more about their parent's mental illness:

I know a lot more about the different things now and I think it's easy to understand why people do the things they do now that I understand more information about it. (Lois)

... it's stuff I didn't really know, like depression and stuff like – you hear voices and sometimes you can't sleep; I didn't know much about that. (Kenny)

Meg appreciated clarifying the myths she had previously held:

I liked the little fact things ... they were really fun to read, most of them I didn't know. I learnt something new. Before (reading the booklet) I'm like to mum, 'can you catch illnesses like a cold?' ... and yeah, I read it in here, and you can't. I didn't know, it was just really interesting.

However, one participant reported that he already knew information about mental illness before taking part in the study and accordingly, found some aspects of the booklet boring:

It was interesting but some bits were boring because I already knew a lot. Most of the interesting bits were learning about the other disorders ... the depression and anxiety bits I already knew most of that stuff (Chris)

### *Accepting the parent's mental illness*

As a result of reading the booklet three young people reported that they felt an acceptance about their parent's illness:

It's just telling you what mental disorder is and it's nothing to feel bad for ... there's nothing wrong with it, it's just something you need to carry on with ... it's still the same person, there's nothing wrong with that person, it's just-they're not the same, they just sometimes might get upset ... you've just got to deal with it and help your parents out. (Kenny)

Similarly, the booklet helped Meg understand her mother:

Now I know what bipolar disorder is, and I know what mum's like. It's not that bad, like every now and again she gets a bit cranky but who doesn't. And she gets tired, then who doesn't?

**Ways of seeking support***Coping*

Three children identified specific coping strategies that they learnt as a result of reading the booklet, in relation to managing or supporting their parent:

I learnt how to deal with it. Like, if they're feeling stressed and stuff, just make mum a coffee, tea and then that makes her happier; and then give her hugs and stuff. (Meg)

I think I know more to do now than I used to; when mum and dad are angry or something ... It gave stuff that you can do if you could help out, make dinner, stuff like that. Just to get them to calm down and stuff ... help out around the house so they're not as stressed. (Lois)

*Talking with parents*

The booklet provided young people with the language and opportunity to initiate conversations within their family about parental mental health, for example one participant reported:

INTERVIEWER: Do you think you'll talk to anyone about the booklet?

Lois: Depends if I'm going through anything or not ... my parents, my sister, or maybe my best friend ... they're the closest people to me and they know the most about what I'm going through ... only if something comes up, if something happens.

Tricia strongly argued that these conversations were best held with her mother:

INTERVIEWER: How would you prefer to hear about this information (in the booklet) if you wanted to find out more about it?

Tricia: From my mum. I think that kids should be told by the parent who has it ... they can explain it. It's better than having to go to someone else who might not know enough about it.

Similarly, Meg suggested that the booklet provided an opportunity to talk to her mother

My favourite part of the book was when I was reading through all the kinds of different disorders, and talking to mum about them, and it was like, really cool because I could spend time with her ... and she understood and stuff. And like we used it to talk about this stuff.

Meg continued by describing how talking about the booklet with a parent might benefit the parent-child relationship:

[A section in the booklet] says they [parent] might – they can – judge themselves. I really liked going through that with mum, and saying 'You're not yourself'. She really enjoyed it apparently, and some of the fact trivia, she liked it too.

**Resource accessibility**

The final main theme was around how young people might access the resource: 'I think that kids should be able to access it anywhere so they have access to the book ... so they have to go out and find them' (Lois). Meg suggested that all children should have access to it because: 'I think there's something in here for everyone ... some people might like some things, other people might like

other things'. Meg continued by suggesting that the resource could be made available in schools though cautioned 'You can't force anyone to do anything. If they want to read it, they can read it. If they don't want to read it then it's their issue'. She also considered that students themselves might promote the booklet amongst their peers, 'Or you can say: "I read this book, a normal book. I read this book on the weekend, you should read it too".'

## Discussion

This pilot study sought to investigate potential changes in mental health knowledge for young people after reading the booklet. This study also sought to identify how young people experienced or used the booklet. The findings of this study tentatively suggest that the booklet, *When your parent has a mental illness*, is useful for youth in understanding and affirming their thoughts about their parent with a mental illness and provided young people with a platform to initiate conversations about mental health in their families.

The interview findings did not, however, translate into a significant improvement on the knowledge scale, though scores demonstrate a trend that in a larger sample size might suggest a significant change in knowledge. Future research needs to involve a larger number of participants. In this regard, it is notable that the frequency statistics in the satisfaction questionnaire supported the qualitative findings (see items two, three, four, six and seven) in terms of youth reporting that the booklet provided ideas to cope, gave them an understanding of their parents' behaviour, and that they could talk to their parents about mental health. Youth reported (items six and nine of the satisfaction questionnaire) that the booklet helped them feel better about their parents' mental illness and that it is okay to experience both positive and negative feelings about their parents illness. Such data demonstrate that the resource was acceptable for the young people involved in the current study.

Previous research highlights the need for children to understand their parent's mental illness (Focht & Beardslee, 1996; Focht-Birkerts & Beardslee, 2000), with some youth struggling to cope with their parent's illness-related behaviour (Focht-Birkerts & Beardslee, 2000). Interview findings reported here suggest that the booklet provided young people with information and a new understanding and acceptance of their parent's illness and suggested ideas to cope. Gladstone et al. (2011) propose that young people engage in many ways to help their parent, by providing instrumental and emotional caring activities to reduce family stress, a finding also told in the current study, for example, 'if they're feeling stressed ... just make mum a coffee, tea and then that makes her happier; and then give her hugs ...'. However, it is not possible to ascertain whether these strategies came as a direct result of reading the booklet.

According to the interview data, the booklet provided an opportunity for young people to initiate conversations with parents about the parent's illness. The booklet appears to be used by youth as a platform or an aid for young people and their families to extend their unique way of discussing parental mental illness. Hence, initiating, creating and sustaining family conversations, through a medium like a booklet, may promote meaningful dialogue and exchange of information between young people and their parents.

On the basis of this study and previous research in this field some practice implications can be made. Practitioners need to be aware that youth want and need information about parent about mental illness (Gladstone et al., 2014). Practitioners might use tools such as the booklet, *When your parent has a mental illness*, to assist young people in initiating conversations about mental health in their family. Resources, for example this educational booklet or a DVD, need to be readily available in places where young people and their parents congregate, including schools or community centres. As suggested by the young people interviewed here, the use of peers to promote the booklet might be further investigated. As social media provides a forum

for young people to share their thoughts and experiences with like-minded young people (Collin, Rahilly, Richardson, & Third, 2011) booklets such as this one might also be available on the Internet and serve as a possible prompt for further discussion and reflection.

A limitation in this pilot study is the small sample size and the use of non-standardised measures. Additional research might develop a standardised scale to assess young people's knowledge of mental illness with a particular focus on the types of knowledge that young people living with parental mental illness might want or need to know. Future research might extend the preliminary findings of this study to investigate the impact of psycho-education and how knowledge resources such as this booklet might be used in families of parents with a mental illness. The perspectives of other family members, especially parents, might be explored in reference to using the booklet to initiate family conversations. Another focus might be to investigate when young people have conversations with their parent, for example in crisis times such as hospitalisation. More generally, how young people use knowledge about parental mental illness and what kind of information they do or do not need, is an avenue of further research.

The *When your parent has a mental illness* booklet provides information to young people about mental illness, along with suggestions regarding coping strategies. The study adds to the limited available research about psycho-educational knowledge for children whose parent has a mental illness. More specifically, the study demonstrated that the booklet could be used as a tool to support young people to initiate conversations and discussions about mental illness with their parents.

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