

Online counseling via e-mail for breast cancer patients on the German internet: preliminary results of a psychoeducational intervention

Online-Beratung via E-Mail für Brustkrebspatientinnen im deutschsprachigen Internet: erste Ergebnisse einer psychoedukativen Intervention

Abstract

Objectives: The internet offers new possibilities in psychosocial patient care. However, empirical data are lacking for oncological patients. A field-experimental study was conducted to obtain initial data to enable evaluation of the effectiveness of online counseling via e-mail for breast cancer patients. A secondary objective was to explore how patients reached by the service can be characterized on psychosocial status and illness.

Methods: On a dedicated German-language website, 235 breast cancer patients registered for psychosocial counseling via e-mail. 133 registrants were randomly assigned to a treatment group to receive immediate counseling or to a waiting list control group. The two-month counseling session took the form of a psychoeducation, individually tailored to each patient. Psychosocial outcome measures including psychological distress (BSI) and quality of life (EORTC QLQ-C30) were assessed at registration and at a two-month follow-up. Descriptive data were recorded at registration. At the conclusion of the program, participants were asked to complete a patient satisfaction questionnaire (ZUF-8).

Results: BSI responses showed that 85% of all patients were initially diagnosable with comorbid psychopathology. Despite high severity of distress and attendant large reductions in quality of life, 72% of all patients were not obtaining conventional assistance. Among counseling participants ($n=31$), no significant improvements in distress or quality of life were found in comparison to the control group ($n=34$), but patient satisfaction was nonetheless high.

Conclusion: The study demonstrates that online counseling via e-mail reaches patients with unmet therapeutic needs, but also indicated its limitations, suggesting that the online setting may be most useful for prompting and supporting a transition to conventional counseling services.

Keywords: breast cancer, oncology, internet, psychoeducation, online counseling, online therapy

Zusammenfassung

Zielsetzung: Das Internet eröffnet neue Perspektiven für die psychosoziale Patientenversorgung. Im Zusammenhang mit onkologischen Patienten fehlt es jedoch an empirischen Erfahrungswerten. Es wurde eine feldexperimentelle Studie durchgeführt, um erste Daten zur Wirksamkeit einer Online-Beratung via E-Mail für Brustkrebspatientinnen zu gewinnen. Weiteres Ziel war die krankheitsspezifische und psychosoziale Charakterisierung des durch den Dienst erreichten Klientels.

Methoden: Auf einer dedizierten deutschsprachigen Beratungswebseite meldeten sich 235 Brustkrebspatientinnen für eine psychosoziale Be-

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ratung via E-Mail an. 133 Teilnehmerinnen wurden randomisiert zu einer sofortigen Beratungs- oder Wartelistenbedingung zugeteilt. Das zwei-monatige Beratungsangebot entsprach einer psychoonkologischen Breitbandintervention und war auf die Patientinnen individuell zugeschnitten. Als Outcome-Variablen wurden psychische Belastung (BSI) und Lebensqualität (EORTC QLQ-C30) bei Anmeldung und nach 2 Monaten gemessen. Zusätzlich wurden deskriptive Daten erhoben und nach Beratungsende die allgemeine Patientenzufriedenheit (ZUF-8) erfasst.

Ergebnisse: Laut BSI wiesen 85% der Patientinnen eine komorbide psychische Störung auf. Trotz hoher Belastung und stark verminderter Lebensqualität erfuhren 72% aller Patientinnen keine konventionelle psychosoziale Hilfe. Bei den beratenen Patientinnen ($n=31$) konnten im Vergleich zur Kontrollgruppe ($n=34$) keine signifikanten Verbesserungen bezüglich der psychischen Belastung und der Lebensqualität festgestellt werden. Die Beratung ging mit einer hohen Patientenzufriedenheit einher.

Fazit: Die Studie zeigt auf, dass mit einer Online-Beratung via E-Mail psychosozial unterversorgte Patientinnen erreicht werden können, sie macht aber auch Grenzen des Beratungsdienstes deutlich. Die Sicherstellung des Erstkontaktes sollte primär die Überführung zu höherschwelligen Hilfsangeboten zum Ziel haben.

Background

Breast cancer patients display a strong need for illness-related information and social support [1], [2]. Beyond conventional psychosocial resources such as medical personnel, family, friends, and print and broadcast media [3], patients increasingly use online resources to seek help in coping with illness. Websites offering illness-related information are being joined by self-help platforms that incorporate first-person narrative, chat rooms, and discussion forums [4], [5], [6], [7], [8]. Given these developments, it may be appropriate to expand current offerings for cancer patients by providing internet-based psychosocial treatments.

Participation rates for psychosocial interventions demanding additional effort from patients (e.g., travel to the counseling site) are considerably lower than for those offered in conjunction with medical treatment. The internet's ease of access, availability, and anonymity could help overcome spatial, temporal, and psychological barriers to psychosocial care [6].

Prior studies have examined internet use by breast cancer patients [5], [9], [10], [11], but the cross-sectional comparisons and correlations between internet users and non-users they produced enable no causal insight into how internet use affects their psychosocial well-being.

More meaningful results are provided by studies investigating the use and effects of internet-based self-help. Those studies have shown that discussion board use raises social support, while cancer-specific informational sites produce relative gains in information [12], [13]. Descriptive analyses of online self-help groups identified patterns of communication similar to those considered typical of and helpful in face-to-face groups [14], [15], [16]. In a randomized controlled trial, Winzelberg et al. [17] substantiated the effectiveness of a self-help forum

in which directive moderation was employed to influence discussion and topic choice. At 12 weeks, its participants reported significant reductions in depression and cancer-related trauma as well as in perceived stress relative to the control group. Likewise, Owen et al. [18] demonstrated in a randomized controlled study the effectiveness of an autonomously operating online self-help group on measures of health-related quality of life.

Psychosocial interventions carried out by professionals using computer-mediated communication are known in the literature as "online therapy" or "online counseling" [19], [20], [21].

Two fundamentally different techniques are in use: structured treatment programs offered online to be completed independently or with minimal therapist contact, and individually tailored, one-on-one contact between therapists and clients via e-mail or chat.

Increasing numbers of practitioners and clients have noted the growing popularity of one-on-one online therapies in recent years [22]. In contrast to structured treatment programs with little or no therapist contact, this form of intervention may offer better possibilities of responding to individual client problems and needs while making the experience of receiving attention and empathy from an expert available to clients. Initial findings indicate that the working alliance in online therapy receives similar positive evaluations from clients as the face-to-face context [23].

Recent years have seen a rise in randomized controlled trials that investigated structured treatment programs for a variety of psychosomatic and health-related psychological issues [24], [25], [26], [27], [28], [29], [30], [31], [32], but empirical data for one-on-one online therapy is limited to case studies and exploratory pilot studies [33], [34], [35]. Generally, there is a lack of both exploratory empirical observations and controlled studies of online

therapy's feasibility and effectiveness for oncological patients.

The current study's primary objective was to obtain data on the effectiveness of e-mail counseling for the psychosocial well-being of breast cancer patients. The study focused on two outcome measures widely regarded as liable to therapeutic influence in the context of conventional psychosocial interventions: psychological distress and health-related quality of life [36].

Drawing on previous studies that had demonstrated the effectiveness of analogous psychoeducational interventions conducted face-to-face [36], we hypothesized that breast cancer patients who received two months of online counseling via e-mail would display a significant reduction in psychological distress as well as significant improvements in quality of life when compared to patients on a waiting list who did not receive counseling. It was assumed that patients would form positive subjective opinions of the service's value and helpfulness.

A secondary objective was to learn how patients using the service could be characterized in socio-demographic and illness-specific terms. Given the relative absence of barriers to participation, we anticipated that the service would reach patients with unmet psychosocial needs who were not obtaining assistance through conventional channels.

Methods

Design and sample

This study was approved by the Institutional Review Board of the Faculty of Medicine and University Hospital Tübingen. During two study phases, June 2005 – March 2006 and May 2007–October 2008, a German-language web site offered free psychosocial counseling for breast cancer patients via web-based e-mail. The service was provided by two experienced clinical psychologists with training in psycho-oncology and online media. Each of the psychologists had several years of professional experience in face-to-face psychosocial support for cancer patients as well as two years of prior experience in the counseling of cancer patients via e-mail.

To assure confidentiality and data security, a dedicated online counseling application was programmed, which was accessible only through password-protected accounts. Data transfer between clients and the server was encrypted using the Secure Sockets Layer (SSL) protocol with 128-bit encryption.

Publicity for the service was created by press releases, paid newspaper advertisements, and placement of announcements and links in relevant German-language online services, including medical internet portals and breast cancer discussion boards.

Over the course of the study, 235 patients completed initial registration for the service. Patients were asked to read a clear and comprehensive explanation of the study

online, and informed consent to participate in the study was a requirement to finalize registration.

Full randomization was not carried out for ethical reasons. Patients were offered immediate counseling whenever capacities permitted. A priori random assignment to a treatment group (TG) for immediate treatment or to a waiting list control group (CG) for deferred treatment took place only when registration rates were especially high and enrollment of new patients could not be managed because of limited capacities. This was primarily the case at the beginning of each of the two study phases after the service was publicly announced (June–July 2005 and May–June 2007). The establishment of a waiting list assured that each case received adequate care.

Random group assignment was performed for 133 patients, creating a TG of 69 and a CG of 64 (see Figure 1). 102 patients who registered for the service were excluded from the analysis because they were offered immediate counseling in place of being randomly assigned to a group.

Online-assessments were performed twice for each group (2x2 repeated measures design). The first evaluation (t1) took place at registration, immediately preceding either counseling or the waiting period. At the conclusion of a two-month counseling or waiting period, patients were asked via e-mail to participate in a second assessment (t2). All questionnaires used in the study were accessed and filled out by patients on the dedicated online counseling application.

Intervention

After registration, a standardized first welcome mail was sent to each participant, introducing the online counselor and giving specific suggestions for topics that might trigger a discussion:

"Please write us what your current concerns are, your reason for registering here, and how your illness has progressed to date. Of course you can also include general information about your personal situation (family, work, etc.) so that we can form a more accurate picture of you!"

The service was designed to meet the communicative expectations of regular internet users, including timely response to patient e-mails (within 24 hours) and a non-directive therapeutic approach. Recommendations or requirements for patient participation in the asynchronous communication, e.g., suggestions about how much time to spend each day or week or the length of each mail, were not provided. The length and frequency of the e-mails exchanged were largely under the influence of the respective patient. Counseling sessions were concluded after two months.

The online counseling service took the form of a psychoeducational intervention individually adapted to each patient. In their correspondence, the counselors adopted a person-centered attitude of empathy and unconditional positive regard [37]: Patients were encouraged to discuss their experiences and express their feelings. Beside in-

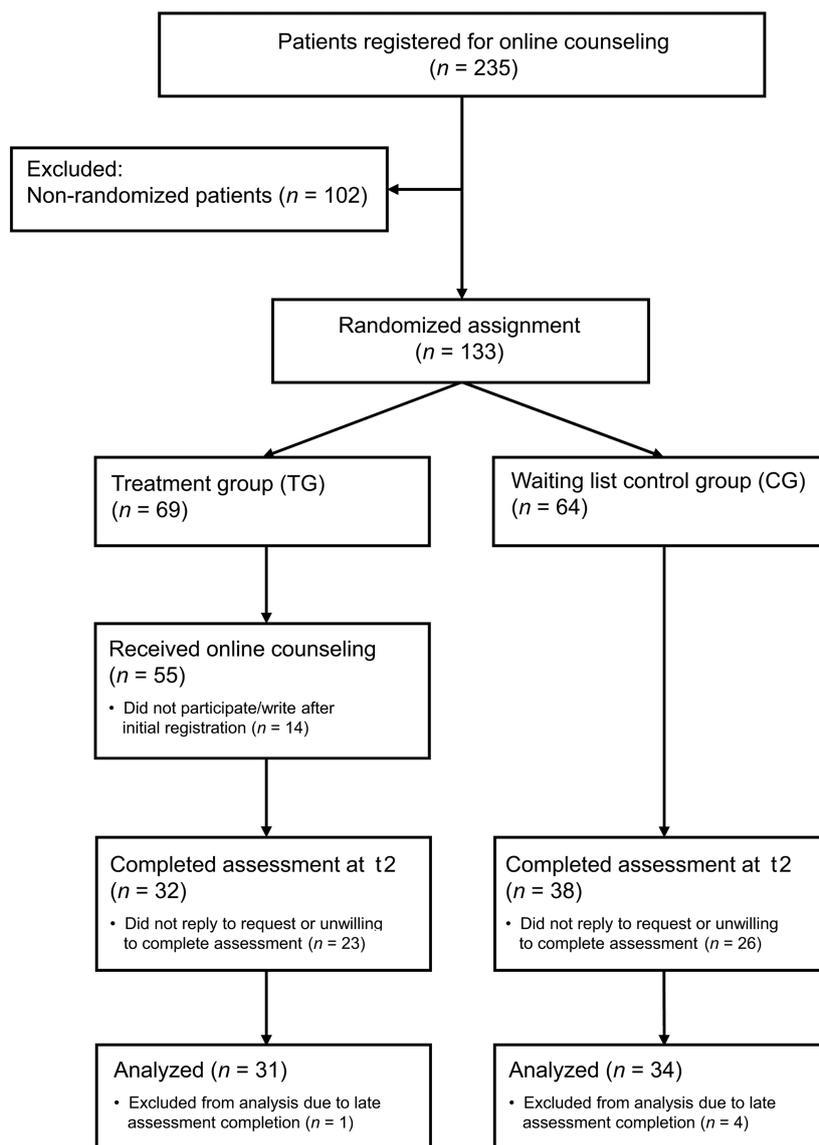


Figure 1: Trial profile outlining experimental design with numbers of patients at each stage

formation transfer and emotional support, the counseling's main components were the application of intervention techniques from cognitive behavioral therapy (e.g. stress management, coping and problem-solving techniques) [38], rational emotive therapy (e.g. identifying and disputing irrational and dysfunctional beliefs) [39] and solution-focused brief therapy (e.g. reframing techniques and miracle, scaling and coping questions) [40].

Measures

At registration (t1), participants provided socio-demographic and clinical data including age, marital status, education, time between diagnosis and registration, cancer staging, medical treatments, conventional psychological assistance at registration, and prior psychological conventional or online assistance experience.

Data for outcome variables and patient satisfaction were obtained using validated, official German versions of three self-report questionnaires.

Psychological distress

The Brief Symptom Inventory (BSI) [41] is a self-report measure of psychopathology consisting of 53 items covering nine symptom dimensions: somatization, obsession-compulsion, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. Scores range from 0 to 4, with higher scores reflecting greater distress, and are interpreted by comparison to age-appropriate norms (T-scores) [42]. Relevant primary outcome measures, in addition to Global Severity Index (GSI) as a global index for measuring overall psychological distress level, were defined as the 3 symptom dimension scales somatization, depression and anxiety. Those dimensions correspond to the BSI-18, a short form of the BSI validated for use in cancer patients [43], [44].

Health-related quality of life

The EORTC core quality of life questionnaire (EORTC QLQ-C30, Version 3.0) [45], [46] uses scales and single-item scores ranging from 0 to 100. A high score on global health status or a functional scale represents a healthy level of functioning, while a high score for a symptom scale or item indicates a high level of symptomatology or problems. Outcome measures seen as primarily relevant were global health status and four of the functional scales: role, social, cognitive, and emotional functioning.

General patient satisfaction

At the conclusion of the service, general patient satisfaction was measured using the "Questionnaire on Patient Satisfaction" (ZUF-8) [47], a validated German version of the Client Satisfaction Questionnaire (CSQ-8) [48]. Eight items are tabulated into a cumulative scale that produces a unidimensional measure of satisfaction. Items can be scored from one (very negative) to four (very positive). Neutral scoring of an item is not possible. The arithmetical value of the neutral value would be 2.5.

Statistical analysis

Statistical analysis was performed using SPSS. Statistical significance was set at $p=0.05$.

Beyond descriptive analysis of the sample, the objective of the statistical analysis was to compare changes in the two experimental groups between t1 and t2 after confirming their comparability at t1 on socio-demographic and clinical variables as well as psychosocial factors reflected in BSI and EORTC-QLQ-C30 scores.

Quantitative socio-demographic data were analyzed using parametric tests (Student *t*-test), while qualitative variables or variables without a normal distribution were analyzed using non-parametric tests (Pearson's chi-square test or Mann-Whitney *U*-test).

Changes in TG and CG between t1 and t2 were compared using general linear models with repeated measurements that take the two measures into account to distinguish between intra-subject effects (time-effect and time-by-group interaction) and inter-subject effects (group-effect). To interpret the EORTC QLQ-C30 scores observed at registration, graphic comparison with reference values was used, as specifically recommended by the EORTC QLQ-C30 Breast Cancer Reference Values Manual [49].

Results

Sample characteristics for repeated measure analyses

At registration (t1), non-randomized excluded ($n=102$) and randomized patients ($n=133$) were comparable for all socio-demographic and clinical variables as well as BSI and EORTC-QLQ-C30 measures.

Of the 133 data sets for randomized patients, 68 could not be utilized for the experimental analysis (cf. Figure 1). For 14 patients in the TG, contact ceased after initial registration (non-writers). The assessment at t2 was not completed by 23 patients in the TG and 26 in the CG. In addition, one patient in the TG and four in the CG completed the t2 assessment after the deadline of ten days following e-mail notification. The patients thus excluded from the analysis did not differ significantly from participating patients with regard to socio-demographic and clinical variables or BSI and EORTC QLQ-C30 scores at t1.

Characterization of patients

The average age of the total sample was 47.0 years ($SD=8.5$), cf. Table 1. The average time span between diagnosis and registration was 2.2 years ($SD=2.5$). For 24%, the diagnosis had come in the past 3 months, for 20% between 3 and 12 months, for 44% more than a year, and for 12% more than 5 years earlier. Based on the TNM Classification of Malignant Tumors (TNM), 26% of the patients had a favorable prognosis indicating a curative therapeutic approach (either "smallest size or direct extent of the primary tumor" [T1] or "lowest grade of the cancer cells" [G1]). For 18%, the illness had progressed to a stage at which it was most likely incurable (in order of increasing severity, "biggest size or direct extent of the primary tumor" [T4], "regional lymph node metastasis present" [N1] and "metastasis to distant organs" [M1]). For the remainder (55%), the illness was in an intermediate stage. The medical care previously provided included an operation for 78%, chemotherapy for 74%, radiation for 54%, and endocrine therapy for 63%.

A large majority (72%) of patients were not receiving conventional psychosocial assistance services at the time of registration, and 40% had no prior experience with psychotherapy, counseling, or psychiatric consultation. At registration all BSI mean T-scores (German female norm group) [42] for the 9 symptom dimensions and global index GSI in the TG and CG were above the critical threshold value of $T = 63$. Based on the criterion of having either T-scores of 63 or greater on two or more symptom dimension scales or a GSI T-score of 63 or greater [41], [42], 84% of the women in the TG and 85% of the women in the CG were diagnosable with comorbid psychopathology.

In Figure 2, the observed EORTC QLQ-C30 scores at t1 for the total sample ($n=65$) are contrasted against EORTC QLQ-C30 Breast Cancer Reference Values (all patients category) [49]. Comparison of the two profiles shows that the online patients had lower values on all functional scales except the physical functioning scale, and that their average level on the majority of symptom scales was higher.

Table 1: Socio-demographic and clinical variables by experimental arm

| Variables | | TG ¹ | CG ² | Total ³ |
|---|--|-----------------|-----------------|--------------------|
| Age | Mean (SD) | 48.2 (9.2) | 45.9 (7.8) | 47.0 (8.5) |
| Marital status | Single | 4 (13%) | 6 (18%) | 10 (15%) |
| | Married | 19 (61%) | 22 (65%) | 41 (63%) |
| | Divorced | 7 (23%) | 5 (15%) | 12 (18%) |
| | Widowed | 1 (3%) | 1 (3%) | 2 (3%) |
| Education | <i>Abitur</i> (academic high school) | 18 (58%) | 16 (47%) | 34 (52%) |
| | <i>Mittlere Reife</i> (vocational high school) | 8 (26%) | 9 (26%) | 17 (26%) |
| | <i>Hauptschulabschluss</i> (vocational school) | 4 (13%) | 7 (21%) | 11 (17%) |
| | Other | 1 (3%) | 2 (6%) | 3 (5%) |
| Psychological offline assistance at registration | None | 22 (71%) | 25 (73%) | 47 (72%) |
| | Psychotherapy | 7 (23%) | 5 (15%) | 12 (18%) |
| | Counseling | 2 (6%) | 1 (3%) | 3 (5%) |
| | Psychiatric consultation | 0 (0%) | 3 (9%) | 3 (5%) |
| Psychological offline assistance experience | Yes | 20 (65%) | 19 (56%) | 39 (60%) |
| | No | 11 (35%) | 15 (44%) | 26 (40%) |
| Previous psychological online assistance experience | Yes | 0 (0%) | 0 (0%) | 0 (0%) |
| | No | 31 (100%) | 34 (100%) | 65 (100%) |
| Time between diagnosis and registration (years) | Mean (SD) | 2.4 (3.1) | 2.1 (2.0) | 2.2 (2.5) |
| TNM Staging System | Favorable prognosis (solely T1 and G1) | 7 (23%) | 10 (29%) | 17 (26%) |
| | Intermediate-stage illness (more than T1/G1) | 18 (58%) | 18 (53%) | 36 (55%) |
| | Late-stage illness (T4 or N1 or M1) | 6 (19%) | 6 (18%) | 12 (18%) |
| Surgery | Yes | 24 (77%) | 27 (79%) | 51 (78%) |
| | No | 7 (23%) | 7 (21%) | 14 (22%) |
| Chemotherapy | Yes | 21 (68%) | 27 (79%) | 48 (74%) |
| | No | 10 (32%) | 7 (20%) | 17 (26%) |
| Radiotherapy | Yes | 17 (55%) | 18 (53%) | 35 (54%) |
| | No | 14 (45%) | 16 (47%) | 30 (46%) |
| Endocrine therapy | Yes | 18 (58%) | 23 (68%) | 41 (63%) |
| | No | 13 (42%) | 11 (32%) | 24 (37%) |

¹Treatment group, n=31²Control group, n=34³Total, n=65

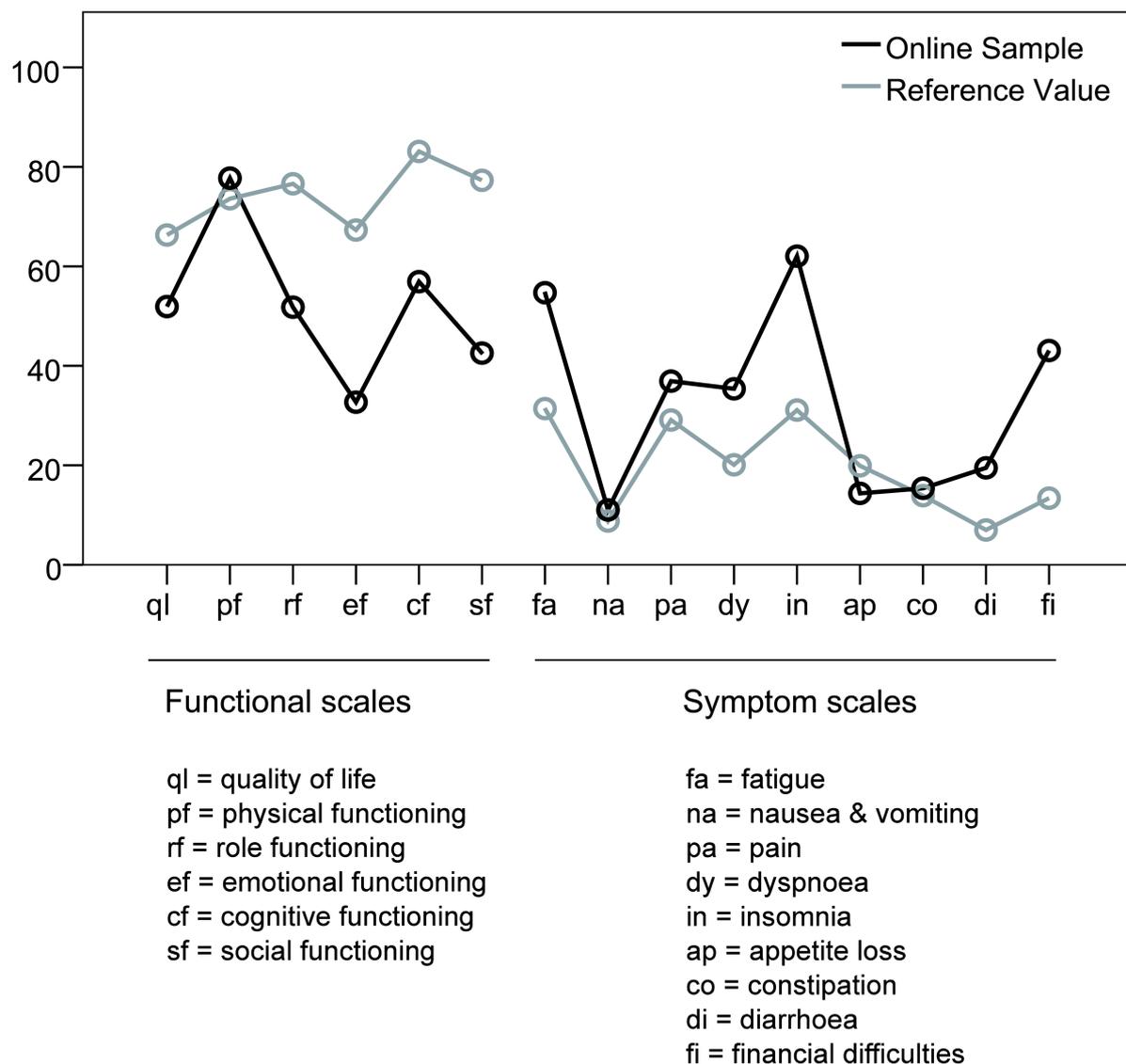


Figure 2: EORTC QLQ-C30 profile for total online sample ($n=65$) at t1 compared to EORTC QLQ-C30 Breast Cancer Reference Values (all patients category) [47]

Counseling correspondence volume, duration and central themes

Patients in the TG wrote a total of 391 e-mails to the therapists. The average number of e-mails written was 12.61 (SD=6.77; Minimum = 3; Maximum = 38) per patient and 12.03 (SD=6.32; Minimum = 4; Maximum = 36) per therapist, not including the standardized first welcome mail. The average word count per e-mail was 282.92 for patients (SD=256.39) and 182.85 for therapists (SD=140.19).

The average duration of counseling correspondence was 48.7 days (SD=18.6). Among patients, 71% utilized the two-month maximum session duration allowed under the protocol. For 10%, correspondence ceased within two weeks, and 19% did not extend counseling beyond one month.

Central themes of the counseling sessions included cognitive and emotional processing of the new life situation (46%); fear that illness will recur (22%); interaction with relatives and friends after diagnosis and in the context of the illness and treatment (16%); bodily handicaps and altered body image (13%); work-related issues (9%); and how to handle pain (8%).

Comparison of patient characterizations between groups

At registration (t1), the TG and CG were comparable for all socio-demographic and clinical variables (cf. Table 1). No differences could be found on age ($p=0.29$), marital status ($p=0.85$), education ($p=0.75$), psychological offline assistance at registration ($p=0.29$), previous psychological offline assistance experience ($p=0.49$), or clinical variables such as time between diagnosis and registration

Table 2: Comparison of change scores between experimental arms

| | | t1 Mean (SD) | t2 Mean (SD) | | F ¹ | p | Eta ² |
|---------------------------------|-----------------|---------------|---------------|---------------|----------------|-------|------------------|
| BSI Somatization | TG ² | 1.08 (0.67) | 1.02 (0.80) | Intra-subject | 0.20 | 0.654 | 0.00 |
| | CG ³ | 1.11 (0.68) | 1.10 (0.79) | Inter-subject | 0.82 | 0.775 | 0.00 |
| | | | | Time x group | 0.12 | 0.735 | 0.00 |
| BSI Depression | TG | 1.28 (0.98) | 1.07 (1.05) | Intra-subject | 11.30 | 0.001 | 0.15 |
| | CG | 1.35 (0.93) | 0.99 (0.87) | Inter-subject | 0.00 | 0.980 | 0.00 |
| | | | | Time x group | 0.77 | 0.383 | 0.01 |
| BSI Anxiety | TG | 1.06 (0.77) | 0.96 (0.94) | Intra-subject | 1.43 | 0.236 | 0.02 |
| | CG | 1.06 (0.79) | 0.96 (0.77) | Inter-subject | 0.00 | 0.997 | 0.00 |
| | | | | Time x group | 0.00 | 0.996 | 0.00 |
| BSI GSI (Global Severity Index) | TG | 1.10 (0.63) | 0.96 (0.74) | Intra-subject | 8.30 | 0.005 | 0.12 |
| | CG | 1.15 (0.64) | 1.00 (0.68) | Inter-subject | 0.09 | 0.767 | 0.00 |
| | | | | Time x group | 0.05 | 0.818 | 0.00 |
| EORTC Global Health Status | TG | 52.96 (20.81) | 61.29 (20.36) | Intra-subject | 6.74 | 0.012 | 0.10 |
| | CG | 50.98 (17.26) | 57.35 (20.39) | Inter-subject | 0.55 | 0.462 | 0.01 |
| | | | | Time x group | 0.12 | 0.730 | 0.00 |
| EORTC Emotional Functioning | TG | 32.53 (23.61) | 44.62 (31.37) | Intra-subject | 11.63 | 0.001 | 0.16 |
| | CG | 32.84 (21.22) | 42.65 (26.41) | Inter-subject | 0.02 | 0.882 | 0.00 |
| | | | | Time x group | 0.13 | 0.722 | 0.00 |
| EORTC Cognitive Functioning | TG | 55.38 (27.68) | 59.14 (33.57) | Intra-subject | 0.10 | 0.757 | 0.00 |
| | CG | 58.33 (25.38) | 56.86 (31.28) | Inter-subject | 0.00 | 0.958 | 0.00 |
| | | | | Time x group | 0.50 | 0.481 | 0.01 |
| EORTC Social Functioning | TG | 41.94 (32.74) | 52.15 (34.36) | Intra-subject | 5.46 | 0.023 | 0.08 |
| | CG | 43.14 (29.34) | 50.49 (31.11) | Inter-subject | 0.00 | 0.974 | 0.00 |
| | | | | Time x group | 0.15 | 0.705 | 0.00 |
| EORTC Role Functioning | TG | 52.69 (28.25) | 53.76 (35.15) | Intra-subject | 0.12 | 0.728 | 0.00 |
| | CG | 50.98 (24.94) | 52.94 (30.00) | Inter-subject | 0.05 | 0.833 | 0.00 |
| | | | | Time x group | 0.01 | 0.919 | 0.00 |

¹df_{factor}=1, df_{error}=63²Treatment group, n=31³Control group, n=34

($p=0.71$), stage ($p=0.82$), surgery ($p=0.85$), chemotherapy ($p=0.29$), radiotherapy ($p=0.89$) and endocrine therapy ($p=0.42$).

No significant difference was found for scores on the BSI and EORTC QLQ-C30.

Comparison of outcome measures within and between groups

As described in Table 2, the general linear models with repeated measurements procedure revealed no significant group effects.

In both groups, changes were observed over time for distress and quality of life. Significant time effects could be found for BSI depression and GSI scores and for

EORTC QLQ-C30 global health status, emotional functioning and social functioning scores.

Significant group/time interaction effects could not be shown. Thus no effect of the counseling was evidenced on BSI somatization, depression, anxiety or GSI scores, nor on EORTC QLQ-C30 global health status or functioning scores.

General patient satisfaction

General patient satisfaction with the service was evaluated after the conclusion of counseling (t2) with the aid of ZUF-8, the eight items of which are listed in Table 3. The average ZUF-8 sum was distinctly positive ($M=3.14$, $SD=0.72$). It was clear on the basis of the answers for the individual items that approximately three-fourths of the patients were largely or very satisfied with the service (see Table 3). For instance, 87% rated the quality of service they had received as “good” or “excellent.” 77% were “very” or “mostly satisfied” with the service generally. 84% “generally” or “definitively” would recommend the service to friends in similar situations.

Discussion

The study's objectives were to obtain data on the effectiveness of psychosocial counseling via e-mail for breast cancer patients and to characterize the clients reached by the service.

The data show that the majority of patients using the service, despite their substantial psychological distress, were not being reached by conventional services. In addition to the high rate of clinical distress, the majority proved to be in illness situations that entailed coping with serious side-effects of cancer treatment, long-term threats to quality of life, or uncertain prognoses. The EORTC QLQ-C30 profile shows that conspicuous losses of functionality in emotional, cognitive, and social areas as well as in role behavior were among the factors adversely affecting patients' quality of life (cf. Figure 2). Relative to the age-specific incidence of breast cancer in Germany [50], the sample is arguably representative only up to age 50. The level of education is relatively high, with 52% qualified to attend university as opposed to 19% of the general German population [51].

A majority of patients expressed a positive subjective view of the counseling service and regarded it as helpful. However, the study did not provide evidence for stable or generalizable effectiveness for the service. No significant improvement was seen with regard to outcome variables measured for the TG from t1 to t2.

Several hypotheses could explain the service's low effectiveness:

The service can fairly be regarded as a weak intervention. The two-month session was short, with therapists and patients exchanging relatively few e-mails. The establishment of therapeutic relationships with patients was further compromised by the asynchronous and exclusively

text-based nature of the interaction. It is unknown to what extent tasks assigned for behavioral therapeutic purposes were accepted by patients. The casual online setting may reduce patients' inhibitions about using the service, but it may also limit its effectiveness.

Furthermore, patients using the service displayed exceptionally high scores for clinical distress at the outset. In a screening study of psychological distress in breast cancer patients ($n=275$), Payne et al. [52] found considerably lower average BSI T-scores (between 53 and 59) with comparable heterogeneity of the sample as regards staging and treatment. BSI mean T-scores at t1 indicate high rates of comorbid psychopathology, pointing to outside factors that may have limited the effectiveness of the intervention. Empirical studies on effectiveness for psychoeducational interventions in cancer patients generally employ samples excluding patients with criteria of significant clinical distress [36].

However, the verification of psychopathological comorbidity among cancer patients demands diagnostic methods that exceed the capacity of screening instruments [53]. Because the BSI assesses somatic symptoms that confound with symptoms due to the malignancy or associated medical treatments, the apparent rate may be exaggerated. Should the severity of distress reported by patients be due in fact to psychopathological comorbidity, then the clinical responsibility arises to recommend appropriate psychotherapy, since a psychoeducational intervention – whether face-to-face or internet-based – is not indicated for such cases.

The study presents certain methodological limitations. Precise determination of an effect for the counseling service is complicated by the field-experimental nature of the study, which employed a self-selected sample and heterogeneous individualized interventions.

The delivery of counseling services to the CG after only two months' waiting time (for ethical reasons) prevents long-term comparative assessment of the effects of the service.

Because study participants were self-selected at varying points in time, they may have registered while in especially acute states of distress, producing extreme initial values. Regression toward the mean may have contributed to both the time effects and the absence of group/time interaction effects.

The study did not measure whether patients on the waiting list received counseling services from other sources during the waiting period. It is possible that recourse to alternative services contributed to the positive change for the CG between t1 and t2.

Effect sizes in psychosocial interventions for cancer patients are generally small [36], [54]. Because of the small sample size, the statistical power was not adequate to detect an effect. Given the small sample size, the minimum effect size detectable by the study for the mean difference between TG and CG at t2 was $d=.71$ with a power of .80 and $\alpha=.05$.

Table 3: Patient satisfaction (ZUF-8)

| ZUF-8 Items | Number (Percentage) |
|--|----------------------------|
| 1. How would you rate the quality of service you received? | |
| Excellent | 11 (35%) |
| Good | 16 (52%) |
| Fair | 3 (10%) |
| Poor | 1 (3%) |
| 2. Did you get the kind of service you wanted? | |
| Yes, definitively | 8 (26%) |
| Yes, generally | 18 (58%) |
| No, not really | 3 (10%) |
| No, definitively not | 2 (6%) |
| 3. To what extent has our service met your needs? | |
| Almost all of my needs have been met | 7 (23%) |
| Most of my needs have been met | 16 (52%) |
| Only a few of my needs have been met | 7 (23%) |
| None of my needs have been met | 1 (3%) |
| 4. If a friend were in need of similar help, would you recommend our service to him or her? | |
| Yes, definitively | 16 (52%) |
| Yes, generally | 10 (32%) |
| No, not really | 4 (13%) |
| No, definitively not | 1 (3%) |
| 5. How satisfied are you with the amount of help you have received? | |
| Very satisfied | 10 (32%) |
| Mostly satisfied | 14 (45%) |
| Indifferent or mildly dissatisfied | 5 (16%) |
| Quite dissatisfied | 2 (6%) |
| 6. Have the services you received helped you to deal more effectively with your problems? | |
| Yes, they helped a great deal | 14 (45%) |
| Yes, they helped somewhat | 10 (32%) |
| No, they didn't really help | 6 (19%) |
| No, they seemed to make things worse | 1 (3%) |
| 7. In an overall, general sense, how satisfied are you with the service you have received? | |
| Very satisfied | 14 (45%) |
| Mostly satisfied | 10 (32%) |
| Indifferent or mildly dissatisfied | 5 (16%) |
| Quite dissatisfied | 2 (6%) |
| 8. If you were to seek help again, would you come back to our service? | |
| Yes, definitively | 16 (52%) |
| Yes, generally | 9 (29%) |
| No, not really | 4 (13%) |
| No, definitively not | 2 (6%) |

Despite this weakness, the study's findings help clarify the challenges that will confront future psychosocial online counseling for cancer patients.

Counseling via e-mail allows patients a high degree of self-determination. Given the anonymity and noncommittal nature of the online context, however, it is difficult for the therapist and the patient to forge a working alliance that provides a stable basis for long-term interventions. Developing strategies to stabilize the online therapeutic relationship should be a priority. It would be helpful to formalize concrete contact modes that would allow a more directive intervention or regulation of the part of the counselor, e.g., the possibility to reestablish contact by telephone after unusually long interruptions.

At the same time, the noncommittal nature of the online setting offers prospects for enhancing patient care. The accessibility and anonymity of the internet are not only useful for lowering inhibitions and generating initial contacts with relatively few barriers to participation – as the current study demonstrated – but could also play a role in temporary supportive treatment during bridging of waiting periods before therapy or in outpatient follow-up care. There is a need to clarify how effectively such approaches can be implemented. An evaluation would require differing measures and success criteria in accordance with the positioning of the service.

The results of the current investigation suggest that criteria other than effectiveness could be appropriate for evaluating e-mail counseling for breast cancer patients. Given the high rate of first contact to high-risk patients, successful referral to services with higher thresholds of participation could serve as a measure of success.

Conclusions

The current study showed that online counseling via e-mail can establish communication with psychosocially disadvantaged breast cancer patients who are not being reached by conventional avenues of therapy. However, positive effects for psychosocial well-being like those attained under the conditions of conventional psychoeducational interventions for cancer patients may be difficult to achieve via an e-mail intervention, particularly for patients who have high levels of psychological distress. Our results indicate that establishing contact with underserved patients, with subsequent referral to conventional support services, may be an appropriate role for online counseling via e-mail.

Notes

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Competing interests

The authors declare that they have no competing interests.

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