Survivalkid(s): Online support for adolescents and young adults with a mentally ill family member
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Citation for published version (APA):
Drost, L. M. (2017). Survivalkid(s): Online support for adolescents and young adults with a mentally ill family member

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General introduction

“Mental illnesses are health conditions involving changes in thinking, emotion or behaviour (or a combination of these) and are associated with distress and/or problems functioning in social, work or family activities” (American Psychiatric Association, 2016). A mental illness is common: one in four to five people develop one or more mental disorders at some stage in life, both in developed and developing countries (WHO, 2001). Dutch figures show the same picture (De Graaf, Ten Have & Van Dorsselaer, 2010).

Mental illness is a family affair (Reupert, Maybery, Nicholson, Göpfert, & Seeman, 2015). People with a mental illness often are parents (Nicholson, Biebel, Katz-Leavy, & Williams, 2002; Östman & Hansson, 2002) and children with a mental illness often have siblings (Boer, 2012).

Prevalence rates for children living with a parent with a mental illness vary widely depending on the source and type of data (Maybery, Nicholson, & Reupert, 2015). Goossens and Van der Zanden (2012) calculated that every year, 405,000 Dutch parents suffer from mood disorder, anxiety disorder (excluding specific anxiety disorder), or ADHD. Altogether, these parents have 577,000 children under 18, which represents about 17% of the Dutch child population. These figures do not include data about parents with a different diagnosis, such as psychosis, eating disorders, schizophrenia, or borderline personality disorder – no recent data about parents with these diagnoses are available. The actual percentage of children living with a mentally ill parent will therefore be higher. There are some estimates. Van der Ende, Van Busschbach, Wiersma, and Korevaar (2011) reckon that in the year 2009, 48% of Dutch patients with severe mental illness had children. This is in line with our own observations at the Indigo/GGZ Drenthe mental health care institute. According to a survey among clients of the institute (N = 313), half of them reported to be parents (GGZ Drenthe, 2007). Figures from the department of Psychiatry of the University Medical Centre in Groningen for the year 2015 show that 37.2% of patients had children.

Prevalence rates for children living with a sibling with a mental illness are scarce (Boer, 2012). Van Dorsselaer et al., (2010) report that over 15% of Dutch youth have relatively large psychological problems. As national statistics indicate that more than nine out of ten Dutch children have at least one sibling (CBS, 2003), many children will have to cope with the symptom behavior of a brother or sister.
Impact on children

Previous studies have shown that children living in a family where a member has a mental illness are at risk of developing various mental health problems themselves (Hosman, Van Doesum & Van Santvoort, 2009; Ma, Roberts, Winefield & Furber, 2015; Reupert & Maybery, 2007; Van Santvoort et al., 2015). Maybery, Reupert, Patrick, Goodyear, and Crase (2009) estimated that between 25% and 50% of children whose parents are affected by mental illness, will experience some level of psychiatric symptoms, compared with 10% of children whose parents are not. An overview of the impact of several parental disorders on family relations can be found with Reupert, Maybery, Nicholson, Göpfert, & Seeman (2015, section 3).

In addition, the studies of Barnett and Hunter (2012) and Dia and Harrington (2006) reveal that children who have a sibling with mental health problems are vulnerable to adjustment difficulties.

Risk and protection

Presenting a developmental model of transgenerational transmission of psychopathology, Hosman, Van Doesum and Van Santvoort (2009) suggest that problems of children living with a family member with a mental illness develop from a combination of risk and protective factors related to the child, the parents, and the environment in which the family lives. Examples of evidence-based factors these authors mention are: the child’s age and its cognitive and social skills, parenting competence and parents’ responsiveness (which may be affected by an outbreak of the illness), and the social support available.

Early interventions aiming to reduce risk and enhance protection are recommended to promote resilience of children. In the Netherlands, a comprehensive preventive approach with the mentioned goals has been developed and implemented. It comprises a wide set of interventions that address reported risk and protective factors in multiple domains, targeting children in different age groups, parents and families, social networks, professionals and the community as a whole (Van Doesum & Hosman, 2009).

Beyond reach

However, many children and parents do not receive the services they need (Charles, Reupert, & Maybery, 2016). About half of the parents (54%) who responded to the GGZ Drenthe survey mentioned above, indicated to be aware of the availability of (some form of) preventive support for their children and only 10% made use of such services (GGZ Drenthe, 2007). Especially the adolescents and young adults are scarcely involved in these preventive interventions (Dijkstra, de Ruiter, Van der Poel, & Boon, 2012; Romijn, De Graaf & De Jonge, 2010).

Factors mentioned to hamper children’s participation are reluctance of the parents to let their children be involved in preventive interventions offered by institutes for mental health care, often caused by concern about the stigma associated with psychiatric disorders (Stallard, Dickens, Salter, & Cribb, 2004), a sense of guilt of parents for bothering their children (Pihkala & Johansson, 2008), and practical problems such as lack of transport facilities (Wolpert, Hoffman, Martin, Fagin, & Cooklin, 2015). For adolescents and young adults with an affected family member, perceived stigma and embarrassment, poor mental health literacy, and a preference for self-reliance were found to be the most important barriers to help-seeking (Gulliver, Griffiths, & Christensen, 2010).

The important period of adolescence

To reach the adolescents and young adults from a risk group with preventive interventions seems of high importance. Adolescence is a complex period wherein many physical, cognitive, and emotional changes occur (Crone & Dahl, 2012). Studies in adults reported that most functional mental disorders seem to begin before the age of 25, and often between 11 and 18 years of age (Kessler et al., 2007; Paus, Keshavan, & Giedd, 2008). Homlong, Rosvold, Sagatun, Wentzel-Larsen, & Haavet, (2015) concluded that exposure to a parent’s mental health problem during adolescence can be a risk for future welfare dependence in young adulthood, although social support that is perceived as such by the recipients, may counteract this risk.

New ingredients for a new intervention

According to the outlines of the Dutch national program, an intervention to prevent mental health problems in this target group should address evidence-based risk factors and protective factors in several domains (Hosman & Van Doesum; 2009; Van Doesum & Hosman, 2009).

To increase chances of reaching adolescents at risk, the preventive interventions may need to become more accessible and better tailored to the adolescents own view on
their situation. There are various ways in which this might be realized. Recently, Gladstone, Boydell, and Keaver (2006) advised to expand the knowledge about risk and protective factors with children’s own accounts on how they face living with a mentally ill family member. Information on how children learn to cope with their family member’s symptoms and on the resources they indicate as helpful in this process may improve preventive interventions by better incorporating adolescents experiential expertise.

Another promising ingredient for the improvement of preventive interventions is a focus on strengths and abilities that adolescents develop when living with a parent with a mental illness. Masten and Tellegen (2012) and Rutter (2012) emphasize that the experience of doing well in difficult circumstances can increase resilience, therefore it seemed important to notice the abilities that children may develop when living with a family member with mental illness. Promoting the strengths of the adolescents and young adults who were to be reached, became an explicit goal of the intended intervention.

Finally, the format of preventive interventions may be improved by using the opportunities the Internet offers. Online interventions offer excellent opportunities to provide accessible health support safely and anonymously (McGinty, Saeed, Simmons, & Yildirim, 2006). Nearly all young people in the Netherlands (96 %) are familiar with the Internet (Van Rooij & Schoenmakers, 2013). Creating an online intervention to support the target group seemed an apparent solution to increase accessibility of preventive support.

All this considered, it seemed useful to develop an online preventive intervention for young people living with a relative with a mental illness taking account of their self-reported experiences and including abilities and strengths that they may have developed in their family situation.

**Aims of the research project**

The principal aim of the presented research project was to develop an online intervention for the adolescent and young adult children with a mentally ill family member that would increase the reach among the target group. Accordingly, our studies examined the strengths children reported to have acquired when living with their mentally ill family member, the ways website visitors used the intervention to adapt to their situation, and the knowledge that is needed to significantly improve services to families where a parent has a mental illness.

Obviously, it would be highly interesting to examine whether the intervention has an effect on the current or future occurrence of psychological problems. Such a research project however, is difficult to perform, not in the least because of privacy matters (Woolderink et al., 2015). It seems quite conflicting to offer room for free and anonymous expression to this rather reserved target group and then ask the participants to fill in their names in questionnaires to measure effects of the intervention. Consequently, the questions in this thesis must be limited.

**Research questions of this thesis**

1. Which knowledge can be found in the scientific literature about what strengths children develop when living with a family member with a mental illness?
2. How can one build a useful online preventive intervention for the target group and what value can an online intervention provide in comparison to face-to-face interventions?
3. How do visitors use the intervention?
4. Which international shared research agenda has the potential to inform future research?

**Outline of this thesis**

Chapter 2 provides a literature review of the strengths children report to have acquired while coping with their parents illness, and the external factors these children indicated had facilitated their coping process. In chapter 3 the development of Survivalkid.nl is described as an interactive, Internet-delivered, preventive intervention for supporting adolescents and young adults with a mentally ill family member. In chapter 4 usage statistics with regard to frequency and duration of visits and amount of activity during visits to Survivalkid.nl are evaluated to study if the range of support of the intervention is larger than face-to-face interventions accomplished.

The case study in chapter 5 illustrates the perspective of one visitor of the intervention on the basis of an exit interview, her messages to her peers and counsellors, her user data and the content of her chat conversations. Chapter 6 reports on an analysis of the conversations, in particular the (un)supportive messages and self-disclosure of experiences of 22 participants in the online chat sessions being part of the intervention.
In chapter 7 a study is presented to identify a shared, international and inter-disciplinary research agenda amongst practitioners, researchers and administrators, in relation to families where a parent has a mental illness.

In chapter 8 the main findings of the thesis are summarized and discussed, and future directions are presented.