

Internet-Based Psychotherapy in Young Adult Survivors of Pediatric Cancer: Feasibility and Participants' Satisfaction

Diana C.M. Seitz, PhD,¹ Christine Knaevelsrud, PhD,² Gabriele Duran, PhD,³ Sabine Waadt, PhD,³ and Lutz Goldbeck, PhD¹

Abstract

The Internet-based psychotherapeutic intervention Onco-STEP for adolescent and young adult (AYA)-aged survivors of pediatric cancer was developed, implemented, and participants' satisfaction was evaluated by use of questionnaires. The intervention consisted of two modules: "Looking Back," aimed to reduce posttraumatic stress symptoms, and "Looking Ahead," supported coping with cancer-related fears of relapse and progression. The writing program was fully completed by 20 participants ($M_{\text{age}} = 27.3 \pm 4.8$ years at study; 70% female). The majority was satisfied and perceived the treatment components as helpful. Results demonstrate that an Internet-based psychotherapeutic intervention for AYA-aged survivors of pediatric cancer is feasible and accepted by the target population.

Introduction

PREVALENCE OF CLINICALLY RELEVANT posttraumatic stress symptoms (PTSS) is elevated in survivors of pediatric cancer.¹⁻³ In addition, survivors experience a certain amount of dysfunctional anxiety⁴⁻⁶ and the most frequent worries are the fear of a relapse, a secondary malignancy, or that their future children might be affected by a cancer diagnosis as well.⁷ With respect to those worries, it is often referred to the concept of fear of progression (FoP) or recurrence.⁸

An integration of psycho-oncological care in routine treatment leads to positive outcomes with respect to the patient's well-being.⁹ A recent German study demonstrated, however, that only half of the young adult survivors of pediatric cancer ever receive any sort of psychotherapeutic care, and especially in the long-term, only a limited number of adolescent and young-adult (AYA)-aged survivors is receiving the required treatment.¹⁰ Although there are many international attempts, which offer special follow-up programs, psychological care for this population needs to be optimized so that a larger proportion of AYA-aged survivors can be reached, especially those in need but not visiting the medical setting regularly or the geographically dispersed.¹¹ Nowadays, many AYAs are "online" and using the Internet when seeking information.^{12,13} The effectiveness of Internet-based psychotherapeutic interventions has been demonstrated in a meta-analysis, and effect sizes are quite similar to face-to-

face therapies.^{14,15} With respect to physical illness, the data available so far are very limited and underpowered but—especially for cognitive behavior therapy—promising.^{16,17} The resources evaluated for cancer patients, however, are either psycho-educational, self-help, or online peer-support groups.¹⁶

The aim of the study was to develop an innovative Internet-based intervention for AYA-aged survivors of pediatric cancer, which is easily accessible and can help them to cope with clinically relevant PTSS and/or anxiety. The new intervention is briefly described, and in addition, we aimed to gather data, with respect to the viability, and to evaluate the participants' satisfaction. We hypothesized that an Internet intervention is feasible, rated as helpful, and that AYA-aged users are satisfied.

Materials and Methods

Procedure

First, a data security policy was developed, a treatment manual prepared, and an Internet platform implemented. Participants were able to register on the homepage between May 2011 and June 2012. They were approached by the distribution of information about the project in flyers, newspaper articles, broadcasts, Internet platforms, and by presentations in hospitals, follow-up clinics, and survivor meetings.

After confirmation of the e-mail address, all participants were asked to complete an online questionnaire by logging on to the secure Web site. The questionnaire was administered to

¹Department of Child and Adolescent Psychiatry and Psychotherapy, University Hospital Ulm, Ulm, Germany.

²Department of Clinical Psychology and Psychotherapy, Free University Berlin, Berlin, Germany.

³Department of Psychosomatic Medicine and Psychotherapy, Klinikum rechts der Isar, Hospital rechts der Isar, Technical University of Munich, Munich, Germany.

determine if all inclusion criteria were fulfilled. Inclusion criteria were: diagnosed with cancer < 19 years of age; current age of ≥ 15 years; completion of cancer treatment ≥ 6 months prior to the study; stable remission; clinically relevant PTSS (score ≥ 11 on the Posttraumatic Stress Diagnostic Scale; range 0–51¹⁸) or symptoms of anxiety (≥ 8 on the anxiety scale of the Hospital Anxiety and Depression Scale; range 0–21¹⁹); not participating in any other psychotherapy during Onco-STEP; and not showing acute suicidality or symptoms of a psychosis.

In case of symptoms of suicidality or psychosis in the study entry questionnaire, participants were contacted by phone to assure that they did not need more close-meshed support. Once all inclusion criteria were fulfilled and participants gave their informed consent (additional parental consent was obligatory for applicants < 18 years of age), participants were able to communicate with their individual therapist. All people who could not be included received individualized feedback and information about other sources of support. The study was approved by the Ethics committee of the University of Ulm and listed in the German Clinical Trial Registry (DRKS00000653, UTM U1111-1119-0859).

Description of the intervention

Onco-STEP is the first manualized cognitive-behavioral intervention consisting of 10 writing assignments extended over a period of approximately 5–6 weeks. It contains two modules, each consisting of five writing sessions. The first module, called “Looking Back,” is based on the principles of Internet-based

therapy of posttraumatic stress disorder (PTSD) and contains five essays.^{20,21} The second module, named “Looking Ahead,” is aligned to an intervention for dysfunctional fear of progression and also includes five essays (see Fig. 1).²²

The participants and therapists communicated exclusively by web-based messages asynchronous on the secure website www.onko-step.de. Prior to every writing assignment, the participants received instructions from their individual therapist, and were asked to spend 45 minutes for each essay according to a scheduled timetable set by the participants. Within 48 hours, all participants received individual feedback and further instructions on how to proceed. The instructions were tailored to each patient’s need but always according to the structured treatment manual. The treatment was delivered by two psychologists located at the Department of Child and Adolescent Psychiatry/Psychotherapy at the University Hospital Ulm, who were trained in the intervention and supervised by experts in Internet-based therapy for PTSD, and experts for an intervention for FoP.

Looking back

In the first three writing assignments, “Worst memory” of the first module, participants are asked to write about their most painful experience during their cancer illness. The goal of these three units is to evoke actualization, self-confrontation, and imaginative exposition with the traumatic experience by a detailed remembrance of the most painful event and the accompanying thoughts and feelings.

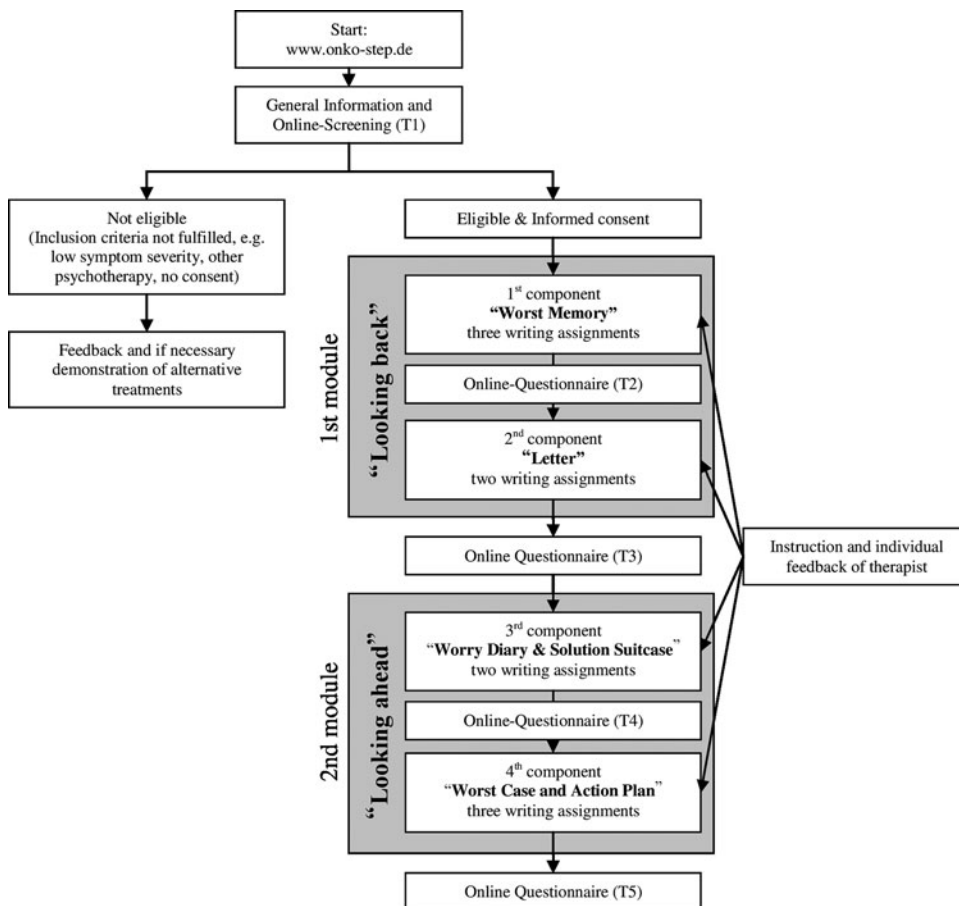


FIG. 1. Schematic description of the Onco-STEP intervention and evaluation.

The goal of the next two essays, called “Letter,” is to evoke cognitive restructuring and transformation of dysfunctional thoughts associated with the traumatic event by writing a supportive letter, addressed to themselves in the past at the time they went through their most painful experiences. When doing so, they should dispute dysfunctional and automatic thoughts, as well as maladaptive feelings that are associated with their own traumatic experience, and tell in which ways they have experienced any positive consequences.

Looking ahead

The second module is aimed to ease coping with cancer-related fears of a relapse and progression. The goal of the two writing assignments “Worry Diary” and “Solution Suitcase” is an actualization of current fears, to strengthen the participants’ self-awareness, to enhance the participants’ existing resources, and to understand the associations between their own experiences, behavior, and consequences. Thus, participants are asked to self-monitor, fill in a table, and note every anxious feeling with respect to their current health, potential progression, or relapse of their cancer disease within the last days. When doing so, participants should specify the situation in which they had experienced the fear, their thoughts, their physiological and emotional reactions, and the intensity of the fear, as well as finding strategies that help them to cope with the individual fears experienced.

The goal of the next two writing assignments “Worst Case” is to decatastrophize, reappraise, and cognitively restructure the maladaptive thoughts by a self-confrontation

with the most worrying fear. Thus, participants are asked to describe what would happen if the most distressing fear would come true. Instead of avoiding and catastrophizing, participants are guided to take on a more realistic view and split the worst event into sub-problems. The goal of the last essay is to reflect on the therapeutic process, to activate resources, and to initiate behavioral change. Participants are asked to write an “Action Plan” in which they summarize what they have learned and how they will cope in the future, so they will not get overwhelmed by their fears in their daily life.

Measures

The self-report online questionnaire included items concerning socioeconomic background (age, sex, educational level, employment status, and partnership), medical information related to cancer illness (cancer site and age at cancer onset, oncology treatment, second malignancies, or cancer relapse), and utilization of psychosocial services, suicidality, and psychotic symptoms.

To evaluate satisfaction, questions developed by the investigators concerning the participants’ subjectively perceived ratings were administered four times, at the end of each component (see also Fig. 1). Helpfulness, whether they would recommend the intervention to a friend, and fulfillment of expectations were rated on a 5-point scale ranging from “not at all/never,” to “totally/always.” Satisfaction with the previous writing assignment was indicated on a scale ranging from 1 = “very satisfied” to 6 = “very unsatisfied.”

FIG. 2. Flow chart of participation.

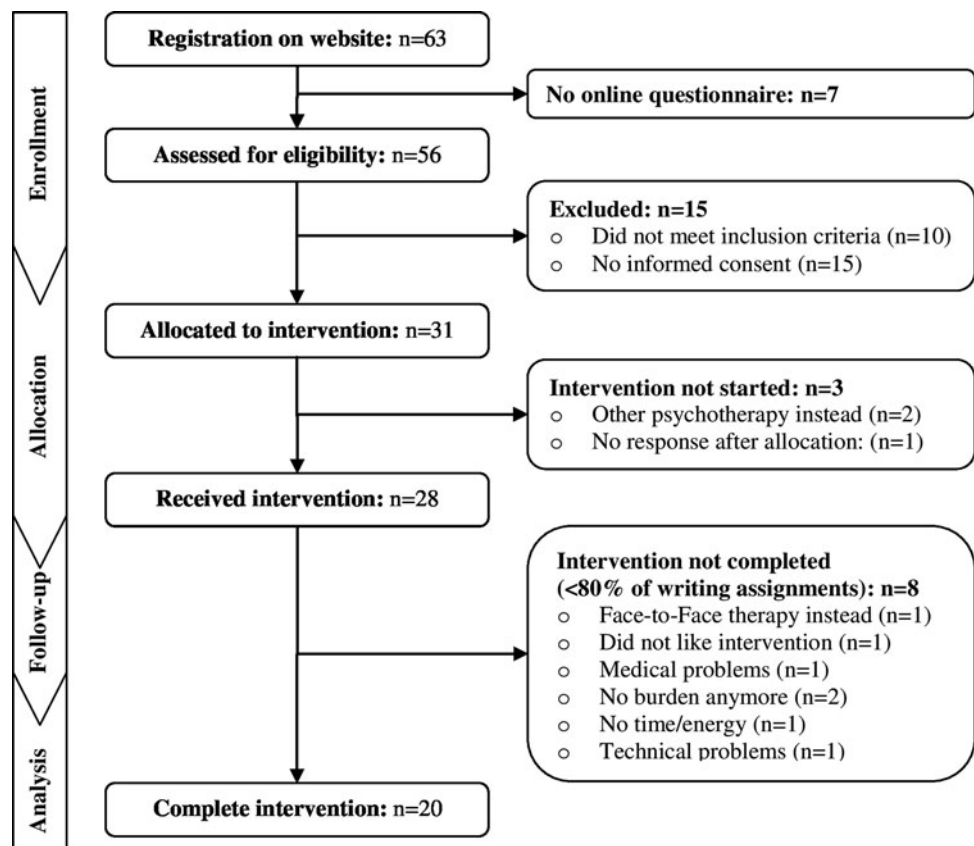


TABLE 1. DEMOGRAPHICS OF THE STUDY SAMPLE

	<i>Survivors (n=20)</i>
Age in years at enrolment to the study ($M \pm SD$, range)	27.25 \pm 4.83 (20–36)
Sex (male:female)	6:14 (30.0%:70.0%)
Partnership	
Stable relationship	10 (50.0%)
No stable relationship	10 (50.0%)
Education level	
None (<9 years of education, without graduating)	1 (5.0%)
Low (mandatory basic school, with 9 years of education)	1 (5.0%)
Middle (intermediate type of advanced school, with 10–11 years of education)	1 (5.0%)
High (advanced school, with 12–13 years of education)	17 (85.0%)
Employment status	
Still in education	5 (25.0%)
Employed	13 (65.0%)
Other (e.g., maternity leave, unemployed)	2 (10.0%)
Age at diagnosis in years ($M \pm SD$)	13.45 \pm 4.71
Time since diagnosis in years ($M \pm SD$)	13.80 \pm 4.70
Type of cancer	
Leukemia	8 (40.0%)
Lymphoma	6 (30.0%)
Central nervous system tumor	4 (20.0%)
Soft tissue sarcoma	1 (5.0%)
Germ cell tumor	1 (5.0%)
Relapse or second malignancy	4 (20.0%)

Participants

Out of 63 people who registered, 56 answered the online questionnaire, and 28 were eligible and began the intervention. The most frequent reason for not fulfilling the inclusion criteria was a symptom score below the threshold. People

who did not provide their written informed consent—presumably because they did not want to lose full anonymity—could also not be allocated to the intervention ($n=15$). Two other people decided to start a face-to-face psychotherapy instead and did not start with intervention as well. Twenty survivors participated in Onco-STEP (dropout rate 28.6%) as intended and successfully completed all of the 10 writing assignments. Figure 2 presents a flow diagram of participants throughout the study and the reasons for not fully completing the intervention. The sociodemographic and medical information can be found in Table 1.

Statistical analyses

Data were evaluated descriptively. Frequencies, means, and standard deviations were computed with the statistics program IBM SPSS Statistics for Windows v20 (IBM Corp., Armonk, NY). In order to make the subjectively perceived ratings of the four components comparable, only data of persons fully completing the intervention were analyzed.

Results

The satisfaction with the four treatment components was positive and best for the components “Worst Memory,” “Worst Case,” and “Action Plan,” where more than 80% indicated that they were satisfied (score ≤ 2 ; scale ranging from 1 = “very satisfied” to 6 = “very unsatisfied”). The lowest satisfaction was revealed for the “Worry Diary” and “Solution Suitcase,” but still 75% indicated that they were rather satisfied than unsatisfied (score ≤ 3). With respect to the perceived helpfulness, more than 80% of the participants indicated that they perceived the treatment components at least partly helpful, whereas the “Worst Case” and “Action Plan” were considered the most helpful (see Table 2).

When being asked which of the two modules participants preferred, 50% indicated that they enjoyed both modules the same, 40% preferred the first module “Looking Back,” and 10% the second module “Looking ahead.” At the end of the intervention, participants indicated whether they would recommend the intervention to a friend going through a similar situation, and 90% answered “totally/always” or

TABLE 2. SUBJECTIVE RATINGS OF THE PARTICIPANTS WITH RESPECT TO SATISFACTION AND HELPFULNESS OF THE FOUR TREATMENT COMPONENTS OF ONCO-STEP ($N=20$)

	“Looking Back”		“Looking Ahead”	
	Worst Memory ($n=20$)	Letter ($n=20$)	Worry Diary and Solution Suitcase ($n=20$)	Worst Case and Action Plan ($n=20$)
<i>Satisfaction</i>				
1 = very satisfied	25% ($n=5$)	30% ($n=6$)	35% ($n=7$)	40% ($n=8$)
2	60% ($n=12$)	30% ($n=6$)	10% ($n=2$)	40% ($n=8$)
3	15% ($n=3$)	25% ($n=5$)	30% ($n=6$)	15% ($n=3$)
4	0% ($n=0$)	15% ($n=3$)	15% ($n=3$)	5% ($n=1$)
5	0% ($n=0$)	0% ($n=0$)	5% ($n=1$)	0% ($n=0$)
6 = very unsatisfied	0% ($n=0$)	0% ($n=0$)	5% ($n=1$)	0% ($n=0$)
<i>Helpfulness</i>				
Not at all/never	0% ($n=0$)	0% ($n=0$)	0% ($n=0$)	0% ($n=0$)
Marginally/infrequently	10% ($n=2$)	15% ($n=3$)	20% ($n=4$)	0% ($n=0$)
Partially/sometimes	10% ($n=2$)	25% ($n=5$)	25% ($n=5$)	15% ($n=3$)
Predominantly/mostly	50% ($n=10$)	15% ($n=3$)	15% ($n=3$)	35% ($n=7$)
Totally/always	30% ($n=6$)	45% ($n=9$)	40% ($n=8$)	50% ($n=10$)

“predominantly/mostly.” With respect to the question of whether Onco-STEP had fulfilled their expectations, 75% noted that this was true “totally/always” or “predominantly/mostly.” Only 15% indicated that they desired a deeper or more intense processing of particular topics, especially of the module “Looking Back.”

Discussion

This pilot study demonstrated that a cognitive behavioral Internet-based psychotherapeutic intervention to reduce PTSS and illness-related anxiety for AYA-aged survivors of pediatric cancer is feasible and rated as helpful, and that participants are satisfied. Onco-STEP, the first individually therapist-guided Internet intervention for AYA-aged survivors of pediatric cancer, turned out to be a viable source of support. The pretreatment dropout rate and number of persons with only partial participation were comparable to other individualized e-health interventions.^{21,23}

The majority rated Onco-STEP—and both modules to the same degree—as very helpful. On the one hand, they were satisfied with sharing their traumatic cancer experience in order to cope in the future; on the other hand, they were also very pleased to be able to dispute their most frightening fear with respect to progression and relapse of their disease, and to generate an action plan. In addition, participants would recommend the intervention to a friend in need. Thus, we can conclude that the participants were satisfied and appreciated the intervention.

Only the satisfaction and helpfulness of the worry diary and solution suitcase were rated lower than the remaining components. This could be due to the format in which they had to be handled (completing a table instead of writing a text) or since they require daily effort and discipline. Thus, the arrangement of those two writing assignments might have to be revised for future applications. On the whole, findings should be interpreted cautiously considering the small sample size, the self-selection to participate, and the lack of a comparison group. Although participants had a wide age range, we did not reach out for adolescents aged 15–17. Nevertheless, we managed to recruit predominantly survivors of leukemia, lymphoma, and central nervous system tumors—the most common pediatric cancer diagnoses. Our sample comprised primarily well-educated females. Therefore, generalization of our findings beyond this population should be done with caution. In the future, we need to consider how to approach adolescent survivors. It also has to be noted that a large number of people were not willing to provide their written informed consent. This barrier of losing anonymity was necessary due to the nature of a research project but would not be mandatory in routine care.

Conclusion

Although psychosocial care is available for survivors of cancer, only a small percentage of patients are receiving the support they need. It is therefore necessary to find methods of support that are tailored to and acknowledged by the target population. Second, an evaluation of its efficacy is warranted, since the empirical evidence for psychotherapeutic interventions for AYAs is very limited.²⁴ Thus, the current paper closes the gap between the unmet needs of survivors of pediatric cancer and the consequently arising question of

empirical evidence. With Onco-STEP, we have a legitimate intervention, which is feasible and practicable. In addition, the results suggest that the intervention was successfully tailored to the participants' needs. The subsequent evaluation of its efficacy revealed that Onco-STEP is efficacious in reducing symptoms of PTSS and anxiety.²⁵ Future efforts should now be put into investigating specific evidence in a randomized controlled trial.

Acknowledgment

The study was funded by the Deutsche Krebshilfe e.V.

Author Disclosure Statement

No competing financial interests exist.

References

1. Rourke MT, Hobbie WL, Schwartz L, et al. Posttraumatic Stress Disorder (PTSD) in young adult survivors of childhood cancer. *Pediatric Blood & Cancer* 2007; 49:177–182.
2. Schwartz L, Drotar D. Posttraumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *Journal of Pediatric Psychology* 2006; 31:356–366.
3. Hobbie WL, Stuber M, Meeske K, et al. Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *Journal of Clinical Oncology* 2000; 18:4060–4066.
4. Seitz DCM, Besier T, Debatin K-M, et al. Posttraumatic stress, depression, and anxiety among adult long term survivors of cancer in adolescence. *European Journal of Cancer* 2010; 46:1596–1606.
5. Michel G, Rebholz CE, von der Weid NX, et al. Psychological distress in adult survivors of childhood cancer: the Swiss Childhood Cancer Survivor study. *Journal of Clinical Oncology* 2010; 28:1740–1748.
6. Servtzigoglou M, Papadatou D, Tsiantis I, et al. Psychosocial functioning of young adolescent and adult survivors of childhood cancer. *Supportive Care Cancer* 2008; 16:29–36.
7. Langeveld NE, Grootenhuis MA, Voute PA, et al. Quality of life, self-esteem and worries in young adult survivors of childhood cancer. *Psycho-Oncology* 2004; 13:867–881.
8. Herschbach P, Berg P, Danker A, et al. Fear of progression in chronic diseases: Psychometric properties of the Fear of Progression Questionnaire. *Journal of Psychosomatic Research* 2005; 58:505–511.
9. Kazak AE. Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology* 2005; 30:29–39.
10. Dieluweit U, Seitz DC, Besier T, et al. Utilization of psychosocial care and oncological follow-up assessments among German long-term survivors of cancer with onset during adolescence. *Klinische Pädiatrie* 2011; 223:152–158.
11. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer* 2011; 117:2329–2334.
12. Gray NJ, Klein JD, Noyce PR, et al. Health information-seeking behaviour in adolescence: the place of the Internet. *Social Science & Medicine* 2005; 60:1467–1478.
13. Gould MS, Munfakh JL, Lubell K, et al. Seeking help from the Internet during adolescence. *Journal of the American Academy of Child and Adolescent Psychiatry* 2002; 41:1182–1189.

14. Barak A, Hen L, Boniel-Nissim M, et al. A comprehensive review and a meta-analysis of the effectiveness of Internet-based psychotherapeutic interventions. *Journal of Technology in Human Services* 2008; 26:109–160.
15. Amstadter AB, Broman-Fulks J, Zinzow H, et al. Internet-based interventions for traumatic stress-related mental health problems: a review and suggestion for future research. *Clinical Psychology Review* 2009; 29:410–420.
16. Leykin Y, Thekdi SM, Shumay DM, et al. Internet interventions for improving psychological well-being in psycho-oncology: review and recommendations. *Psychooncology* 2011; 21:1016–1025.
17. Andersson G, Ljotsson B, Weise C. Internet-delivered treatment to promote health. *Current Opinion in Psychiatry* 2011; 24:168–172.
18. Ehlers A, Steil R, Winter H, et al. Deutsche Übersetzung der Posttraumatic Stress Diagnostic Scale (PDS). University of Oxford, Oxford, unpublished, 1996.
19. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* 1983; 67: 361–370.
20. Knaevelsrud C, Maercker A. Internet-based treatment for PTSD reduces distress and facilitates the development of a strong therapeutic alliance: a randomized controlled clinical trial. *BMC Psychiatry* 2007; 7:13.
21. Lange A, Rietdijk D, Hudcovicova M, et al. Interapy: a controlled randomized trial of the standardized treatment of posttraumatic stress through the Internet. *Journal of Consulting & Clinical Psychology* 2003; 71:901–909.
22. Herschbach P, Book K, Dinkel A, et al. Evaluation of two group therapies to reduce fear of progression in cancer patients. *Supportive Care in Cancer* 2010; 18:471–479.
23. Duffecy J, Sanford S, Wagner L, et al. Project onward: an innovative e-health intervention for cancer survivors. *Psychooncology* 2013; 22:947–951.
24. Seitz DCM, Besier T, Goldbeck L. Psychosocial interventions for adolescent cancer patients: a systematic review of the literature. *Psycho-Oncology* 2009; 18:683–690.
25. Seitz DCM, Knaevelsrud C, Duran G, et al. Efficacy of an Internet-based cognitive-behavioral intervention for long-term survivors of pediatric cancer: a pilot study. *Support Care Cancer* 2014 22:2075–2083.

Address correspondence to:

*Dr. Diana C.M. Seitz
Department of Child and Adolescent
Psychiatry and Psychotherapy
University Hospital Ulm
Steinhoevelstr. 5
89075 Ulm
Germany*

E-mail: diana.seitz@uniklinik-ulm.de