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

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CHAPTER 8

Summary and general discussion

The primary aim of this thesis and its related research project was to develop and evaluate a new intervention for 12 to 24 year old children with a mentally ill family member, i.e. children with an increased risk to develop a mental illness themselves. We tried to achieve this by creating an intervention that is more accessible and better tailored to young people than existing interventions for this group. We developed an online intervention that takes into account the experiential expertise of youngsters living with a parent with a mental illness.

Overview of the chapters

Chapter 1 provides the background for the studies presented in the thesis. In the literature review in chapter 2 we search for the strengths that children reported to develop when living with a family member with a mental illness and the resources they said to appreciate. In chapter 3 we describe the development of an online preventative intervention for the target group. Chapter 4 gives an account of the reach, after implementation, of this intervention. In the chapters 5 and 6 we present how visitors in general, and one visitor in particular, used the intervention. The study described in chapter 7 reports on priority research areas in the field of families affected by mental illness. In this final chapter 8, the findings and their implications for future research and clinical practice are discussed.

Youth's experiential expertise

Although the appreciation for the situation of children living with a mentally ill family member is growing (Gladstone, Boydell, Seeman, & McKeever, 2011), most of the studies about experiences of children from mentally ill parent were not specifically designed to identify children’s strengths or resources. Instead, they focussed more generally on the negative experiences of the children with their mentally ill parents. In our literature review (Chapter 2) on those reports, we showed that these children also mention to have developed several strengths when coping with their relative’s symptomatic behaviour, even without being explicitly asked to do so. Examples of the reported strengths were empathy, independence, and creativity. In addition, children were able to indicate which support would be attractive for them. When living with a mentally ill parent, information and social support, particularly support from a mental health-care professional, were regarded as most helpful.
Better knowledge about the special abilities that these children can develop in the process of living with a mentally ill family member may provide important clues for professionals in their approach of these children. Helping children to identify their strengths may enhance their self-esteem.

An online intervention for young people with a mentally ill family member

Supported by website builders with expertise in creating child-friendly websites, we developed the website ‘Survivalkid’ (Chapter 3). The website offers privacy and anonymity, is continuously accessible, and gives targeted, easy to read information, psycho-education, and opportunities for social support. To make maximum use of the appeal of social media for young people, we paid extra attention to attractiveness, readability, interaction, and individual choices. The website can be used on demand; youngsters who visit the site do so on their own initiative and at the time of their choice, be it in the middle of the night or when travelling to school or work. Because the chat sessions with peers and a counsellor are open for all site visitors, chat participants can choose when to join a session. This is in line with our aim to address children who actually feel a need for support, but do not instantly wish to seek a face-to-face consultation with an adult professional (Gould et al., 2004).

By approaching them as independent, autonomous adolescents, by helping them to identify their personal strengths and by stimulating peer support exchange, the site promotes the resilience of the participating visitors.

According to the results of a survey among website visitors reported in the same chapter, the chat sessions were the most helpful features of the intervention. However, it should be noted that about 80% of the website visitors were females and that almost all chat participants were girls and young women. Therefore, these findings cannot automatically be extrapolated to boys and young men with a mentally ill family member.

Increased reach

In Chapter 4 we report on the reach of the intervention. In the first three years of its existence, 534 visitors registered to use the restricted pages of the ‘Survivalkid’ website. A majority of the visitors came from the region of the community mental health provider that initiated and hosted the site: 382. This last-mentioned number of visitors is far greater than the six adolescents participating in the preventative face-to-face groups in the same region each year. Increasing the reach in the region has been a major objective of the project. Online support that is regionally offered has the advantage that it can be combined with face-to face help in what is called ‘blended care’, depending on individual abilities, needs, and preferences of the clients (Wentzel, Van der Vaart, Bohlmeijer, & Van Gemert-Pijnen, 2016). For instance, some of the girls who participated in an email conversation accepted the invitation for a face-to-face contact with the counsellor they already had been ‘talking to’ online.

It should be noted, however, that still only a small part of the target group has been reached. Goossens and Van der Zanden (2012) calculated that at least 577,000 Dutch children under 18 years live with a mentally ill family member. About a third of this number belongs to our target group (12-24 years). Although not all of them will need help (Collishaw et al., 2016) and although the numbers reached are a fourfold of the numbers reached by face-to-face approaches, absolutely, we reached only a very small part of the youth we aimed at. This is a matter of concern. It remains necessary to bring the site explicitly to the attention of young people by all kinds of means: leaflets, posters, links from other websites etc. The site should also be updated regularly, both technically and in terms of content, so that it stays attractive for the target population.

Gaining insight into young people’s situation

The online intervention appeared to be a medium through which we could learn more about living with a mentally ill parent, the needs and strengths that are associated with that condition, and the role of the website therein. In the case study (Chapter 5) we analysed the contributions to the website of one female visitor. Her online messages revealed her sense of responsibility, her loyalty, and empathy with her mother and other family members, but also her struggle to find proper help for herself. Five themes could be extracted from the analysis of her chat session texts, they are: (i) unpredictability of life at home, (ii) reluctance to bother others, (iii) the awareness of not leading a normal life, (iv) the resignation of being mother’s helper, and (v) finding a way out by the gradual acceptance of help. They demonstrated clearly the struggle an adolescent can experience while growing up with a mentally ill parent. They further showed how the provided information and online contacts with a counsellor can create the opportunity to reflect upon one’s situation and how peer contacts can be supporting.

Although limited conclusions can be drawn from a single case study, the results
Knowledge needed by professionals

To indicate priority research areas in the field of families affected by mental illness, experts were asked which additional knowledge they needed (Chapter 7). Areas that were mentioned as important were: strategies to implement more family focused services, development of evidence based interventions, and strategies to reduce stigma.

Reupert and Maybery (2016) emphasize that to meet the needs of families with mental illness, it will not be enough just to do more research. They plea for a significant paradigm shift across all levels of policy and service development to ensure that mental health professionals can work with clients and their children in an inclusive, family-centred manner. Parenting status, for example, needs to be a standard intake question and family-sensitive policies and guidelines need to be considered when determining work allocation, interagency collaborations and service evaluation methods. This is in line with the recommendations of Van Santvoort (2013), Van Loon (2015), and Wansink (2016) for Dutch mental health services.

Different types of effective interventions for children and parents living with parental mental illness already exist (Reupert et al., 2012; Siegenthaler, Munder, & Egger, 2012). Marston et al. (2016), sought to identify how interventions effect change by conducting a content analysis of the key components across interventions. Interventions directed to parents encouraged them to support their children, while in comparison, children’s interventions were designed to promote children’s adaptive coping and problem solving skills, with little focus directed toward the parent. Such apparent contrary approaches suggest some confusion regarding how families might be supported and who within the family should be targeted. Our approach suggests that an intervention focusing exclusively on the children living in a family with mental illness can be seen as a necessary element. This might be due to the age of the participants: adolescents and young adults are characterized by having a great desire for self-reliance (Gulliver, Griffiths, & Christensen, 2010) and a tendency to seek help among friends (Gould et al., 2004). However, Rickwood, Mazzer and Telford (2015) emphasize that in seeking help for mental health problems, the personal connection of young people with parents and family remains paramount, and needs to be supported through family mental health literacy. A combined approach in mental health care is probably preferable: parents and their children living with mental illness might be offered information about risks, resilience, and possibilities for support as a standard procedure in treatment.

Social support in chat conversations

To learn more about the exchange of social support in the online chat sessions, in Chapter 6 we studied the conversations between chat participants among themselves (unmonitored) as well as between chat participants and counsellors (monitored). We found that most chat participants used the opportunity to exchange a considerable amount of constructive emotional support and that they disclosed information about living with a mentally ill family member.

In the unmonitored sessions, when there was no counsellor present, some participants seemed to take over a counselling role by inviting their peers to have a conversation and offering emotional support more frequently. From the chats we could not extract if these girls did so because they felt capable to help others, an experience that may have enhanced their own self-esteem, or assumed a caring role because a formal carer (a counsellor) was missing. The latter may be a sign of parentification; something that is not necessarily positive. In the monitored sessions, participants did react to the presence of an adult moderator: they made far more disclosing statements and much less supportive statements compared to the unmonitored sessions. These phenomena should be better sorted out so that chat participants not will be burdened inadvertently, and also to get more insight in the mechanisms of building up strengths.

Chat participants presented their problems to peers and counsellors often mingled with small talk and sometimes while they were busy with other things as well. This corresponds with how young people normally make use of social media (Lenhart, 2015), but differs from the way professionals expect children of mentally ill parents to attend in face-to-face groups (Gladstone, McKeever, Seeman & Boydell, 2014; Van Santvoort, Hosman, Van Doesum, & Janssens, 2013). Interacting with youngsters in an ‘en passant’ not formally structured way (as in contrast with sitting in a group meeting), might be a better way to get their attention.
Limitations of the study

One of the limitations of our study was that in the reviewed literature mental illness of a family member was not always clearly defined. Also the severity of the symptoms at the time of measuring was often not designated. Coping with a family member suffering from an anxiety disorder however, will be a different experience for a child than having to hide for a family member who appears to become violent under the influence of alcohol or drugs. According to Van Santvoort et al. (2015), the transgenerational transmission of risk to develop psychiatric symptoms appears to be partly specific; in their review of 188 studies they found a strong tendency for children to develop the same disorder as their parent. This was especially true for anxious parents and their children. We were, however, not able to observe whether a differentiated approach would have been more helpful.

A second limitation is that we had no detailed information on the nature and severity of the illness of the family member and the situation of the website visitors. Because it seems unlikely that people who were not children with a mental ill family member themselves would have entered the website and actively utilized it for an extended period, we focussed on visitors who returned to the website several times. We cannot exclude, however, that some of them did make use of the site without belonging to the target group we aimed at.

A third limitation of our study is the relatively small number of participants of the online chat sessions and the fact that it were almost exclusively girls who participated in the chat sessions. The intervention and particularly the chat opportunity did not seem to present a real improvement in the approach of male adolescent and young adult children with a mentally ill family member. We have to consider the clinical implications of that. These limitations have consequences for the external validity of the results related to the Survivalkid website. We cannot be sure that these findings relate to children in general who live with a mentally ill family member.

A fourth limitation is that we could not personally approach the site visitors for pre- and post-test measures. This would have been inconsistent with the intent to offer anonymous support. As a consequence we were not able to study the effectiveness of the online intervention.

Clinical implications

The results of our study may lead us to reconsider the current interventions for children from mentally ill families. Following Rutter’s (2012) opinion that people can be reinforced through the experience of doing well in difficult circumstances, preventive interventions will need to give more attention to the factors that encourage individual children’s successful coping, such as the recognition of their individual efforts and capabilities. The counsellors in the chat sessions for instance, might receive instructions to provide more informational and esteem support. According to Van Santvoort (2013, p. 151), Dutch preventive interventions tend to focus mainly on (mental) health risks for children of mentally ill parents and on social skills training. However, our findings suggest that focusing on strengths may be just as important. In addition, one-sided emphasis on preventing risks, instead of enhancing self-esteem, may lead to more instead of less stigmatization (Hinshaw, 2005; Tanner, 2010).

Furthermore, the timing of interventions should be better tailored to the individual. Given the personal differences in coping abilities and unpredictability of changes in the circumstances such as a sudden relapse of the illness of the parent (Mordoch & Hall, 2008; Trondsen, 2012), it is desirable that individually targeted help is available at the moment it is needed most. Specific information, for instance about the onset and progression of anxiety disorders might be a part of that. The use of Internet technology can be an important tool for a better timing and tailoring of the intervention to individual needs.

Third, more attention should be paid to the gender issues. In our studies, most website visitors and nearly all chat participants were females. Girls have a greater tendency to discuss their problems with friends than do boys (Rose & Rudolph, 2006), and boys report higher avoidant coping than girls (Eschenbeck, Kohlmann & Lohaus, 2007). In addition, Rowlands et al. (2015) noticed that young women experiencing stigmatized conditions were more likely than other people to search the Internet for health information and support. Therefore, Hampel and Petermann (2005) suggest gender-specific conceptualizations of preventive programs, focusing on the acquisition of adaptive coping strategies such as distraction or positive self-instructions in girls, and the acquisition of prosocial behaviour in boys. Since boys spent a large part of their online time with gaming (Lenhart, 2015), the development of serious games seems to be especially promising for this group (Check et al., 2015).

Fourth, our findings indicate that visitors of online interventions use them in a way
that differs from attending a face-to-face group. They may be occupied with other activities at the same time as well. Attrition in online learning, for instance, is often higher than in traditional settings because the students do not appropriately focus (Kizilcec & Halawa, 2015). Professionals should be aware of those differences and take them in account when offering online interventions.

It is also important to note that online interventions, even more than face-to-face interventions, require maintenance. Once launched, websites have to be made widely known, updated, both technically and in terms of content, and the counsellors need support. It appears to be difficult for institutions for mental health to find continuing financing for such services (Woolderink et al., 2015).

**Research implications**

In the literature review we found that children from mentally ill families reported to have developed certain strengths when coping with their relative’s symptomatic behaviour. We like to emphasize that other researchers or health care professionals may have a different interpretation of these findings. For instance, they may not interpret ‘empathy for the parent’s needs’ as an acquired strength, but as harmful for the child or they may regard a child’s independent behaviour as a hindrance for adequate help seeking. Therefore, it is necessary to describe the processes between risk factors, protective factors, the child’s coping behaviour, and his or her (un)healthy development more precisely taking into account not just the reported behaviours but also the development of these behaviours, their intentions and their consequences for the children (and the mentally ill family members).

A theoretical basis for interventions, such as the attachment paradigm for infants (Van Doesum, Hosman & Rilsen-Walraven, 2005), is still missing in the doubtlessly more complex case of older children. Reupert, Maybery, and Nicholson (2015) documented several models that conceptualize the transgenerational transmission of mental illness. A difficulty of these models is that they do not explain which processes occur between the listed factors. Gladstone et al., (2006) even point out that in these models the child is often depicted as a passive victim of the resultant of several risk and protective factors and not as an active human being, contributing to family life. Thus it is necessary to assess the strengths and coping capabilities of a child to learn how support strategies may individually be tailored.

Despite the strengths that children living with a mentally ill family member can develop, they are at risk for the development of various mental health problems themselves. Though people can be reinforced through the experience of doing well in difficult circumstances, failure can make them vulnerable (Rutter, 2012). A lack of unconditional security (predictability) in the home (Mordoch & Hall, 2008; Tronsden, 2012) might make them wary and vigilant. These adaptive responses to chronic stress serve them poorly in situations where they must concentrate to learn successful coping behaviour (Thompson, 2014). Offering safe and nurturing support, such as the opportunity for anonymous online chat contacts with understanding peers and counsellors may reduce the stress children experience. Unfortunately, in this study we were not able to test this hypothesis and to measure the impact of the online intervention of the children’s well-being. Randomized controlled trials are needed to test the effectiveness of the newly developed online intervention that is studied in this thesis.

Future research should also seek to describe the learning processes of children when trying to cope with the symptom behaviour of a mentally ill family member. As the ‘meaning’ of experiences appears to be of great importance for a learning process (Ellis & Grieger, 1986), (qualitative) research is needed to understand individual children’s ideas (cognitions) about events and their connexion with self-esteem and well-being. Although such personal cognitions are unique to each individual child, it might be possible to find general patterns which can serve as starting points for a further improvement of preventive interventions. Since the needs of these children are - to a large extent - determined by their ill family member, it might be important to control in future studies for the nature and severity of condition of the ill family member.

Finally, further studies are needed to learn more about how boys with a mentally ill family member can be better supported.