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

Drost, L.M.

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

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Children from families with a mental illness are at increased risk of acquiring a psychiatric disorder when compared with other children in the community (Beardslee, Gladstone, & O’Connor, 2011; Ma, Roberts, Winefield, & Furber, 2014; van Santvoort et al., 2015). Preventative interventions for this group of young people are usually aimed at improving their knowledge about mental illness, enhancing their adaptive coping skills,
Various factors make it difficult for children from families with a mental health problem to find adequate social support when they are in need. These factors include not being identified by mental health services (Maybery, Goodyear, O’Hanlon, Cuff, & Reupert, 2014), parental denial of the impact of the illness on their children (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004), and adolescents’ and young adults’ increasing need for autonomy for which they do not easily seek help (Shaw, 2001).

E-health interventions may help to overcome barriers to the delivery of traditional face-to-face programs (Drost, Systema, & Schippers, 2011; Meier, Fitzgerald, & Smith, 2013). Online interventions might be of particular interest to young people, due to their high level of anonymity, easy access regardless of the time of day and the person’s location, cost-effectiveness for large populations, and potential to be perceived as less stigmatizing than traditional interventions (Ali, Gulliver, & Griffiths, 2015). Woolderink et al. (2015) interviewed young people with an addicted or mentally ill parent who took part in a prevention course, which was delivered online. Remaining anonymous, participants reported that they felt protected, and this encouraged them to be more open. Trondsen (2012) observed that participants in an online self-help group for adolescents with a mentally ill parent did indeed discuss the challenges related to their parent’s illness that they faced, and they also exchanged strategies for actively managing the challenges.

The present study examined whether the goals of the website’s chat-room service were being reached. It did so by examining participants’ contacts with their peers and counselors during the sessions. The following questions guided the analysis:

1. What are the characteristics of participants in this online service?
2. What features of the conversations can be identified, and how prevalent are they in monitored versus unmonitored sessions?
3. Are there differences between the kinds of statements that participants make and those that their counselors make?
4. Is sent versus received social support related to and the degree to which participants self-disclose?
5. Do the amount of social support that is exchanged and the amount of self-disclosure vary among participants from different age groups?
Methods

Chat-room sessions

The chat-room is accessible at specified times. Monitored chat-room sessions, which last 90 minutes, are offered weekly. At each session, a professional counselor is present who introduces the theme of the session and leads the discussion, if this is needed. Examples of themes are: “Ambivalent emotions,” “How to tell your friends,” “What makes you happy?” All of the counselors are trained in online counseling for young people. At other times, the chat-room is open for unmonitored sessions without a professional counselor present. At the entrance to the chat-room, the rules for the sessions are clearly posted. They include: “Keep your real name confidential”; “Be polite to other visitors, even if you do not agree with them.” Also it is explicitly stated that one of the counselors will read the script from each unmonitored session the following day. Inappropriate posts can be deleted, and the administrator can exclude participants from the chat-room sessions if they do not comply with the rules.

Sample of sessions

The sample of sessions consisted of 17 monitored and 17 unmonitored chat-room sessions, all of which occurred within four months, namely in April and October, 2014, and in April and September, 2015. The researchers observed all of the monitored chat-room sessions that occurred during the four months. Of 40 unmonitored sessions during the same four months, the 17 sessions with the longest duration were selected for analysis.

From each participant in these sessions, the following information was recorded: The participant’s age, sex, and the family member’s reported diagnosis, and the number of visits to the monitored and unmonitored chat-room sessions that the participant made. Participants and counselors were made anonymous by replacing participants’ nicknames and counselors’ names with numbers and letters, respectively.

Coding

To code participants’ online interactions, the session transcripts were electronically imported into the qualitative analysis software Atlas.ti, version 7.5.4 (Friese, 2014a). Atlas.ti allows for on-screen coding and enables multiple codes to be created, including groups (families) of codes. Atlas.ti also contains an advanced search option that facilitates the identification of multiple themes across large amounts of text and permits common participant responses to be analyzed (Friese, 2014b).

Codes were assigned to the conversational statements. A conversational statement was defined as a separate line from a chat-room transcript that was recognizable as a distinct message (see also Fukkink, 2011). For example, “Try to find people to talk with” (Statement 1); “You deserve it” (Statement 2); “Your general practitioner will remain silent; he took an oath of secrecy” (Statement 3). The 34 observed chat-room conversations contained a total of 4,124 conversational statements.

Two of the authors (LD and ZI) formed a coding team. After initial coding, decisions were made about which codes were most meaningful. A list of codes was then developed, based on the five categories of supportive communication (Cutrona & Suhr, 1992) described earlier. To distinguish between support for disclosure of problems in the home situation, which was coded as emotional support, and support for disclosure of other information (for instance: “I hope you pass your exams”), the code “conversational support” was included. The list of codes was further extended by including the categories: (a) “disclosure,” defined as sharing personal experiences and thoughts on the subject of having a family member with a mental illness, (b) “action” or “no action,” when the person who received the advice made it clear that he or she would or would not follow it, (c) “unsupportive reaction,” e.g., unpleasant messages, and (d) “chit-chat” to indicate small talk (van Uden-Kraan et al., 2008a) that was unrelated to participants’ unique situation, such as exchanging greetings, sharing the experience of having a dental appointment, or being moved by a film that had been seen. The sender and the recipient of each conversational statement were indicated by including “to” between each speaker’s unique code (for example, “5 to 22/chit-chat”). Thus, all statements were counted at least twice, once as a message sent by a participant and once as a message sent to one or more participants.

Following Friese’s (2014b, p.134) recommendations, the code definitions was refined on a sample of transcripts of chat-room conversations. Then, two coders independently coded eight transcripts once more. Successively, the third author coded the remaining chat-room conversations. A new sample of a different four transcripts indicated strong agreement among the coders. A glossary of the code definitions is available from the corresponding author on request.
Data analysis

The characteristics of participating chat-room visitors were identified from the website’s database. To establish the prevalence of the different characteristics of the chat-room conversations, all of the coded statements were organized into groups (“code families” in Atlas.ti) for each code category. For each code family, the rate of occurrence was calculated. To identify differences in interactions between monitored and unmonitored sessions, the frequency of coded statements in the monitored and unmonitored sessions was compared.

To determine the relationship between sent and received social support, for each participant all exchanged statements were organized into a code family. For example, the code family “participant 5-all exchanges” included among other statements the statements that were coded as follows: 5 to 22/(sent) informational support; 5 to (counselor) K and to 7, and to 20/(sent) self-disclosure; 20 to 5/(received) emotional support. The number of sent and received supporting statements and self-disclosing statements were summed, and correlations were run to identify relationships among the different types of statements. In addition, an analysis was run to determine whether types of statements that participants made were related to their age.

Ethical considerations

Before the research protocol was developed, the authors discussed the same ethical issues regarding studying a sample of Internet participants that Eysenbach and Till (2001) identified. Several conclusions were reached. First, the study involved passive analysis of messages that had been posted. The researchers themselves were not involved in any of the chat-room conversations. Second, participation in the chat-room sessions was anonymous. To insures confidentiality, pseudonyms instead of names or nicknames used in the chat-room sessions are used in all of the quotations that were translated into English. Finally, the Ethics Committee of GGZ Drenthe, the institute for mental health that administers the website, approved the study.

Results

Characteristics of participants

In the chat-room sessions that were included in the analysis, there were 22 participants, all of whom were female, and their age ranged from 12 to 23 years (mean 17.5; sd 3.2). There were 15 participants in the unmonitored sessions, and there was an average of three participants per session. There were also 15 participants in the monitored sessions, with an average of four participants per session; however, some of these participants were the same as those in the unmonitored sessions. There were seven counselors (six females, one male) who moderated the sessions.

Of the 22 participants, ten, three, one, and one of them, respectively, indicated that they had a mother, father, sister, or brother with a mental illness. The mental illnesses named and the number of participants who named them were as follows: anxiety disorder (1), borderline personality (2), depression (6), obsessive-compulsive disorder (1), and autism (PDD-NOS; pervasive developmental disorder-not otherwise specified) (1). Four participants revealed that they had a family member who had committed suicide. Some participants reported that they had more than one family member with a mental illness, but seven participants did not disclose information about their family member’s mental illness.

Characteristics of the conversations in monitored and unmonitored sessions

The statistics for the 4,124 conversational statements that were observed are shown in Table 1. Here we see the frequencies and percentages of the coded conversational statements, separately for the monitored and unmonitored sessions. The distributions are approximately the same for the two types of sessions. About half of the statements were characterized as small talk (i.e., chit-chat). About one-third of the statements were judged to be supportive. Neither unsupportive reactions nor suggestions for taking action hardly ever occurred.

Regarding only the participants’ statements, twice as many disclosures were sent in the monitored sessions as in the unmonitored sessions (29.4% vs. 15.3%), and half as many supportive statements (mainly conversational and emotional support) were sent in the monitored sessions as in the unmonitored sessions (15.4 vs. 33.9%). By contrast, the counselors gave abundant conversational (28.3% of the statements) and emotional (19% of the statements) support, but, as would be expected, they did not make any self-disclosures.
Participants differed widely in the number of statements that they were observed to make. The number ranged from 22 to 2,012; the mean number was 349, and the median was 139. The percentage of statements that participants received from others ranged from 44.2% to 77.3%. The percentage of supportive statements that participants received ranged from 2.9% to 63.3%, with a mean of 33%. The percentage of supportive statements that participants sent ranged from 0% to 50.8%, with a mean of 25%. The percentage of disclosures that participants received ranged from 0% to 60.0%, with a mean of 22%.

In neither the monitored nor the unmonitored sessions was there a strong relationship between the number of socially supportive statements that were sent and those that were received (Spearman’s rho = -.26 and .26, respectively, p < .35). The number of disclosures that were sent in both the monitored and the unmonitored sessions was strongly positively associated with the number of socially supportive statements that were received (Spearman’s rho = .76, p < .001, and .68, p < .005, respectively). There was a negative relationship between the number of disclosures that were sent and the number of socially supportive statements that were sent, but only in the unmonitored sessions (Spearman’s rho = -.55, p < .04); in the monitored sessions, Spearman’s rho was -.14, p < .65.

Finally, no significant differences were found between younger and older participants in the characteristics of their chat-room conversations.

### Discussion

To the best of our knowledge, this study is the first study to examine how visitors of monitored and unmonitored online chat-room sessions could be part of a preventive intervention for children from families with a mental illness. The results provide a snapshot of such chat-room conversations, and they show how these conversations could be an important resource for social support.

The chat-room service that the website provided appeared to meet expectations. Participants used the online chat-room sessions to exchange a considerable amount of social support and to disclose problems in their home situation.

During both the monitored and the unmonitored sessions, the young people...
appeared to be able to engage in constructive online conversations about both their daily experiences and the difficulties they had while trying to cope with their relative’s mental illness. More than half of participants’ statements were coded as supportive or self-disclosing. Participants discussed their experiences at home, and they exchanged support with one another; however, the disclosures were intermingled with everyday conversation about, for example, experiences at school or on outings, as if they were talking with friends. Many of the females of our target group appeared to be “searching for normality” (Fjone, Ytterhus, & Almvik, 2009, p. 461), and the chat-room conversations provided them with an opportunity to chat with peers who understood both their circumstances (Grove, Reupert, & Maybery, 2015; Thomas, et al., 2003) and the difficulties that they were experiencing at home.

Participants’ level of self-disclosure was strongly positively associated with the amount of social support that they received in the chat-room sessions. Inasmuch as all of the participants were in the same situation, they probably felt that it was appropriate to reveal their experiences (Gladstone, McKeever, Seeman, & Boydell, 2014), but at the same time they were aware of how hard this probably was for some of their peers.

Self-disclosure was greater in the monitored sessions than in the unmonitored sessions; it was counselors who offered most of the social support in the monitored sessions. The presence of a counselor seemed to instill confidence in the participants.

In the unmonitored sessions, some of the participants seemed assume the role of counselor when they invited their peers to engage in conversation and then frequently offered them emotional support. This might be viewed as positive, because giving support to peers might have enhanced their self-esteem (van Uden-Kraan et al., 2008c); however, more research is needed to clarify this, because offering support to others might also be viewed as parentification (i.e., assuming a parenting role), which has been associated with experiencing stress and internalizing one’s problems (van Loon, van de Ven, van Doesum, Hosman, & Witteman, 2015).

In the unmonitored sessions, a negative relationship was found between the degree to which participants self-disclosed and the degree to which they offered social support. The explanation for this association is not clear. Revealing one’s own similar circumstances may be intended as emotional social support where it displays an understanding of what the other person goes through (Grove, Reupert, & Maybery, 2015). Another explanation is that the girls who assumed a counseling role, indeed behaved more like counselors and thus made fewer disclosing statements about themselves.

The most common kinds of social support were conversational support and emotional support. Consistent with earlier results (Fukkink, 2011), tangible support (offers of goods or services) was rare in the context of the computer-mediated social support. Only a small proportion of the supportive statements were coded as informational support or esteem-enhancing support. This was true for both the counselors and the participating peers. The adolescents in Trondsen’s (2012) study acknowledged that the information that had been provided to them on how to cope with their relative’s behavior had inspired them to reflect on how they might handle their own situation. Van Santvoort (2012, p. 158) recommends that special attention be given to enhancing self-esteem in preventive programs for children of mentally ill parents. Additionally, Fukkink (2011) states that the quality of online support that participants provide is related to variations in their supportive communications. This suggests that counselors should be more attentive to the information that is being communicated within chat-room sessions.

The results indicated that there were no significant differences between younger and older participants in the amount of social support that they exchanged or the degree to which they self-disclosed. In both the monitored and unmonitored sessions, there were wide variations among the participants. Consequently, it did not seem worthwhile to try to further characterize subgroups within each type of session.

Some of the statements that were coded as chit-chat indicated that participants frequently used two or more kinds of media concurrently. Remarks such as, “Sorry, I did not reply immediately, since I am also watching this television program” and “I may have missed a bit of the discussion, as I am playing games” suggest that some of the chat-room participants did not specially focus on the preventive intervention; instead, they routinely opened their electronic devices and kept their eyes on what was happening in the chat-room. Rideout, Foeh, and Roberts (2010) reported that young people engage in such media multitasking more than 29% of the time; they might be engaging in some combination of the following simultaneously: watching TV, using a computer, playing a video game, listening to music, printing, talking on a cell phone, or watching a movie. Future providers of online interventions should take this phenomenon into account.

Limitations of the study and research implications

All of the chat-room participants were female. Further studies are needed to learn
how males who live with a family member with a mental illness can best be supported. In addition to the information the females themselves reported, there might be characteristics of chat-room participants that could affect their chat-room behavior, but which we not take into account in the current study. These characteristics might include being a young provider of care or having a family member with acute symptoms of a mental illness. In future, research should examine relationships between social support and self-disclosure and the key variables that affect them. Finally, research is needed on the long-term outcome of chat-room participants, including their psychosocial functioning and their level of distress.

Conclusions

Despite its limitations, the current study provides some important insights into the behavior of chat-room participants. For example, the participants exchanged a considerable amount of social support, and they talked about how they were coping with the symptomatic behavior of their relatives. Interventions delivered over the Internet have the capacity to reach larger numbers of participants than face-to-face interventions. Consequently, in future chat-room sessions might be offered either as complementary to or in place of face-to-face groups (Naslund et al., 2016) to support adolescents with a mentally ill family member.