The web around patients with neuroendocrine tumors
Bouma, Grytsje

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CHAPTER 2

Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis

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Abstract
In this review the effect of internet-based support programs on psychosocial and physical symptoms resulting from cancer diagnosis and treatment is analyzed. Selection of studies was based on the following criteria: (non-)randomized controlled trials, performed in adult cancer patients, comparing quantitative psychosocial and/or physical outcomes of an internet-based support program with (a) comparison group(s). Literature search yielded 2032 studies of which 16 fulfilled the eligibility criteria.

Three different internet-based support programs were identified: social support groups, online therapy for psychosocial/physical symptoms and online systems integrating information, support and coaching services. Outcomes improved by these programs in nine studies. Especially fatigue, social support and distress improved, regardless of the program type. All online systems showed positive effects, mainly for social support and quality of life. This analysis indicates that internet-based support programs are effective in improving psychosocial and physical symptoms in cancer patients.

Keywords: oncology, internet, online, support, therapy, effectiveness.
Introduction
A diagnosis of cancer often has a disruptive impact on a patient’s life. Cancer patients frequently experience psychosocial and/or physical distressing symptoms [1-3]. The importance of supporting patients adequately regarding symptoms resulting from diagnosis and treatment has been widely recognized [4,5]. However, supportive care needs still go unnoticed frequently [6,7]. To detect and meet the needs of this rapidly expanding patient population, the health care system is urged to develop and employ (cost-)effective programs to educate and support patients.

The internet is a viable medium by which patients can be supported regarding psychosocial and/or physical symptoms. Already in 2007, a Dutch cross-sectional survey on cancer-related internet use demonstrated that 60% of patients frequently used internet by themselves and 9% via others [8], reflecting the high acceptance of internet as a support and information channel. It has important advantages given its wide availability and accessibility, cost-efficiency and ability to provide tailored information and support [8-13]. During the last years, many new eHealth technologies have been introduced in cancer patient care, such as internet-based support programs addressing psychosocial/physical problems, internet-based communication and decision aids to promote shared decision making [14] and mobile applications providing survivorship care plans [15].

Internet-based support programs seem particularly well-suited to fulfill the unmet supportive care needs [4]. These programs have been linked to positive outcomes such as increased knowledge, perceived social support and improved health behaviors for people with chronic diseases [16]. Given the comparable nature of chronic diseases and cancer, these outcomes may also apply to cancer patients [17]. Additionally, several studies showed the feasibility and acceptability of internet-based support programs for both psychosocial and physical symptoms in these patients [4,18,19].

Despite these promising findings, the effects of internet-based support programs specifically designed for cancer patients are less clear. Reviews on the effects of internet-based support programs are scarce in the field of oncology. This paucity is due to the heterogeneous nature of these programs as well as measured study outcomes which renders rigorous evaluation of the effects difficult. The available reviews are either rather broad, for example summarizing all types of internet-based support including non-professional resources [20], or specifically focus on a single type of support program (e.g. online psychological therapy [4]) or tumor type [12]. Also, assessment of study quality has received limited attention. Therefore, the aim of this review was to analyze published clinical trials to assess the effects of internet-based support programs. More specifically, it was examined whether these programs are capable of alleviating psychosocial and/or physical symptoms resulting from cancer diagnosis and treatment. Additionally, the (methodological) quality of the included studies was evaluated.
Methods

Eligibility criteria for article selection
Articles were selected based on the following eligibility criteria.

Study design. Eligible studies were randomized controlled trials (RCT) and non-randomized controlled trials (CT), performed in adult cancer patients (≥18 years), comparing quantitative psychosocial and/or physical outcomes of an internet-based support program with (a) comparison group(s). ‘Cancer patients’ were defined as individuals diagnosed with any solid cancer type, irrespective of disease stage, treatment phase, type of treatment and time since diagnosis. Studies in mixed populations were only included if data for cancer patients were reported separately. Studies must have reported original data. Letters to the editor, patient stories, posters, thesis, review studies and non-English records were excluded. Internet-based support program. An internet-based support program was defined as any program that aimed to rehabilitate or support cancer patients regarding psychosocial and/or physical symptoms resulting from diagnosis and treatment. Programs that were not primarily designed to support/rehabilitate (e.g. treatment decision aids and health behavior change interventions) were beyond the scope of this review and excluded. Programs focusing exclusively on education were only included if the education aimed to support/rehabilitate cancer patients. The internet-based support program should have been designed by (a) health care professional(s). Studies regarding social support groups were eligible if the groups were moderated by a health care professional. Studies that described programs without access to the internet (e.g. CD-rom or DVD) or to a website (e.g. therapy via e-mail) were excluded.

Outcomes. Quantitative psychosocial (e.g. distress, anxiety, depression and quality of life (QoL)) and physical variables (e.g. fatigue, insomnia, pain, and sexual problems) were the outcomes of interest.

Search strategy and selection method
The CINAHL, MEDLINE (PubMed) and PsychINFO databases were searched from inception without limitations. For each database, one review author screened the titles and abstract of the retrieved records. Studies that were identified as clearly nonrelevant were excluded at this stage. Studies that were considered as potentially relevant or as ambiguous regarding eligibility were accessed in full-text and evaluated by two authors independently. The last search was performed on 31-01-2014. The following search terms were used alone or in combination: neoplasm, cancer, carcinoma, oncology,
internet, web, online, eHealth, telemedicine, patient education, social support, psycho-education, rehabilitation, support group, support system, therapy, disease management (see Appendix 1 for the full search). The search terms were extensively tested against the output retrieved from initial hand searches. Additionally, reference lists from retrieved articles and relevant systematic reviews were scanned to identify other eligible studies.

**Quality assessment**

Each included study was assigned a level of evidence according to the Oxford Centre of Evidence Based Medicine [21]. That system distinguishes five levels of evidence ranging from 1 (systematic review of randomized trials; the highest level of evidence) to 5 (mechanism-based reasoning; the lowest level of evidence). Additionally, we assessed the methodological quality of the included studies following a checklist used in a review regarding internet-based interventions in chronic diseases [17], which is an adapted version of the Cochrane Collaboration Back Review Group [22]. We changed the item ‘method of randomization explained’ into ‘randomized groups’ as we also included non-randomized CTs. The item on ‘assessor blinding’ was excluded since it is not feasible to blind the assessor in case of self-report measures. The quality score could range from 0 to 12 points. See Table 3 for the checklist and scoring procedures.

**Results**

The initial search yielded 2,032 articles and was reduced to 15 original articles (=15 studies) after application of the eligibility criteria. One additional article was identified after examination of the references of included articles and relevant systematic reviews (see Figure 1).

**Description of selected included studies**

Characteristics of the included studies are summarized in Table 1. All studies were published in 2001 or later, with the majority (N = 10) being published after 2010. Sample sizes ranged from 27 to 450 participants. All studies had a pre- and post-test design to measure outcome differences in the group(s). Twelve studies were RCTs. Three studies used several experimental [23] or control [10,24] groups, all other studies used a single experimental and control group (e.g. wait-list control, control group receiving usual care). One study examined two different types of programs, i.e. an online therapy for psychosocial symptoms with or without additional use of a support group [25].
Table 1. Methodological characteristics of the included studies

<table>
<thead>
<tr>
<th>Program</th>
<th>Experimental (E) and control groups (C)</th>
<th>Target population and sample size</th>
<th>Disease stage</th>
<th>Treatment phase</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Online support groups</strong></td>
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<tr>
<td>GyneGals [31]</td>
<td>E (N=13): GyneGals C (N=14): wait-list control group</td>
<td>Sexually distressed gynecologic cancer patients (N=27) (&lt;5 years post-diagnosis)</td>
<td>Stage III</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Online cancer support group [34]</td>
<td>E (N=48): internet cancer support group C (N=20): usual care</td>
<td>Spanish-dominant speaking immigrant breast cancer patients (N=68)</td>
<td>Not specified</td>
<td>During treatment and follow-up</td>
</tr>
<tr>
<td>Online support group [35]</td>
<td>E (N=24): moderated online support group C (N=26): peer-led online support group (no use of preselected topics or input from a moderator)</td>
<td>Breast cancer patients (N=50)</td>
<td>Stages I-IV</td>
<td>Follow-up: completed treatment ≤32 months</td>
</tr>
<tr>
<td>Online support group [29]</td>
<td>E (N=20): educational and support network program C (N=20): wait-list control group, received resource kit including pamphlets</td>
<td>Prostate cancer patients (N=40) (&lt;5 years post-diagnosis, being married/living with significant other)</td>
<td>Not specified</td>
<td>Not specified</td>
</tr>
<tr>
<td><strong>Online therapy for psychosocial/physical symptoms</strong></td>
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<tr>
<td>CAREss (Counseling about regaining erections and sexual satisfaction) [24]</td>
<td>E1 (N=33): internet-based version of CAREss C1 (N=48): wait-list control group C2 (N=40): face-to-face version of CAREss’</td>
<td>Prostate cancer patients (N=121) (heterosexual couples with the male partner having undergone localized prostate cancer treatment)</td>
<td>Stages I-III</td>
<td>Follow-up: definitive surgery or radiotherapy between 3 months and 7 years previously</td>
</tr>
<tr>
<td>Sleep Healthy Using The Internet (SHUTi) [26]</td>
<td>E (N=14): SHUTi C (N=14): wait-list control group</td>
<td>Patients with any type of cancer and insomnia (N=28)</td>
<td>Stage I-IV (at inclusion in remission)</td>
<td>Follow up: completed active treatment ≥1 month</td>
</tr>
</tbody>
</table>
### Table 1. Methodological characteristics of the included studies (continued)

<table>
<thead>
<tr>
<th>Program</th>
<th>Experimental (E) and control groups (C)</th>
<th>Target population and sample size</th>
<th>Disease stage</th>
<th>Treatment phase</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Online systems</strong></td>
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<tr>
<td>CHESS (Comprehensive Health Enhancement Support System) [23]</td>
<td>E1 (N=118): CHESS information services</td>
<td>Breast cancer patients (N=450) (≤2 months of diagnosis of primary breast cancer or recurrence)</td>
<td>Not specified</td>
<td>Not specified</td>
</tr>
<tr>
<td></td>
<td>E2 (N=109): CHESS information + support services</td>
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<td></td>
<td>E3 (N=111): CHESS information + support + coaching services</td>
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<tr>
<td></td>
<td>C (N=112): internet only</td>
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<tr>
<td>CHESS [36]</td>
<td>E (N=147): CHESS (full version)</td>
<td>Younger (≤60 years) breast cancer patients (N=295)</td>
<td>Stages I-IV</td>
<td>Not specified</td>
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<tr>
<td></td>
<td>C (N=148): received copy of Dr Susan Love’s Breast Book</td>
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<tr>
<td>CHESS [37]</td>
<td>E (N=286): CHESS (full version)</td>
<td>Low-income breast cancer patients (N=286) (&lt;1 year of diagnosis or metastatic cancer)</td>
<td>Stages I-IV</td>
<td>Not specified</td>
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<tr>
<td></td>
<td>C (N=51): control group (drawn from a separate RCT)</td>
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<tr>
<td></td>
<td>C1 (N=83): internet access + list of high quality breast cancer websites</td>
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<tr>
<td></td>
<td>C2 (N=83): books or audiotapes on breast cancer resources</td>
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<tr>
<td></td>
<td>E (N=136): Health Navigation</td>
<td>Various cancer patients (breast, stomach, colon, uterine, lung, thyroid) with moderate to severe fatigue (N=273)</td>
<td>Stages I-II</td>
<td>Follow up: completed primary treatment ≤24 months</td>
</tr>
<tr>
<td></td>
<td>C (N=137): waiting-list control group</td>
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<tr>
<td></td>
<td>C (N=145): standard care</td>
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<tr>
<td></td>
<td>C (N=163): information sheet with suggestions for publicly available cancer-relevant internet sites</td>
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</tbody>
</table>

* Randomized groups were reported only in the current analysis
Description of participants
The 16 studies comprised 2620 patients. Eight studies focused exclusively on female breast cancer patients. Four studies contained patients with various tumor types [25-28], of which breast cancer patients constituted 39-64%. The remaining studies were performed in patients with prostate [24,29], head and neck [30] and gynecologic cancer [31]. Nine studies included only women and two studies only men [24,29]. The overall median age of the patients was 52 years (range 42-67 years; two studies did not report on age). Seven studies analyzed cancer patients with all disease stages (stage I-IV), whereas four studies only included patients with locally or locally advanced cancer (stage I-III) [24,28,31,32]. Five studies did not specify patients’ disease stage [23,29,30,33,34]. Six studies included solely patients who had completed cancer treatment during their follow-up [24-26,28,31,35], one study only included patients during treatment [27] and two studies patients in all treatment phases [30,34]. The remaining studies did not specify patients' treatment phase.
Figure 1. Inclusion process for the literature analysis

Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis

2032 articles identified by database search:
- 1038: MEDLINE (PubMed)
- 746: CINAHL
- 248: PsychINFO

451 duplicates excluded

1581 articles

1419 ‘clearly not relevant’ articles excluded based on title and abstract

162 articles

140 articles excluded after reading full-text (N) based on:
- No focus on cancer survivors (4)
- No use of the internet or website (10)
- Not designed to support/rehabilitate (5)
- No outcomes reported (23)
- Feasibility/developmental study (13)
- Not designed/moderated by professional (17)
- Unstructured use of the internet (2)
- Review, letter to the editor, patient story, thesis or book chapter (20)
- No relevant outcomes reported (22)
- No full-text available (24)

22 articles

7 articles considering single-arm studies excluded

15 articles

1 article included (extracted from references of included articles)

16 articles remaining for analysis
Description of internet-based support programs

Table 2 shows the characteristics of the internet-based support programs. Three different types of programs could be distinguished: social support groups [29,31,33-35], online therapy for psychosocial/physical symptoms [24-26,32] and online systems integrating multiple services such as information, support, communication and coaching services [10,23,27,28,30,36,37]. All but one study [34], provided patient education within the program. The majority of the programs provided the opportunity to communicate with peers [10,23,25,27,29-37] and/or professionals [10,23,24,27,28,30,31,34-37]. Exercises such as cognitive-behavioral homework and coping-skills training were part of the program in five studies [23-26,32]. Except for one internet-based support program [26], all programs were facilitated by a moderator. The moderator's role varied and included facilitating a discussion and/or introducing new topics in a support group [33,35], being the expert to ask questions [10,23,27,36,37] or having an active role in the intervention such as chatting, discussing and mailing with participants [24,27,30,31,34]. Two studies [28,29] did not describe the role of the moderator. The duration of the programs ranged from 6 weeks to 1 year.

Outcomes of included studies

The used measurement instruments and corresponding outcomes of the studies are presented in Table 2. Psychosocial outcome measures, such as (health-related) QoL, depression, distress/stress and perceived social support were the most common used outcome measures. Some studies used validated as well as self-constructed or modified questionnaires [10,23,24,26,28,30,31,33,34,36,37].

Positive effects of the internet-based support programs on outcome measures and/or measurement points were reported in nine studies. Of these, seven studies used online systems, one a social support group and one online therapy. Two studies mentioned that the number of included patients was insufficient to detect significant differences [25,31]. Patients in the experimental group experienced a better QoL compared to those in the control group(s) in three studies examining online systems [10,28,30] whereas eight other studies did not report any differences in QoL [23,26,27,29,32,34,36,37]. Two studies found positive effects within the experimental group(s) over time and stable or decreased QoL in the control group, but did not report differences between groups [24,29]. Only one [33] out of seven studies measuring depression found a significant positive effect in favor of the intervention group. A social support group for breast cancer patients resulted in less perceived (post-traumatic) stress [33] and an online system for breast and prostate cancer patients diminished global symptom distress [27]. Other studies using psychological [24,31,32] or sexual distress [31] as outcome measure did not show any effects. Of the six studies having social support as an outcome, three [10,36,37] examining the ‘CHESS’ program found a positive effect in favor of the intervention group.
Programs focusing on cancer-related fatigue [28] and insomnia [26] showed a positive effect on fatigue.

Only three studies examined long term effects (>3 months post-intervention) [10,23,24] of which one had positive long term effects up till 9 months after the end of the intervention on QoL and social support [10].

Quality assessment of included studies
Using the adapted Cochrane list for internet-based interventions, the median total score for methodological quality was 6 (observed range 1-8). The level of evidence based on the Oxford Centre of Evidence Based Medicine together with the (methodological) quality of the included studies is summarized in Table 3.
## Table 2. Characteristics of the internet-based support programs and outcomes of the included studies

<table>
<thead>
<tr>
<th>Program</th>
<th>Description of program</th>
<th>Duration program and measurement points</th>
<th>Outcome measures and measurement instruments</th>
<th>Positive effect(s) for experimental group(s) compared to control group(s)</th>
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<tbody>
<tr>
<td><strong>Online support groups</strong></td>
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</table>
| Bosom Buddies [33] | Support group moderated by a mental health professional. Weekly, breast cancer related topics were introduced and discussed. | 12 weeks. Measures at baseline and 12 weeks. | • Depression: CES-D<sup>a</sup>  
• Posttraumatic stress disorder: PCL-C<sup>b</sup>  
• Anxiety: STAI<sup>b</sup>  
• Stress: PSS<sup>b</sup>  
• Self-efficacy: CBI<sup>c</sup>  
• Style of coping with cancer: MINI-MAC<sup>d</sup>  
• Group experience<sup>e</sup> | + Depression  
+ Posttraumatic stress disorder  
+ Perceived stress |
| GyneGals [31] | Asynchronous discussion forum moderated by psychologists and provision of psycho-educational materials addressing psychosocial impact of gynaecologic cancer. Weekly, new topics were introduced. | 12 weeks. Measures at baseline and post-intervention. | • Sexual distress: FSDS-R<sup>f</sup>  
• Anxiety and depression: HADS<sup>j</sup>  
• Illness intrusiveness: IIRS<sup>m</sup> | No significant outcomes  
(Study not powered to detect significant differences) |
| Online cancer support group [34] | Support group moderated by a trained bilingual facilitator. Weekly, issues of interest were discussed. | 30 weeks. Measures at pre- and post-intervention. | • Depression: CES-D<sup>a</sup>  
• Personal growth: PTGI<sup>ab</sup>  
• QoL: FACT-B<sup>ab</sup>  
• Pain<sup>a</sup> | No significant outcomes |
| Online support group [35] | Support group in a semi-structured (psycho-educational) format using asynchronous communication moderated by a social worker. Weekly, new topics were introduced and discussed. | 12 weeks. Measures at baseline, 6, 12 and 16 weeks. | • Depression: CES-D<sup>a</sup> | No significant outcomes |
| Online support group [29] | Educational and support network program for prostate cancer patients. | 6 weeks. Measures at baseline, 6 and 8 weeks. | • QoL:  
- SF-12v2<sup>i</sup>  
- EPIC-26<sup>i</sup>  
- Satisfaction with life scale  
- Relationship satisfaction questionnaire | No significant outcomes  
(at 6 weeks: 3 (out of 10) quality of life subscales significantly improved over time) |
| **Online therapy for psychosocial/physical symptoms** | | | | |
| CAREss<sup>c</sup> [24] | Sexual counseling program moderated by therapists. Couples received cognitive-behavioral homework considering sexually-related issues. | 12 weeks. Measures at baseline and 12 weeks + 3, 6, 12 months beyond intervention period. | • Sexual satisfaction and function for men: IIEF<sup>f</sup>  
• Distress-BSI-18<sup>i</sup>  
• Relationship satisfaction: A-DAS<sup>i</sup> | No formal statistical comparison of E1 with C1/C2 reported  
(IIEF scores of E1 and C2 improved significantly over time, whereas C1 did not) |
| Internet-based coping program [32] | Self-guided intervention consisting of coping-skills training exercises, a small discussion board coping group and education on symptom management. | 12 weeks. Measures at baseline and 12 weeks. | • Health related QoL: FACT-B<sup>e</sup> and EuroQol-5D “feeling thermometer”  
• Distress: IES<sup>i</sup>  
• Physical well-being: MSAS<sup>v</sup> | No significant outcomes |
<table>
<thead>
<tr>
<th>Program</th>
<th>Description of program</th>
<th>Duration program and measurement points</th>
<th>Outcomes and measurement instruments</th>
<th>Positive effect(s) for experimental group(s) compared to control group(s)</th>
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<tr>
<td><strong>Online therapy for psychosocial/physical symptoms</strong></td>
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<tr>
<td>Onward [25]</td>
<td>Program for depression treatment based on cognitive behavioral principles, including an internet support group. Twice a week new lessons and tools were released.</td>
<td>8 weeks. Measures at baseline, 4 and 8 weeks.</td>
<td>• Depressive symptoms: HADS[^1]</td>
<td>No significant outcomes (Study not powered to detect significant differences)</td>
</tr>
<tr>
<td><strong>Online systems</strong></td>
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<tr>
<td>CHESS [23]</td>
<td>Home-based system integrating information, support (including discussion groups, ‘ask an expert’) and coaching services (e.g. for easing distress, healthy relating).</td>
<td>3 months. Measures at baseline, 2 and 6 weeks, 3, 6 and 12 months. (Analysis reported for 6 weeks, 3 and 6 months)</td>
<td>• Emotional processing[^6] • Positive coping: Carver’s Brief Cope • Functional well-being: FACT-B[^7] • Breast cancer concerns: FACT-Bo • Social support: Wisconsin social support scale</td>
<td>6 weeks + Emotional processing (E1&gt;C) + Positive coping (E2&gt;C) 3 months + Emotional processing (E1&gt;C; E2&gt;C)</td>
</tr>
<tr>
<td>CHESS [36]</td>
<td>Home-based system integrating information, support and decision services (including health charts, decision aid, action plan).</td>
<td>6 months. Measures at baseline, 2 and 5 months.</td>
<td>• Social support[^8] • QoL: FACT-B[^9]</td>
<td>5 months + Social support</td>
</tr>
<tr>
<td>CHESS [10]</td>
<td>See description above.</td>
<td>5 months. Measures at baseline, 2, 4 and 9 months.</td>
<td>• QoL: FACT-B[^11] • Social support[^8]</td>
<td>2 months + QoL (E1&gt;C1) + Social support (E1&gt;C1) 4 months + QoL (E1&gt;C1) + Social support (E1&gt;C1; E1&gt;C2) 9 months + QoL (E1&gt;C2) + Social support (E1&gt;C2)</td>
</tr>
<tr>
<td>Electronic health information support system [30]</td>
<td>Electronic health information support system, integrating communication (send messages), information, support (peer-to-peer via forum) and health-monitoring.</td>
<td>6 weeks. Measures at baseline, 6 weeks and 3 months.</td>
<td>• QoL: QoL questionnaire[^d]</td>
<td>6 weeks + 5 (out of 22) subscales 3 months + 1 (out of 22) subscale</td>
</tr>
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</table>
Table 2. Characteristics of the internet-based support programs and outcomes of the included studies (continued)

<table>
<thead>
<tr>
<th>Program</th>
<th>Description of program</th>
<th>Duration program and measurement points</th>
<th>Outcomes and measurement instruments</th>
<th>Positive effect(s) for experimental group(s) compared to control group(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Online systems</strong></td>
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</tbody>
</table>
| Health Navigation  | Tailored education program for cancer-related fatigue. Consisting of self-assessment and graphic reports, health advice, online education, enhanced and short message services, caregiver monitoring and support, and health professional monitoring. | 12 weeks. Measures at baseline and 12 weeks. | • Cancer related fatigue: BFI and FSS\(^{y}\)  
  • HRQol: EORTC QLQ-C30\(^{a}\)  
  • Energy conservation: ECSI\(^{b}\)  
  • Physical activity: MET\(^{c}\)  
  • Nutritional status: MNA\(^{d}\)  
  • Psychological distress: HADS\(^{l}\)  
  • Pain: BPI\(^{m}\)  
  • Sleep quality/quantity: MOSS-SS\(^{n}\)  
  • Cancer related fatigue  
  • Health-related quality of life (only cognitive functional scale) | +  
| [28]               |                                                                                        |                                        |                                                                                                        |                                                                         |
| WebChoice          | Interactive health communication application for reducing symptom distress containing an assessment component, tailored symptom self-management support, information section, communication section and a diary. | 1 year. Measures at baseline, 3, 6, 9 and 12 months. (analysis for 12 months reported only) | • Symptom distress: MSAS-SF\(^{v}\)  
  • Depression: CES-D\(^{a}\)  
  • Self-efficacy: CB\(^{i}\)  
  • Health related QoL: 15D-HRQol instrument  
  • Social support: Medical Outcomes Study Social Survey  
  • 1 (out of 3) subscale of MSAS-SF (global distress index) | +                                                                         |
| [27]               |                                                                                        |                                        |                                                                                                        |                                                                         |

\(^{a}\)Self-constructed questionnaire by the authors, \(^{b}\)Questionnaire translated by authors, \(^{c}\)Only reporting measurement instruments and outcomes for the male partner, \(^{d}\)3 out of 22 subscales were self-constructed.

\(^{e}\)Center for Epidemiological Studies-Depression Scale, \(^{f}\)PTSD Checklist-Civilian version, \(^{g}\)State-Trait Anxiety Inventory-state Scale, \(^{h}\)Perceived Stress Scale, \(^{i}\)Cancer Behavior Inventory, \(^{j}\)MINI-Mental Adjustment to Cancer Scale, \(^{k}\)Female Sexual Distress Scale-Revised, \(^{l}\)Hospital Anxiety and Depression Scale, \(^{m}\)Illness Intrusiveness Rating Scale, \(^{n}\)Posttraumatic Growth Inventory, \(^{o}\)Functional Assessment of Cancer Therapy-Breast, \(^{p}\)Short Form Health Survey, \(^{q}\)Extended Prostate Cancer Index Composite, \(^{r}\)International Index of Erectile Function, \(^{s}\)Brief Symptom Inventory-18, \(^{t}\)Abbreviated form of the Dyadic Adjustment Scale, \(^{u}\)Impact of Events Scale, \(^{v}\)Memorial Symptom Assessment Scale-(short form), \(^{w}\)Insomnia Severity Index, \(^{x}\)Multidimensional Fatigue Symptom Inventory-Short Form, \(^{y}\)Brief Fatigue Inventory, \(^{z}\)Fatigue Severity Scale, \(^{aa}\)European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-C 30, \(^{ab}\)Energy-Conservation Strategies Inventory, \(^{ac}\)Metabolic Equivalent of Task, \(^{ad}\)Mini-Nutritional Assessment questionnaire, \(^{ae}\)Brief Pain Inventory, \(^{af}\)Medical Outcome Study-Sleep Scale.
Table 3. Quality assessment of the included studies<sup>a,b</sup>

<table>
<thead>
<tr>
<th>Study</th>
<th>Level of evidence&lt;sup&gt;c&lt;/sup&gt;</th>
<th>Methodological quality</th>
<th>Total score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Online support groups</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bosom Buddies [33]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>GyneGals [31]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Online cancer support group [34]</td>
<td>3</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Online support group [35]</td>
<td>3</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Online support group [29]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td><strong>Online therapy for psychosocial/physical symptoms</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet-based coping program [32]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Onward [25]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>SHUTi [26]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td><strong>Online systems</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHESS [36]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>CHESS [37]</td>
<td>4</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>CHESS [10]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Electronic health information support system [30]</td>
<td>3</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Health Navigation [28]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>WebChoice [27]</td>
<td>2</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

<sup>a</sup>1 = Specification of eligibility criteria, 2 = randomized groups, 3 = treatment allocation concealed, 4 = groups similar at baseline, 5 = explicit description of interventions, 6 = description of compliance, 7 = description of dropout and comparison with completers, 8 = long-term follow-up (>3 months after post-intervention assessment), 9 = timing of outcome assessment comparable, 10 = sample size described with power calculation, 11 = intention-to-treat analyses, 12 = point estimates and measures of variability.

<sup>b</sup>✓ = reported item or yes (1 point), — = unreported item or no (0 points), ? = unclear item or unable to determine (0 points). Total score can be 12.

<sup>c</sup>Level of evidence according to the system used by the Oxford Centre for Evidence-Based Medicine.
Discussion
The most apparent result from this review is that the majority of the included studies reported positive effects on patient-reported psychosocial and physical symptoms, regardless of the used program type. This result differs from a similar review conducted in 2010 [20]. That review focused on empirical studies (N = 24 including 37 articles) reporting outcomes of the use of online support/resources by adult cancer survivors. The authors concluded that use of online support/resources showed promising but inconclusive evidence for positive outcomes due to a lack of rigorous evaluations. In the current review rather strict criteria for the final inclusion for analysis of studies were used. For example, only (non-) randomized controlled trials focusing on professionally designed internet-based programs for cancer patients were included. As a result, only five studies included in the previous review met our inclusion criteria. Moreover, our review includes ten studies published since 2010, of which six reported positive outcomes.

Comparable reviews analyzing studies conducted in patients with chronic diseases also showed positive effects of internet-based support programs. A recent systematic review included 17 studies examining online mental health interventions in patients with chronic gastrointestinal conditions. That review showed that these online interventions resulted in less somatic symptoms and an improved quality of life [38]. Another systematic review in patients with various chronic diseases including diabetes, heart failure and COPD (N = 18 RCTs) found beneficial effects of internet-based interventions on patient empowerment [17]. A Cochrane systematic review involving 24 RCTs including in total 3739 patients with chronic diseases found a positive effect of online systems on perceived social support [16]. This finding is in line with our review that showed positive effects for all online systems, mainly for the outcome social support. Given these findings, online systems may well be a generic tool to support patients with various diseases, in different disease stages and treatment phases.

The supportive care needs of cancer patients may differ depending on their socio-demographic and illness-related characteristics. For example, several studies reported that supportive care needs vary by age [39-41]. Therefore, it has been recommended that interventions fit the characteristics and needs of recruited patients [4]. In the current review, patients’ median age was relatively young (52 years) compared to the median age of cancer patients at diagnosis which is 66 years [42]. The majority of the studies included in this review focused on breast cancer patients. Whether internet-based support programs should be adapted to age groups and/or tumor types to optimize effectiveness is unclear. Happily, several ongoing trials will shed light on this aspect as studies are ongoing in patients with tumor types such as prostate cancer, lung cancer and neuroendocrine tumors (ClinicalTrials.gov Identifiers NCT01716702, NCT01012401, NCT01849523) [43].
Our methodological quality assessment showed that the included studies could have been improved on several aspects in order to obtain a higher quality level. For example, in 14 of the 16 studies, study completers were not compared with drop-outs. This comparison may provide valuable information regarding which patients benefit from the internet-based support programs. Twelve of the included studies were conducted in the US. Caution is warranted in generalizing these results to patients in other countries because of possible differences in health care systems and expectations of the role of health care professionals as noted by the aforementioned Cochrane review [16].

A few limitations could be noted regarding our review. The included studies made use of many different outcomes. This heterogeneity hampers firm conclusions regarding effects on some less frequently studied outcomes. Also, some included studies had small sample sizes (e.g. [25,31]). The absence of significant effects might be caused by a lack of power instead of true ineffectiveness of the intervention.

Since cancer patients make widespread use of internet-based technologies, the challenge is to provide easy accessible tools that will be of benefit for the individual patient. Internet-based technologies appear at a much greater pace than research can keep up with. A way to resolve this challenge is to examine the efficacy of generic program components and/or underlying principles that are more timeless than the programs themselves as has been proposed previously [44]. Successful implementation into routine cancer care represents another challenge but is crucial to reach the full potential of internet-based support programs. A barrier for patients might be a lack of accessible internet-based support programs that match their supportive care needs and preferences. Patient preferences for internet-based support vary considerably as demonstrated by a recent study on use patterns of the online system ‘WebChoice’ [45]. It cannot be expected that a few accessible programs will cover the supportive care needs of all patients. We recommend that more effort should be put in the disclosure of available web-based support programs and tools. For example, a portal website could be constructed which contains all available supportive care programs/tools including apps, websites and social media for cancer patients. As such, patients are provided with a choice what type of supportive care programs/tools matches their need and preferences. Ultimately, patients will receive the supportive care they wish for and benefit from the wealth of tools and programs delivered through the internet.

**Conflict of interest statement**
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**Acknowledgments**
All authors drafted, read and approved the final version of the manuscript.
References


Appendix 1. Full search databases

MEDLINE (PubMed)

(((Neoplasms[MESH] OR Carcinoma[Mesh]) OR (cancer*[TIAB] OR neoplasm*[TIAB] OR carcinoma*[TIAB] OR oncology[TIAB])) AND ((Internet[Mesh] OR web*[TIAB] OR online*[TIAB] OR internet*[TIAB]) OR (e-health*[TIAB] OR eHealth*[TIAB]) OR (telemedicine[MESH:noexp]))) AND ((“Patient Education as Topic”[Mesh]) OR (“Social Support”[Mesh]) OR (psychoeducat*[tiab]) OR (“rehabilitation”[MESH]) OR (support group*[tiab]) OR (support system*[tiab])))

CINAHL

(((MH “Neoplasms+”) OR (MH “Oncology+”) OR TI (“cancer*” OR “neoplasm*” OR “carcinoma*” OR “oncology”) OR AB (“cancer*” OR “neoplasm*” OR “carcinoma*” OR “oncology”)) AND ((MH Internet+ OR MH telehealth+) OR TI (“internet*” OR “web*” OR “online*” OR “e-health*” OR “eHealth*”) OR AB (“internet*” OR “web*” OR “online*” OR “e-health*” OR “eHealth*”)) AND ((MH “Patient education”) OR (MH “Support, psychosocial”) OR (MH “Psychoeducation”) OR (MH “Rehabilitation, Cancer”) OR (TI “support group*”) OR (TI “support system*”) OR (AB “support group*”) OR (AB “support system*”))

PsychINFO


Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis