



*Internet-Based Cognitive Behavioral Therapy for Sexual Dysfunctions after
Breast Cancer*
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SUMMARY

As a result of improved detection and treatment of breast cancer (BC), survival rates have improved, resulting in more attention for quality of life-related topics in BC survivors, including sexual functioning. Sexual problems are a frequent, long-term consequence of the diagnosis and treatment of BC. Frequently occurring sexual problems in BC survivors include decreased sexual desire, decreased sexual arousal and vaginal lubrication, dyspareunia, and vaginal dryness and atrophy. Although the prevalence of sexual problems among BC survivors is high, not all of these women experience sexual problems that meet criteria for a diagnosis of sexual dysfunction according to the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV). Women with a DSM-IV dysfunction experience severe sexual problems that cause significant distress and that warrant professional help. The trial described in this thesis included BC survivors with a diagnosis of sexual dysfunction according the criteria of the DSM-IV.

Chapter 1 introduces Internet-based cognitive behavioral therapy (CBT) as a promising treatment option for DSM-IV-based sexual dysfunctions in BC survivors. Although traditional treatment methods such as face-to-face CBT are effective in alleviating sexual dysfunctions, there is a discrepancy between the reported need for sexual health care and the actual uptake of such care by BC survivors. Internet-based CBT could be an alternative, especially considering aspects of online therapy such as anonymity and accessibility, which may be particularly attractive in the treatment of sexual problems and which might lower the barrier for BC survivors to seek professional help for their sexual problems. Therefore, we evaluated the efficacy of an Internet-based CBT program to improve the sexual functioning of BC survivors with a DSM-IV sexual dysfunction.

In this thesis, we posed the following research questions:

1. Which patient-related and clinical factors are associated with BC survivors' sexual functioning and sexual distress, and with the sexual functioning of their partners?
2. What is the short-term efficacy of Internet-based CBT in improving the sexual functioning, sexual distress and other psychosocial outcomes in BC survivors with a DSM-IV sexual dysfunction?
3. What is the long-term effect of Internet-based CBT on the sexual functioning, sexual distress and other psychosocial outcomes in BC survivors with a DSM-IV sexual dysfunction?
4. What are the predictors of post-CBT sexual functioning and sexual distress of BC survivors with a DSM-IV sexual dysfunction who received Internet-based CBT?
5. What is the effect of Internet-based CBT on the sexual functioning and relationship satisfaction of partners of BC survivors with a DSM-IV sexual dysfunction?

Chapter 2 describes the design of the randomized controlled trial (RCT) in which we evaluated the efficacy of Internet-based cognitive behavioral therapy (CBT) program for sexual dysfunctions in BC survivors. Primary outcomes included sexual functioning and relationship intimacy, and secondary outcomes included body image, marital functioning, menopausal symptoms, psychological distress and health-related quality of life (HRQL). We compared the Internet-based CBT program to a waiting-list control group. Briefly, the CBT consisted of 4-5 modules (selected out of a total of 10 modules by the psychologist/sexologist) that best suited the sexual problems of each participant. Each module contained several interventions, each of which comprised the following elements: an introduction, psycho-education, homework assignments, reports to the therapist and receiving feedback from the therapist. This resulted in a program of approximately 20 therapist-guided weekly sessions that had to be completed within 24 weeks. The contact between the therapist and participant took place via email and was asynchronous. Women were encouraged by their therapist to involve their partner in the treatment. However, participation of the partner was not mandatory. Outcome measures were assessed at baseline (T0), mid-CBT (T1), immediate post-CBT (T2), and at equivalent times in the control group. Women in the intervention group completed additional questionnaires at three (T3) and nine months (T4) follow-up. Women in the waiting-list control group were offered the CBT program after completion of the T2 assessment.

Chapter 3 describes the baseline data that were collected as part of our RCT and provides insight into the sexual functioning of BC survivors with a DSM-IV sexual dysfunction and their partners. The most frequently diagnosed sexual dysfunctions in our sample of BC survivors were hypoactive sexual desire disorder (83%), sexual arousal disorder (40%) and dyspareunia (33%). Women who had been treated with endocrine therapy were more often diagnosed with hypoactive sexual desire disorder (HSDD), and women treated with immunotherapy more often with dyspareunia. In line with research in the general population, older age was associated with less sexual distress. Not only the BC survivors' sexual functioning, but also that of their partners was affected, as was evident from the large proportion (55%) of the male partners that reported moderate or severe erectile dysfunction. The effect of the women's BC treatment on the partner was also reflected in the finding that partners of women who had undergone breast reconstruction reported better orgasmic and overall sexual functioning than partners of women who had received breast-conserving therapy. Both the BC survivors and their partners reported low levels of sexual functioning. We identified few correlations between the self-reported sexual functioning of the women and that of their partners. This might be explained, at least in part, by differences between male and female sexual functioning, such as men reporting higher sexual desire than women, the gender differences in the degree of concordance between the perception of genital response and actual genital sexual arousal, and dif-

ferences in orgasm frequency. Nevertheless, the findings suggests that it is important for health care professionals to involve both partners in the discussion about sexuality after BC, and especially - if applicable - in subsequent sex therapy.

Chapter 4 presents the results pertaining to the short-term efficacy of the Internet-based CBT program in improving BC survivors' sexual functioning, relationship intimacy, body image, marital functioning and HRQL, and in decreasing their menopausal symptoms and psychological distress. Compared to women in the waiting-list control group, women who received the Internet-based CBT reported a greater improvement in overall sexual functioning, sexual desire, sexual arousal, vaginal lubrication and sexual pleasure, and a greater decrease in discomfort/pain during sex and sexual distress than women in the control group. Women in the intervention group also reported a larger improvement in body image compared with the control group. A clinically significant change in sexual functioning was observed in 63% of women who received the intervention, versus in 32% of women in the waiting-list control group, indicating that the odds of a clinically significant improvement for the intervention group were 3.66 times greater than those of the waiting-list control group. No significant effects were observed for menopausal symptoms, orgasmic function, sexual satisfaction, frequency of sexual activity, relationship intimacy, marital functioning, psychological distress or HRQL. This study demonstrates that Internet-based CBT has a positive effect on the sexual functioning and body image of BC survivors with a sexual dysfunction.

Chapter 5 describes the long-term effects of the Internet-based CBT program on sexual functioning, relationship intimacy, body image, marital functioning, menopausal symptoms, psychological distress and HRQL of BC survivors with a DSM-IV sexual dysfunction. Eighty-four women of the intervention group of the study were included in the analysis. The positive effects of the treatment program on overall sexual functioning, sexual desire, sexual arousal, vaginal lubrication, discomfort/pain during sex, sexual distress and body image observed at the end of CBT were maintained during a three- to nine-month follow-up period. Body image improved even further after the completion of the CBT. Sexual pleasure was the only domain that, after an improvement during the Internet-based CBT, decreased significantly during the follow-up period. It did not, however, return to baseline levels. The loss of therapist encouragement to engage in sexual activity after completion of the CBT may have resulted in some loss of effect in this area. This is supported by the fact that a modest, although not statistically significant, decrease was observed in the other sexual function measures. The results indicate that the positive effects of the Internet-based CBT on most sexual functioning domains, sexual distress and body image of BC survivors with a DSM-IV sexual dysfunction are maintained well beyond the immediate post-treatment period.

Chapter 6 describes which factors were predictive of a successful outcome of the Internet-based CBT, and presents the participant's evaluation of the therapy program. Better post-CBT sexual functioning was associated with better sexual functioning of women and their partners at baseline and higher therapy compliance. Lower post-CBT sexual distress was associated with lower baseline sexual distress, better baseline female sexual functioning, higher baseline relationship satisfaction of the partner, and higher therapy compliance. Therapy compliance, in turn, was predicted by the active involvement of the partner in therapy and a better therapeutic relationship. This suggests that, although these two latter factors are not associated directly with therapy success, they do influence the success of the therapy indirectly via their association with compliance. The baseline levels of sexual functioning and distress were predictive of the level of sexual functioning and distress over time (e.g., women with better baseline sexual functioning also had better post-CBT sexual functioning), but not of the effectiveness of the Internet-based CBT. The specific components of BC treatment were also not predictive of post-intervention sexual functioning. These findings suggest that any BC survivor, regardless of her baseline level of sexual functioning or distress or her specific BC treatment, may benefit from Internet-based CBT for sexual dysfunction. Overall, the majority of women indicated that they were satisfied with the CBT. The fact that both the women and therapists were positive about the quality of the therapeutic relationship is important, because it shows that, even when therapy is provided via the Internet, a strong therapeutic bond can be established. We recommend that, to enhance compliance with the CBT program as well as the effectiveness of the program, particular attention be paid to the therapeutic relationship and to the involvement of the partner in therapy.

Chapter 7 reports on the longitudinal evaluation of the effect of the Internet-based CBT program on the sexual functioning, relationship intimacy and relationship satisfaction of 69 partners of BC survivors. The results indicated that the partners' overall sexual functioning, erectile functioning, orgasmic functioning, intercourse satisfaction, overall sexual satisfaction, sexual relationship intimacy and sexual relationship satisfaction improved during the Internet-based CBT. However, only the improvement in the partners' overall sexual satisfaction, sexual relationship intimacy and sexual relationship satisfaction were maintained during a nine-month follow-up. No significant changes over time were observed for sexual desire or any of the other areas of relationship intimacy or relationship satisfaction. The intervention thus appeared to have more sustained, long-term effects on the BC survivors as compared to their partners. This difference in effect is not entirely unexpected in that the Internet-based CBT specifically addressed the sexual functioning of the BC survivors. This may have resulted in both members of the couple acquiring skills that benefit the women's long-term sexual functioning, but not that of the partner. Because not only the sexual functioning of BC survivors, but also that of their male partners is affected by BC

and its treatment, we recommend expanding the content of Internet-based sex therapy for post-BC sexual dysfunctions to include more tailored information and interventions for the partners, in order to provide them with tools to not only facilitate improvement in their spouse's sexual functioning, but that of themselves as well.

Chapter 8 discusses the main findings of this thesis, including the methodological limitations relating to the content and form of the CBT, the design of the study, the nature and quality of the assessments, and issues of cost-effectiveness. Our Internet-based CBT program realized long-term improvement in the sexual functioning, sexual distress and body image of BC survivors. Although partners did not report sustained positive effects of the intervention on their sexual functioning, they did benefit in terms of overall sexual satisfaction, feelings of sexual intimacy and sexual relationship satisfaction. Future Internet-based interventions should involve the partner to a greater extent, by including a range of modules specifically targeting male sexual dysfunction. More research is needed to determine the optimal involvement of the partner in sex therapy after cancer treatment and the prerequisites to effectuate a sustained effect in the partner's sexual functioning. Given the very rapid advances in the development of eHealth interventions and related technology, future trials should enable continuous enhancement of the intervention during the course of the study. Constructive Technology Assessment (CTA) can be used to investigate this dynamic process. Future trials should also evaluate how the use of different components of the treatment program or technology, or combinations of components, contribute to the efficacy of the treatment program. Additionally, further research into the predictors and moderators of the success of (eHealth) interventions is warranted, to be able to select patients who will benefit most from the intervention or to tailor the content to the needs of the individual patient. Lastly, more information is needed on the cost-effectiveness of Internet-based sex therapy programs for sexual dysfunction after BC. A potentially cost-effective alternative to the intervention evaluated in this thesis could be a self-management version of the CBT program. Another potential benefit of such a 'light' version of our program could be that it can be offered to the many BC survivors who experience milder sexual problems after BC treatment. We intend to develop and test, in an RCT context, a (guided) self-management version of our Internet-based CBT program. The intervention described in this thesis can be viewed as a proof of principle for the efficacy of Internet-based CBT for sexual dysfunctions in BC survivors.