The Mental Health of Visitors of Web-Based Support Forums for Bereaved by Suicide

Jeannet Kramer[1], Brigitte Boon[1], Marijke Schotanus-Dijkstra[1], Wouter van Ballegooijen[2,3], Ad Kerkhof[4], and Agnes van der Poel[1]

[1]Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Utrecht, The Netherlands
[2]Department of Clinical Psychology, VU University Amsterdam, and the EMGO Institute for Health and Care Research, Amsterdam, The Netherlands
[3]Department of Psychiatry, VU University Medical Centre/GGZ inGeest, Amsterdam, The Netherlands
[4]Department of Clinical Psychology and EMGO+ Research Institute Faculty of Psychology and Education, VU University Amsterdam, The Netherlands

Abstract. *Background:* Persons bereaved by suicide are reluctant to ask for social support when they experience feelings of guilt and blame. A web-based peer forum may provide a safe and anonymous place for mutual support. *Aims:* This study examined the mental health changes of visitors of two online support forums for persons bereaved by suicide and their experiences with the forum over 1 year. Method: Visitors of two forums completed self-report measures at baseline and at 6 and 12 months' follow-up. Repeated measures analyses were used to study changes in well-being, depressive symptoms, and complicated grief. Additionally, participants were interviewed about their experiences with the forum. *Results:* The 270 participants were mostly female, low in well-being, with high levels of depressive symptoms and complicated grief. Suicidal risk was high for 5.9%. At 12 months, there were small to medium-sized significant improvements in well-being and depressive symptoms ($p < .001$) and nearly as much for grief ($p = .08$). About two thirds reported benefit from visiting the forum. Because of the pre–post design we cannot determine whether a causal relationship exists between the form and changes in mental health. *Conclusion:* After 1 year some positive changes but a large group was still struggling with their mental health. Interviews indicate that the forum was valued for finding recognition.

Keywords: suicide survivors, peer support, mental health, web-based forum, depressive complaints

In Europe over 120,000 persons die of suicide each year (Nock et al., 2012). In 2006 the suicide rate was estimated at 7.9 per 100,000 in The Netherlands and 15.2 per 100,000 in Belgium (World Health Organization, 2014). For every suicide, about six persons are affected (Shneidman, 1969) and this number is estimated at 10–15 persons if friends, neighbors, work colleagues, professionals, and therapists are also counted (Dyregrov, 2011).

Those bereaved by suicide more often experience rejection, shame, stigma, and need to conceal the cause of death when compared with those bereaved by other causes of death (Jordan, 2001; Sveen & Walby, 2008). They are less likely to ask for social support as they experience feelings of guilt and feel blamed for the suicide (Cvinar, 2005). For this reason, peer support provides the opportunity for support without feeling troubled by guilt, as the other person is dealing with a similar situation. Peer support can be defined as the social, instrumental, or emotional support that persons sharing similar circumstances provide to each other in a reciprocal fashion (Barlow et al., 2010). Some studies showed that peer support may be helpful and peers are often motivated to help (Barlow et al., 2010; Feigelman, Gorman, Beal, & Jordan, 2008). Compared with face-to-face peer-support, web-based peer support has a number of advantages: 24/7 accessibility, anonymity and privacy, no travel time, and low costs. Web-based support groups were even valued more than face-to-face peer groups for meeting the needs of bereaved parents (Feigelman et al., 2008). They can help create a safe place to talk about suicide openly, to share information and experiences, and to get and provide psychosocial support (Feigelman et al., 2008; Schotanus-Dijkstra et al., 2014; Swartwood, Veach, Kuhne, Lee, & Ji, 2011). Web-based support groups seem to encourage disclosure (Barak & Gluck-Ofri, 2007; Swartwood et al., 2011) and disclosure can have an empowering effect on people in distress (Barak, Boniel-Nissim, & Suler, 2008). By open discussions outside the family circle, survivors of suicide fulfill their own need for support without upsetting other family members (Barlow & Coleman, 2003). At the same time, there is no evidence that

peer support is effective (Cerel, Padgett, Conwell, & Reed, 2009) and it might also have negative aspects. In a longitudinal community-based cohort study, mutual support was associated with a higher risk of complicated grief among persons bereaved by suicide (De Groot & Kollen, 2013). This finding might have to do with a self-selection process, as those who were doing less well might have been more inclined to seek mutual support. The use of a support forum for the bereaved, of which 10% were bereaved due to suicide, did not show any effects on grief, depressive symptoms, emotional loneliness, and positive mood over 3 months (Van der Houwen, Stroebe, Schut, Stroebe, & Van den Bout, 2010). According to the authors, the lack of effects could have to do with the limited follow-up of 3 months that might be too short for changes to become evident. Also, it might be that social support does not accelerate the bereavement process (Stroebe, Zech, Stroebe, & Abakoumkin, 2005). In the present work, we conducted an exploratory study among adults bereaved by suicide to find out more about their mental health and the role a peer support forum plays in their bereavement process. We studied how the feelings of well-being, depression, and complicated grief as well as suicide risk changed over 12 months in visitors of two peer support forums. We also conducted interviews to evaluate the forum and assess its role in the grieving process.

The study protocol was approved by a Dutch Ethics Committee (CCMO nr. NL28240.097.09).

Method

The Support Forums

Two government-funded web-based peer support forums for the bereaved by suicide were involved in the study: one in The Netherlands, founded in 2010, and one in Dutch-speaking Belgium, founded in 2006. A forum is an online discussion site where people can read and/or post messages about a specific topic. The Belgian forum is part of an open-access website (http://www.werkgroepverder.be) focused on the bereaved by suicide. It also offers information, an online chat group, and a memorial website. The Dutch forum is part of an open-access suicide prevention and information website (http://www.113online.nl) mainly focused on people who are suicidal, with options for help by telephone, e-mail, and chat, but the site also provides a peer support forum for those bereaved by suicide. The two forums are similar in terms of layout, structure, and most of the predefined sub-forums. Recently the two forums were analyzed on types of communication used in the messages (Schotanus-Dijkstra et al., 2014). Outcomes showed that sharing personal experiences, expressing support or empathy, and providing advice and recognition were types of communication most frequently used.

On the Dutch forum, registration is needed both for reading and posting. On the Belgian site, registration is needed only for posting messages. Volunteers moderate the forums: They monitor the messages posted and make sure that the visitors follow the rules.

Procedure and Recruitment

All individuals who accessed one of the peer support forums received a notification, asking them to participate in the study. Those interested were referred to web-based information about the study. They could participate if they were aged 18 years or older, had lost someone by suicide, gave informed consent, and completed the baseline questionnaire. Invitations for the web-based follow-up questionnaires were sent 6 and 12 months later. Three reminders were sent if necessary between 1 week and 1 month after the invitation.

Measures

Well-being was assessed with the WHO-Five Well-being Index (WHO-5). The five items of the WHO-5 (Bech, Olsen, Kjoller, & Rasmussen, 2003) cover positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things) and are rated on a 6-point scale ranging from 0 (*never*) to 5 (*all of the time*). The transformed score is calculated by multiplying the total score of the five items by 4, so the total transformed score ranges from 0 to 100. A higher score indicates more well-being, and a score below the cut-off of 52 indicates poor well-being. The WHO-5 was validated in different populations (Bech at al., 2003; Henkel et al., 2003) and Cronbach's α in the present study was at least .87 at baseline and at the 6-month and 12-month follow-up.

Symptoms of depression in the past week were assessed with the 20-item Center for Epidemiological Studies Depression Scale (CES-D; Bouma, Ranchor, Sanderman, & Van Sonderen, 1995; Radloff, 1977). The total score ranges from 0 to 60, with higher scores reflecting more depressive symptoms. A score of 16 or higher indicates a possible case of a clinically relevant depression. Construct validity and reliability of the CES-D are well established; the internal consistency ranges from .79 to .92 (Bouma et al., 1995). In the present study, Cronbach's α was at least .94.

Complicated grief was measured with the Inventory of Traumatic Grief (ITG; Boelen, Van den Bout, De Keijser, & Hoijtink, 2003; Prigerson et al., 1995). The ITG consists of 29 items referring to cognitions, emotions, and behaviors that define normal and complicated grief. The total score has a range of 29–145 with higher scores indicating a higher likelihood of complicated grief. Respondents with scores over 90 possibly meet the criteria for complicated grief. In the present study, Cronbach's α was at least .94.

Suicide risk was assessed with a subscale of the MINI-International Neuropsychiatric Interview in a self-report format (six items, MINI-Plus; Sheehan et al., 1998; Van Vliet, Leroy, & Van Megen, 2000). It classifies respondents into four groups: no risk, low risk, medium risk, or high risk.

A baseline measurement was made of what visitors hoped to find at the forum. Predefined categories were: *information*, *contacts with peers*, *help*, and *other*. The use of the forum was measured at 6 months and 12 months by asking how often participants had read and posted messages in the past 6 months on a 5-point scale ranging from *less than once a month* to (*almost*) *every day*. At 12 months participants were asked if they had experienced benefit from the forum, which could be answered with *yes*, *a little*, and *no*. Sociodemographic information was assessed at baseline.

Interviews

At 12 months, participants could indicate if they wanted to take part in a telephonic interview. Interviewees were selected on (1) representation of those who did and those who did not benefit from the forum, and (2) availability for the interview within 2 months after completing the 12-month questionnaire. The interview was conducted using a semistructured interview scheme by a Dutch and a Belgian research associate, taking 20–30 min each. The questions were about the visitors' expectations regarding the forum, their use of it, the atmosphere and the activity on the forum, the positive and negative aspects of the forum, and what the forum had offered them. They were also asked what they needed at present and what other sources of support or professional help they had.

Table 1. Baseline characteristics of all participants and interviewees

	All participants (N = 270)	Interviewees (n = 29)
Participants on the Belgian forum (n, %)	103 (38.1)	9 (31.0)
Female (n, %)	238 (87.2)	26 (89.7)
Age in years (M, SD)	42.9 (12.4)	45.3 (10.8)
Education level (n, %)		
Low	22 (8.1)	1 (3.4)
Middle	133 (49.3)	14 (48.3)
High	115 (42.6)	14 (48.3)
Living situation (n, %)		
With partner (and children)	149 (55.2)	19 (65.5)
No partner, with children	43 (15.9)	7 (24.1)
Alone	50 (18.5)	3 (10.3)
With parents	11 (4.1)	0 (0)
Other	17 (6.3)	0 (0)
Having a paid job (n, %)	151 (55.9)	19 (65.5)
Time since suicide took place (n, %)		
Less than 1 year ago	87 (32.2)	11 (37.9)
Between 1 and 5 years ago	101 (37.4)	10 (34.5)
5 or more years ago	82 (30.4)	8 (27.6)
Person(s) deceased was/were a (n, %)		
Husband or wife	73 (27.0)	9 (31.0)
Parent	68 (25.2)	4 (13.8)
Child	55 (20.4)	8 (27.6)
Sibling	57 (21.1)	9 (31.0)
Friend	21 (7.8)	0 (0)
Other	21 (7.8)	3 (10.3)

Data Analyses

Data were analyzed with the Statistical Package for the Social Sciences (SPSS, version 19.0). Changes in continuous health variables from baseline to 6 and 12 months were analyzed by means of repeated measures ANOVA. Effect sizes were calculated using Cohen's d (Cohen, 1988) with a positive effect size indicating improvement and a negative effect size a deterioration. For psychological or behavioral interventions, values of d from 0 to 0.32 may be regarded as small, values from 0.33 to 0.55 as moderate, and values from 0.56 or greater as large (Lipsey, 1990). All interviews were recorded, transcribed verbatim, and analyzed with software for qualitative data analysis (MaxQda, version 2007), using a framework approach (Pope, Ziebland, & Mays, 2000; Ritchie & Spencer, 1994).

Results

Participants

Of the 309 people showing interest in the study during the recruitment period from March 2010 to September 2011, n = 270 (87%) completed the baseline questionnaire and were included in the study. Questionnaires were completed at 6 months by 72% (n = 194) and partly by 12% (n = 31). At 12 months, 62% (n = 168) fully completed the questionnaires and 8% (n = 22) partly. Noncompleters did not significantly differ from completers and Belgian participants did not differ from Dutch participants in baseline characteristics, as presented in Table 1 (tested at $p < .05$). Most participants were female (87%). The mean age was 42.9 years (SD = 12.4). Twenty-two participants (8%) reported that they lost more than one person by suicide.

Table 2 shows the mental health variables at baseline for all 270 participants. According to cut-off points, substantial percentages of participants reported mental health problems: about two thirds reported low well-being (WHO-5) and clinical depression (CES-D), while one third showed complicated grief (ITG). Suicide risk was medium to high for nearly one quarter of participants. At baseline, Belgian participants experienced more grief (ITG, M = 83.29, SD = 21.15) than Dutch participants did, M = 77.49, SD = 20.26, $t(268) = -2.25$, $p = .03$. There were no differences between Belgian and Dutch participants on well-being, depression, and suicide risk.

Table 2. Well-being, depressive complaints, complicated grief, and suicide risk at baseline

Variables	All participants (N = 270)	Interviewees (n = 29)
Well-being (WHO-5, range 0–100; *M, SD*)	40.3 (22.4)	37.4 (18.8)
Low well-being (WHO-5 < 52; *n*, %)	179 (66.3)	21 (72.4)
Depressive symptoms (CES-D, range 0–60; *M, SD*)	23.1 (12.6)	24.4 (10.0)
Possible case of depression (CES-D ≥16; *n*, %)	191 (70.7)	25 (86.2)
Grief (ITG, range 29–145; *n*, *SD*)	79.7 (20.8)	81.0 (15.8)
Complicated grief (ITG > 90; *n*, %)	87 (32.2)	11 (37.9)
Suicide risk medium to high (MINI-plus)		
Medium (*n*, %)	46 (17.0)	6 (20.7)
High (*n*, %)	16 (5.9)	0 (0)

Note. WHO-5 = WHO-Five Well-being Index; CES-D = Center for Epidemiological Studies Depression Scale; ITG = Inventory of Traumatic Grief; MINI-plus = MINI-International Neuropsychiatric Interview.

Table 3. Outcomes on well-being and symptoms of depression and grief for completers of questionnaires at baseline, 6 months, and 12 months (n = 155)

Variables	Baseline *M* (*SD*)	6 months *M* (*SD*)	12 months *M* (*SD*)	Statistics
Well-being WHO-5[a]	38.45 (21.81)	43.58 (22.02)	46.27 (23.48)	$F(2, 308) = 14.74$, $p < .001$
Depressive symptoms CES-D[b]	23.59 (12.21)	21.35 (11.77)	20.12 (12.81)	$F(2, 308) = 10.24$, $p < .001$
Grief ITG[b]	80.66 (20.24)	79.72 (21.30)	78.18 (21.11)	$F(1.9, 295.4) = 2.59$, $p = .08$

Note. WHO-5 = WHO-Five Well-being Index; CES-D = Center for Epidemiological Studies Depression Scale; ITG = Inventory of Traumatic Grief; MINI-plus = MINI-International Neuropsychiatric Interview.
[a]A higher score is a more preferable outcome. [b]A lower score is a more preferable outcome.

Mental Health Variables: Changes Over Time

Changes over 1 year were analyzed using data from participants returning information about the mental health questions in all three questionnaires. Mental health outcomes at baseline, 6 months, and 12 months are listed in Table 3. Repeated measures analyses showed a significant increase in well-being and a decrease in depressive symptoms. The pre–post effect sizes were small to medium for well-being (6 months: d = 0.24, 12 months: d = 0.36) and small for depressive symptoms (6 months: d = 0.18, 12 months: d = 0.28). The change in symptoms of grief nearly reached significance (p = .08, 6 months: d = 0.05, 12 months: d = 0.12).

When the cut-off scores were considered at 12 months, 57% of participants (n = 88) still had a low sense of well-being (WHO-5 score below 52), 61% (n = 94) showed signs of clinical depression (CES-D score of 16 or higher), and 27% (n = 42) of the participants were probably experiencing complicated grief (ITC score over 90).

At total of 154 persons returned information on the three measurement points on suicide risk (Table 4). Outcomes in Table 4 show that at 12 months, 17.2% of participants (n = 28) had a medium to high risk for suicide as compared with 20.8% (n = 32) at baseline (there were no significant changes).

Use of the Forum

Table 5 presents an overview of the use of the forum as reported by participants at 12 months. The forum was used more for reading than for posting and participants registered on the Belgian forum visited it more often than those registered on the Dutch forum did: The forum was visited at least once a month by 47% Belgian versus 15% Dutch participants at 6 months, χ^2 (1, n = 225) = 28.76, $p < .001$, and at 12 months by 37% Belgian versus 12% Dutch participants, χ^2 (1, n = 189) = 15.62, $p < .001$.

Expectations and Benefits From Using the Forums

Expectations regarding the forum reported in the baseline questionnaire were as follows: 60% of participants (n = 163) indicated that they were looking for contact with peers, 44% hoped to find information (n = 118), and 20% (n = 55) hoped to find help. Other reasons mentioned for visiting it were curiosity, to be of help, to find out why their loved one had taken his/her own life, and to see if the forum could be a substitute for a face-to-face self-help group.

At 12 months, 35 participants (22.3%) experienced benefit from taking part in the forum, 63 (40.1%) experi-

Table 4. Suicide risk for completers of questionnaires at baseline, 6 months, and 12 months (n = 154)

	Baseline	6 months	12 months
	n (%)	*n* (%)	*n* (%)
No risk	88 (57.1)	89 (57.8)	101 (65.6)
Low risk	34 (22.1)	29 (18.8)	25 (16.2)
Medium risk	26 (16.9)	26 (16.9)	18 (11.7)
High risk	6 (3.9)	10 (6.5)	10 (6.5)

enced "a bit" of profit, and 59 (37.6%) participants did not experience benefit at all.

Outcomes of the Interviews

Telephonic interviews were conducted with 29 persons representing those who did (n = 16, 55.2%) and those who did not benefit from the forum (n = 12, 41.4%). For one person the benefit was unknown. Baseline characteristics of the interviewees are shown in Tables 1 and 2. Nine (31.0%) interviewees visited the Belgian and 20 (69%) the Dutch forum. The majority of interviewees were female (n = 26, 89.3%).

Right after they first registered for the forum, the frequency of visiting the forum was the highest for most interviewees. The reasons mentioned for visiting the forum were to find similar situations as their own (n = 16, 55%), to find recognition (n = 14, 48%), and to find peers to share experiences with (n = 7, 24.1%). Other reasons were to find information (n = 5), out of curiosity (n = 3), to find professionals (n = 1), to look for positive aspects (n = 1), and to be of help to others (n = 1). Twelve interviewees (41.4%) had posted messages. They reacted to others and posted their own stories and nearly all got reactions they appreciated. Those who did not post (n = 17, 58.6%) felt no need to, did not want to share personal information with strangers, and expected sad and/or confrontational stories and reactions from others. Positive aspects of the forum were mentioned by nearly all (n = 27, 93%) interviewees. They indicated they were greatly helped by finding recognition (n = 19, 65.5%), support (n = 4, 13.8%), and the idea that there was now a place to go to when in need (n = 7, 24.1%). Recognition of similar situations was sometimes challenging and could evoke intense emotions but this was also what they were looking for: similarities. They also liked the forum for its anonymity, low threshold, and openhearted atmosphere. Sixteen interviewees (55%) expressed criticism about the forum. They mentioned that the forum gave a depressive feel because of the negative load of the topics and that the forum was cluttered and needed more structure. Furthermore, it was found that reaction speed to messages was sometimes too low, that messages were too old to react to, and that there was little positive news at the forum, something that would have been very welcome giving hope that things could eventually get better. Eight (27.6%) respondents in the Dutch forum indicated that too few messages were posted. One person thought that written words came across harder than spoken words. A good thing is that no improper behavior of others was mentioned, which might have to do with the work of the moderators.

Eight (28%) interviewees reported having visited the forum recently, the majority (n = 21, 72%) did not do so. Reasons were that they distanced themselves from the situation, felt better, did not want to stir up emotions anymore, and wanted to get on with their lives. One person was advised by a therapist not to visit the forum because it hindered her coming to terms with her sorrow. When asked what they presently needed most, 50% (n = 13) mentioned they needed peace and to move on with their lives, 34.5% (n = 10) wanted to talk normally about the deceased or share experiences with others, two persons needed professional help, two sought information, and one person wanted to be of help to others. Apart from the forum, 72% (n = 21) had social support from their relatives, friends, neighbors, and co-workers, 45% (n = 13) had face-to-face contact with others who were bereaved by suicide, 79% (n = 23) visited a health professional like a psychologist/psychiatrist, and five (17%) visited the general practitioner related to the loss.

Discussion

To date, not much evidence has been provided on the effects of forums for the bereaved by suicide on mental health (Van der Houwen et al., 2010). Although our study showed that over 1 year there were small to medium-sized positive changes in well-being and depressive complaints in visitors of two forums, the design of the study did not

Table 5. Platform use at 6 months and 12 months

	6 months (n = 225)		12 months (n = 189)	
	Reading *N* (%)	Posting *N* (%)	Reading *N* (%)	Posting *N* (%)
Less than once a month	165 (73.3)	210 (93.3)	152 (79.6)	179 (94.7)
One or two times a month	35 (15.6)	9 (3.3)	24 (12.6)	7 (2.6)
One or two times a week	11 (4.9)	5 (1.9)	4 (2.1)	2 (1.1)
Three or four times a week	6 (2.7)	1 (0.4)	4 (2.1)	0 (0.0)
(Nearly) every day	8 (3.0)	0 (0.0)	7 (3.7)	1 (0.5)

allow us to conclude that these changes were brought about by using the forum. At the same time, 63% of participants reported they had experienced benefit from using the forum. According to the interviews, the value seemed to lie in recognition and in having a place to go to when in need, which is in line with the findings of Feigelman et al. (2008). After a while the visitors seemed to distance themselves from the forum, mostly because they wanted to move on with their lives.

The limited use of the forum by participants in our study contrasts sharply with the study of Van der Houwen et al. (2010) and Feigelman et al. (2008), where participants spent 6–7 hr per week interacting on the forum. The low frequency in our study might have to do with social support or professional help outside the forum, as 72% of the interviewees indicated they had support from their social network and from professionals. This might imply that the forum was not a substitute for other sources of support in this study, but that is was an addition, as also found in the study of Van der Houwen et al. (2010). Moreover, in our study not many persons posted messages. Perhaps the benefit for mental health would have been higher if more visitors had posted their own stories, as sharing personal experiences seems to be an effective mechanism for coping with grief (Feigelman, Jordan, & Gorman, 2009). At the same time, reading about experiences of others can be just as empowering as posting messages (Van Uden-Kraan, Drossaert, Taal, Seydel, & Van de Laar, 2008). Still, the forum needs enough participants willing to share their experience and to respond to others to make it feel like a community.

Despite the positive changes seen over time, at 12 months a large group still struggled with their grief and mental health: 61% of participants were probably clinically depressed, 57% had a low level of well-being, 27% showed symptoms of complicated grief, and 6.5% had a high risk of suicide. These high levels of mental health problems are in line with studies indicating that increased suicidality, depression, and complex grief are mental health problems commonly identified among those bereaved by suicide (Feigelman et al., 2008).

Limitations

Our study had several limitations. First and as already mentioned, we cannot draw conclusions about the influence of the forum on the changes in mental health, as these can also be part of the natural recovery processes or due to other sources of support or professional help. A randomized trial is needed to assess the added effect of a support forum. Second, data of the two forums were combined. Although baseline characteristics were similar for participants on the two forums, there were significant differences in levels of grief at baseline, which might challenge the decision to combine the data. However, the statistical power was too weak to analyze the data from the two forums separately or to compare them. Furthermore, we had to rely on self-report about the mental health outcomes and that might have caused recollection bias. For the frequency of forum use, we also had to rely on self-report at 6 and 12 months which might not give us the right indication of forum use. The interviews indicate that the forum was used the most by visitors right after they had registered on it. It is advisable to track online the individual use of the forum to get a clearer view of the users' visiting patterns. Another limitation is that a large group (43%) did not complete all three questionnaires, a fairly well-known phenomenon in web-based studies (Eysenbach, 2005). Dropout might have influenced outcomes, for instance, when responders felt much better or much worse compared with those who did not respond. Also, we do not know if the participants in this study were representative of the users of peer support forums or of those bereaved by suicide in society. As 87% of the participants were female, the findings are mostly generalizable for females visiting the forum.

A final limitation was that the Dutch forum was launched 1 month before the recruitment started, when the forum was not yet at its full capacity.

Conclusion

Web-based peer support forums for those bereaved by suicide attract many persons struggling with well-being, depressive symptoms, and grief. The participants in this study showed small to medium improvements in well-being and depressive symptoms over 1 year. Although it is not clear what the impact of the forum is on mental health and the grieving process, two thirds of the participants found the online forum beneficial. The use of the forum was valued as a way to find recognition, as a place to go to in difficult times, for the social support, and for the transition support.

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About the authors

Jeannet Kramer, PhD, is a scientific researcher and developer of e-mental health interventions in the Innovation Centre of Mental Health & Technology (I.COM) of the Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Utrecht, The Netherlands. She has been conducting several randomized trials focused on the effectiveness of e-mental health interventions.

Brigitte Boon, PhD, is the head of the department of Public Mental Health of the Trimbos Institute (Netherlands Institute of

Mental Health and Addiction), Utrecht, The Netherlands. She is charged with the development, evaluation, and implementation of interventions directed at promoting mental health and the prevention of mental disorders, with a special focus on e-mental health.

Wouter van Ballegooijen, PhD, is a postdoctoral researcher in the Department of Clinical Psychology at VU University Amsterdam, The Netherlands, and at the Department of Psychiatry of GGZ inGeest, Amsterdam, The Netherlands. His interests include Internet interventions, online screening, and other e-mental health applications for depression, anxiety disorders, and suicidal ideation.

Marijke Schotanus-Dijkstra, MSc, is a scientific researcher and PhD student at Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Utrecht, The Netherlands. She works in the field of public mental health and evaluates prevention interventions with a main interest in positive psychology interventions.

Ad Kerkhof, PhD, is a professor of clinical psychology, psychopathology, and suicide prevention at the Faculty of Psychology and Education of the VU University in Amsterdam, The Netherlands. He is former editor-in-chief of *Crisis*. His main interests are the epidemiology of suicidal behavior, public health and suicide prevention, and online suicide prevention.

Agnes van der Poel, PhD, is member of the senior scientific staff of the program Public Mental Health of the Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Utrecht, The Netherlands. As project leader, she works in the field of prevention of depression (implementation and research).

Jeannet Kramer

Trimbos Institute
Innovation Centre of Mental Health and Technology (I.COM)
P.O. Box 725
3500 AS Utrecht
The Netherlands
Tel. +31 30 295-9380
Fax +31 30 297-1111
E-mail jkramer@trimbos.nl

