Survivalkid(s): Online support for adolescents and young adults with a mentally ill family member
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Evaluating the reach of a website designed to improve contact with young people living with a mentally ill family member

Abstract

The aim of this study was to investigate whether a website specifically designed for young people living with a mentally ill family member could substantially improve contact with adolescents over that achieved through face-to-face procedures. The number and characteristics of high-risk young people who visited a website were compared with those reached through face-to-face contacts. Website visitors were tracked who logged in two or more times or who received online support for five minutes or longer, and visitors who sought support by means of email correspondence or a chat session were recorded. Finally, visitors’ self-reported psychosocial problems were compared with those of students who participated in a school survey.

The website attracted far more at-risk adolescents than did standard preventative services provided by mental health institutions. At least 19% of them used the opportunity to seek advice by email, participated in monitored chat sessions, or asked for a private chat session. A majority of the respondents on the online questionnaire reported having psychosocial problems.

A website specifically designed for young people living with a mentally ill family member extends the range of support for this target group, helps to reach those members of the target group who are already showing subclinical symptoms of a psychiatric disorder, and enhances the young people’s exposure to preventative support.

Introduction

Epidemiologic and clinical research indicates that the children from families affected by mental illness have an increased risk for developing a serious disorder themselves (Beardslee, Gladstone, & O’Connor; Hosman & Van Doesum, 2009). Consequently they should be the target of prevention programs (Garber, 2006). Various forms of preventive care have been created to support these children (Reupert, et al., 2012). For Dutch adolescents and young adults preventative face-to-face groups have been developed (Van Doesum & Hosman, 2009). However, as we experienced ourselves at the institute for Mental Health Care Indigo/GGZ Drenthe, many barriers hinder the delivery of preventive interventions to the target group. Professionals often do not feel competent to discuss the topic with their adult patients (Maybery & Reupert, 2009); parents focus on their own

This chapter is a compilation of the following three publications:


problems or do not wish to bother their children (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004), and young people themselves are reluctant to seek support because of embarrassment, poor mental health literacy, and a preference for self-reliance (Gulliver, Griffiths, & Christensen, 2010).

Prevalence

Nemesis, a prospective study on the prevalence of psychiatric disorders among members of the Dutch population aged 18–64 years (Bijl, Ravelli & van Zessen, 1998), revealed that 41.2% of the adults had experienced at least one lifetime psychiatric disorder according to DSM-III-R criteria. Based on these results, Bool, Smit, and Bohlmeijer (2007) estimated that about 1.6 million children in the Netherlands grow up with one or two mentally ill parents, 700,000 of whom are adolescents. In 2007, 670 Dutch adolescents and young adults participated in the targeted face-to-face groups (Van der Veen & Voordouw, 2008). Extrapolating from the national statistics, we estimated that in the province of Drenthe, which includes 490,870 inhabitants, 25,000 young people are in need of support. This might, however, be an overestimate because many children of mentally ill parents remain healthy (Gladstone, Boydell, & McKeever, 2006).

Thus, according to Bassani, Padoin, and Veldhuizen’s (2008) suggestion, we conducted a survey among clients at the Indigo/GGZ Drenthe mental health institute (N = 313) and discovered that 25% of the adults had children between the ages of 12 and 24 years, suggesting that at least 1,000 adolescents in our catchment area live with a parent who receives treatment for psychiatric problems. Moreover, 20% of the clients who were parents reported that at least one of their children was receiving professional help. By contrast, fewer than 60 adolescents (comprising mainly younger adolescent girls without observable problems) had participated in the preventative group sessions offered in the region during the prior ten years. Thus, although the adolescents were at risk, the service did not seem to succeed in reaching the target group in a timely manner.

Online support

The increasing use of the Internet generates a noteworthy medium for delivering mental health information and support to young people. In 2007, 97.2% of Dutch households with young people less than 18 years old had computers with Internet access at home; in fact, 29.9% of these young people were able to use the World Wide Web privately, in their own room (Duimel & de Haan, 2007). A substantial proportion of both young males (31%) and young females (60%) report using the Internet to look for information about health and dieting (Van Rooij & van der Eijnden, 2007). The Internet’s accessibility and the anonymity that it provides might relieve young people’s concerns about loss of autonomy (Shaw, 2001) and lack of confidentiality (Jacobson, Richardson, Parry-Langdon et al., 2001) that they have by using other resources. Because earlier initiatives that sought to improve young people’s well-being via the Internet appeared to be successful (Gerrits, Van der Zanden, Visscher, & Conijn, 2007; Michaud & Colom, 2003; Nicholas, Oliver, Lee, & O’Brien, 2004) the website Survivalkid was created, an online preventative intervention for adolescents at risk, and launched in June 2006.

Survivalkid: A website for prevention

The Survivalkid website was established as an online resource that would encourage members of the target group from all educational backgrounds to stay in contact long enough to meaningfully process the content provided and where they could return if their current situation required them to seek additional information or support (Drost, Cuijpers, & Schippers, 2011). As a link in the healthcare chain in the region, the site is directed especially, but not exclusively, at the regional target group.

On the public homepage, the purpose and objectives of the site are explained for parents, teachers, and the target group, and then the target group is invited to register by choosing a username and password and then to log on to the pages which only members of the target group can access. Participation is anonymous, but for evaluation purposes, visitors are asked to enter their age, gender, and educational level, and to indicate their connection to the province of Drenthe.

On the restricted pages of the site, visitors can find stories, tests, and quizzes, which are designed to deliver psycho-education and advice tailored to the individual’s needs. One of the options is to receive feedback about signs of psychosocial dysfunction as measured by the Short Indicative Questionnaire for the Early Detection of Psychosocial Problems in Adolescents (KIVPA; Bos, Van Ede, & Maarsing, 2004). The KIVPA has been validated against other instruments, including the Youth Self Report (Reijneveld, et al., 2003), and it is used in the Netherlands in public health care for young people to screen for psychosocial problems. Mangunkusumo et al. (2005) found that a computerized version of the KIVPA produced the same results as the paper-and-pen version. As recommended by the authors, a cut-off score of 6 or higher was defined as indicative of psychosocial problems.
To enable visitors to have contact with one another, a moderated forum and a chat room were created. Additionally, visitors are given the opportunity to contact a counsellor. From “My Own Page,” each visitor can send secure email messages to a prevention specialist working at the institution, who could offer a face-to-face session, if the visitor desires it.

The objectives of the website are to increase the target group’s access to relevant information and to promote mutual support and positive help-seeking behaviour among its members. The aim of this study is to determine whether we have succeeded in our intent to reach more young people than with the face-to-face offerings, whether site visitors indeed belonged to the targeted group of young people who need preventive support because of their home situation, and whether they actively used the offered preventive care.

Methods

When evaluating online interventions use can be made of various parameters, such as number of visitors, characteristics of visitors, number of visits, duration of visits, and content of the conversations (Danaher & Seeley, 2009). To determine whether the Survivalkid intervention reaches substantially more adolescents in the target group than were reached through face-to-face services, between June 2006 and June 2009, the number of Survivalkid visitors and their demographic characteristics were recorded. Also the number of adolescents who visited the site at least twice and those whose visit lasted five minutes or longer were observed. Finally, the visitors in the latter group were compared with the number and demographic characteristics of high-risk adolescents reached through face-to-face contacts. The following information was tabulated:

(i) The age, sex, educational levels of the visitors, and their connection to the province of Drenthe, as determined from the details that they provided during their registration at the website;

(ii) Visitors’ psychosocial problems, as measured by the KIVPA questionnaire that they took online;

(iii) The number of visitors who used the email service to contact a counsellor and the number of chat-room participants who discussed their psychosocial problems.

Results

The Survivalkid website statistics for the period June 2006 – June 2009 indicated that there were 10,000 hits and an average of 600 different visitors each month, and during this period, 534 visitors registered to use the restricted pages. The recorded characteristics of the visitors are shown in table 1.

| Table 1: Characteristics of registered visitors (June 2006- June 2009) |
|---------------------------------|-------------------|-----------------|
| N = 534                         | Number of visitors| percentage      |
| Gender                          |                   |                 |
| Female                          | 444               | 83.1            |
| Male                            | 90                | 16.9            |
| Age                             |                   |                 |
| ≤ 16                            | 313               | 58.6            |
| > 16                            | 221               | 41.4            |
| Education                       |                   |                 |
| Elementary and extended elementary | 238            | 44.6            |
| Secondary                       | 219               | 41.0            |
| Otherwise                       | 77                | 14.4            |
| Origin                          |                   |                 |
| Visitors from the local region  | 278               | 52.1            |
| Parents live in the local region| 104               | 19.5            |
| Otherwise                       | 152               | 28.5            |

Most of the visitors were female; 444 females versus 90 males visited the site. The mean age was 16.6 (sd = 4.67) years. Regarding education, 44% and 41.0% of the visitors reported that they were receiving (extended) elementary and secondary education, respectively, and 15% checked the ‘other’ category, which likely meant that they had dropped out of school. The educational level of the sample is similar to that reported in national and regional statistics (CBS, 2016; Kruijer & Kassenberg, 2008). Regarding their connection to the local region, 52%, 20%, and 28% of the visitors indicated, respectively, that they were from the region, that their parents lived in the region, or that they had no connection to the region.
The results of this study revealed that we have reached more young people living with a family member with a mental illness than with the face-to-face offerings. During the first three years of its existence, nearly 90% of the 530 visitors whom we could track visited the site for at least 5 minutes, which was long enough for the components of the site to have made an impression (Danaher, Mullarkey, & Essegaier, 2006). This number of visitors is far greater than the six adolescents who participated in preventative face-to-face groups each year.

Despite the fact that Survivalkid was publicized only regionally, 28% of the visitors reported having no connection with the region. They located the site independently of any advertising and thought it interesting enough to visit and to register. Current usage continues to be robust.

Half of the email messages were related to ongoing problems about a family member’s mental illness. Because all of the chat sessions were moderated, we can confirm that all of them included a discussion of how to cope with a family member’s illness. Participants who disclosed a major problem were encouraged to seek help by peers as well as by counsellors. Several young people disclosed to have had adverse experiences with previous treatment; this required special skill on the part of the counsellors. It was gratifying, however, to see that some of the visitors later communicated the relief that they had experienced (‘Thanks for giving me confidence’; ‘They really do not laugh at you!’).

Seventy-eight percent of respondents to the KIVPA questionnaire scores above the cut-off for psychosocial problems. For comparison: from 4,890 students who had taken the paper-and-pencil version of the KIVPA at school, 969 (20%) had a score indicative of psycho-social problems (Van Ede, 2007). This may indicate that (part of) the site visitors not only had to deal with problems, but also experienced them as a considerable burden.

Although far more females than males visited the website, the problems of the two sexes were equally severe. As expected, the adolescent girls had a significantly higher score on internalizing behaviours than the adolescent boys (Rudolph, 2002; Leadbeater, Kupermine, Blatt, & Herzog, 1999); this seems to confirm the isolation that adolescent girls can experience (Champion et al., 2009). Use of the website might bring them relief, since communication via the Internet appears to have beneficial effects on depressed adolescents who report not having close friendships with others (Selfhout, Branje, Delsing, ter Bogt & Meeus, 2009). These results cannot, of course, simply be generalized to all of the site users.
participants. Perhaps the adolescents who completed the questionnaire were the ones who felt most unhappy.

Finally, 35% of the visitors completed the questionnaire, 19% participated in the chat sessions, and 12% used the email facility. Although there will be some overlap, this means that more than a third of the visitors were active users. Preece, Nonnecke and Andrews (2004) report that in many successful communities the number of participants that generates most of the responses varies from 10 - 50%. Besides, Van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar (2008b) indicate that reading in itself can be sufficient to profit from participation in an online support group.

Limitations

This study has certain limitations. First, we had no way to assess the validity of the information that the visitors provided anonymously. It does, however, seem very unlikely that the respondents (who used a pseudonym and who in many cases actively chatted about their problems) would have faked their answers to the questionnaire. It also seems unlikely that people who were not members of the target group would have entered the website and actively utilized it. Other weaknesses are the small sample size and the fact that recruitment for the survey may have been biased.

Conclusions

Despite limitations of the study, several conclusions can be drawn. The results show, for example, that it is both technically and practically feasible to provide the concealed population of adolescents with a mentally ill family member (Gray & Robinson, 2009) with preventative support. The website made it possible for us to contact participants who reported having psychosocial problems at an early stage. Many visitors returned to the site many times and also participated in the chat sessions, making the site a meeting place for young people with a common problem where they could find refuge from stigmatization (Fjone, Yterhus, & Almvik, 2009).

Although the results of the study are encouraging, there are difficulties that need to be overcome. One problem is the gap between the services that Survivalkid provides and more intensive services that some visitors need. Finally, it should be noted that although financial support for future services is not yet secure, we believe that the Internet has great potential for supporting and empowering young people in need of help.