

Title: A systematic review of types and efficacy of online interventions for cancer patients

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Abstract

Objective: This review examines the evidence-based literature surrounding the use of online resources for adult cancer patients. The focus is online resources that connect patients with their healthcare clinician and with supportive and educational resources, their efficacy and the outcome measures used to assess them.

Methods: The following databases were systematically searched for relevant literature: MEDLINE, PsychINFO, Cochrane Central Register of Controlled Trials, CINAHL, Inspec and Computers and Applied Science. Included were studies conducted in an outpatient setting, and reporting a measurable, clinically relevant outcome. Fourteen studies satisfied the inclusion criteria.

Results: The efficacy of online interventions was varied, with some demonstrating positive effects on quality of life and related measures, and two demonstrating poorer outcomes for intervention participants. The majority of interventions reported mixed results. Included interventions were too heterogeneous for meta-analysis.

Conclusions: The overall benefit of online interventions for cancer patients is unclear. Although there is a plethora of interventions reported without analysis, current interventions demonstrate mixed efficacy of limited duration when rigorously evaluated.

Practice Implications: The efficacy of on-line interventions for cancer patients is unclear. All on-line interventions should be developed using the available evidence-base and rigorously evaluated to expand our understanding of this area.

Keywords: “Cancer”, “Oncology”, “Online”, “Internet”, “Social media”, “Quality of life”

1. Introduction

Recent advances in the detection and treatment of cancer have led to an increase in the number of patients living with this burden of disease[1]. Currently, more than 60% of people diagnosed with cancer in Australia will live more than 5 years after diagnosis, and this figure is expected to rise[2]. Optimal management involves a multidisciplinary team, commonly accessed through an outpatient setting within a hospital system[3]. Increasing subspecialization of cancer care leads to centralization of services for specialized surgery and radiotherapy and access to clinical trials. However, centralized outpatient care is an episodic approach to assessment and treatment, and does not meet the fluctuating care needs of those living with cancer.

The Internet, and in particular various types of social media, provide new communication possibilities, with the potential to change the organization of health care[4, 5]. There are many online health care options with possible benefits, especially for cancer patients, where an increasing number of survivors are requiring long-term care. Aside from the practical benefits, including avoiding the waiting room and scheduling appointments around other activities[6], online resources may be used to connect patients with their healthcare professionals, connect with others in a similar situation or to provide educational resources.

The desire or willingness for cancer patients to receive interventions online is currently unknown. However, given the increasing use of the Internet and social media for health-related searches and discussion, online interventions have the potential to be powerful tools in patient management [7-9]. Patients who would benefit most from the implementation of online interventions in a practical sense are those who have difficulty attending outpatient appointments (due to distance, lack of transport, deformity or disability)[5] and those with uncommon conditions, where expert management teams and support networks of peers with similar conditions may be hard to access[10]. The geography of Australia, with its highly concentrated populations and large landmass, raises problems for both the government in providing, and the regional population in accessing, the full range of healthcare services[11, 12]. This is reflected in the decline in availability of cancer and oncology services in Australia as geographical distance from a major city increases[13]. Regional patients must therefore travel to access the necessarily centralized healthcare services. This carries a significant burden, both physically with regards to travel, and emotionally in terms of leaving support networks[12, 14].

Access to healthcare is a significant contributor to the poorer health status of regional patients[15]. A significant and unacceptable health gradient exists between patients in major cities and those in rural and remote areas, with health outcomes generally worsening with distance from the capital cities[15]. Although this trend is exemplified in the Australian population due to the nation's geography, cancer patients have demonstrated poorer health outcomes due to distance from treatment in many populations worldwide[16, 17]. Innovative solutions are needed to provide specialist healthcare and support for these patients. The Australian Government has recognized the potential for online interventions to overcome health status disparities, naming health as a major objective of implementation of the National Broadband Network[18], recognizing that online interventions can remove the distance, time and cost barriers which make access to centralized healthcare services in rural and remote

settings difficult[18]. Online interventions providing healthcare and support have the potential to transform quality of life for these patients.

The use of the Internet for health-related applications is widespread, with up to 80% of Internet users ~~in the US~~ having searched for health information[7-9]. Although direct Internet search has been the mainstay, social media is emerging as a popular source of online health information[7, 19, 20]. Social media provides a platform for interactions around health topics relating to education and access to healthcare[21]. This ability for patients to engage and interact around their health, gives social media the potential to be used as a therapeutic measure. However, in order for social media to form an important part of disease management, it needs to be tailored to the individualized needs of patients[22]. This will involve further research into the affordances of social media and other online platforms, that is, their perceived and preferred uses and actions[22]. Affordances may differ with the user and the variety of online platforms that exist, which include real-time interactive groups, asynchronous bulletin boards and blogs with the opportunity for peer comment.

An increasing emphasis has been placed on the importance of QoL in the assessment of patients with cancer over the past two decades. This trend demonstrates understanding of the cancer experience that takes into account the physical aspects of cancer and treatment, as well as the psychological and emotional. Outcomes related to QoL were the focus of this review, and included both direct measures of QoL, and measures of outcome directly related to QoL, such as mood or symptom burden.

This review examines the evidence-based, outcome-focused literature surrounding interactive online resources for cancer patients within the healthcare system. We review 1) the types of interventions that have been trialled in cancer patients, 2) the outcome measures used to assess efficacy, with a focus on QoL measures, and 3) the efficacy of these online interventions.

2. Methods

2.1 Identification and selection criteria

The databases of MEDLINE, PsychINFO, Cochrane Central Register of Controlled Trials, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) were searched for publications of interest via a series of set headings and key terminology (searched Jan 2013). A further search of the databases Inspec and Computers and Applied Science was undertaken for completeness (June 2013). The search was updated in February 2014 and one additional article satisfying the inclusion criteria was identified and included in the analysis. No date limits were employed for these searches. The search strategies employed are available in appendix 1. Studies were excluded from the analysis if they reported only descriptive outcomes (such as feasibility or basic user satisfaction), if the focus was not on the cancer patient or survivor (e.g. caregiver outcomes) or if they involved non-Internet computer, telemedicine or device based interventions.

The following inclusion criteria were applied:

- (1) Study of an online intervention as a major part of the study design
- (2) Study of an interactive intervention for patient education, to connect patients with each other or connect patients with their healthcare clinicians

- (3) Study of cancer survivors, defined as patients who have had a cancer diagnosis in the past, including those currently receiving active treatment, those in remission or cured and those who are in the terminal stages of disease
- (4) Study conducted in an outpatient setting
- (5) Study with a measurable outcome related to QoL, which may be an assessment of QoL or a measure directly related to QoL
- (6) Study involving adults >18 years
- (7) Study available in full text in English
- (8) Submitted journal letters, conference proceedings, and case reports were included.

Search terms were developed with a specialist librarian at The University of Melbourne. Database searches and initial screening of titles and abstracts were conducted by a single author (HM) according to the pre-determined selection criteria decided by a panel of three (HM, LJ, KJD for the first search and HM, MM, FM-S for the second search). If it was unclear from assessment of the title and abstract whether selection criteria were met, the full text was evaluated. Any further ambiguity led to full text assessment by KJD and LJ for determination of inclusion. Figure 1 illustrates the search process.

(Insert Figure 1.)

2.2 Categorization of interventions.

The articles included in the review can be classified according to the type of intervention, or by the purpose of the intervention. The heterogeneity of the majority of studies determined that the more useful categorization for the purpose of review was by purpose of intervention. The interventions were therefore categorized into three groups based on the purpose of intervention: those which linked the patient with their treating team of healthcare clinicians, those which connected patients with each other and those which served as educational resources. A summary of the interventions studied and the categories to which they belong is found in Table 1.

2.3 Categorization of outcomes.

Outcomes related to QoL, in its broadest sense, were the focus of this review, and these included direct measures of QoL, and measures of outcome directly related to QoL such as mood, symptom burden and social support. All measures are outlined in Table 2. Commonly, outcome measures without clinical relevance were used, including user satisfaction and feasibility, and these were not included in the review.

3. Results

3.1 Identification and selection criteria

The following initial search results were obtained: Medline (n=265), CINAHL (n=93), Cochrane (n=71), PsychINFO (n=50), Inspec (n=829) and Computers and Applied Sciences (n=145). After scrutinization, fourteen studies were included that satisfied the selection criteria (Fig. 1). Additional related studies were examined for background.

3.2 Feasibility and acceptability studies.

Many studies of online interventions for cancer patients looked primarily at the feasibility and basic acceptability of these interventions. As they did not have an objective outcome measure they did not fit the inclusion criteria for full analysis. Overall these studies demonstrated that the use of online interventions for support or therapy in this population was feasible to implement and acceptable to the recipients in a general sense[5, 23-30].

3.3 Cancer population

The relative scarcity of literature surrounding online interventions for cancer patients has necessitated inclusion and comparison of studies of patients with various cancer types. This review includes studies of patients with lung cancer[31], prostate cancer[32], head and neck cancer[33] and breast cancer[34-40], as well as mixed cancer populations[41-44].

3.4 Intervention type and outcome measures

All three intervention types were represented. Outcome measurement tools differed between studies and while most used direct measures of QoL, others measured outcomes directly related to QoL. These included measuring mood, cancer symptoms, social support, health competence, health status, coping, self-efficacy, distress, stress, post-traumatic stress disorder, adjustment to cancer, self-rated global health, positive change, pain, hope and sleep. Nine of the studies were Randomized Controlled Trials (RCTs) and the remaining five used rigorous study designs such as repeated measures and controlled trials that were not randomized.

3.5 Online platforms

Interventions were delivered using various online platforms including e-mail, online educational resources, online support groups or message boards, cancer information websites and interactive websites. Online support groups and interactive websites were the most commonly used. Only Web 1.0 platforms were represented in the current study, and no online interventions for cancer patients based on social media platforms were identified in the literature. These results are demonstrated in Table 3.

3.6 Meta-analysis

The studies included could not be pooled for meta-analysis due to methodological variances in experimental design and outcome measures.

(Insert Table 1. here)

3.7 Multidimensional interventions

Most studies were of only one intervention category, however the “WebChoice” intervention described by Ruland et al.[41] included all three categories, and studies by Gustavson et al.[35], Owen et al.[38], Meneses et al.[34], Osei et al.[32] and van den Brink et al.[33] had components of both educational resource and connecting patients. It was not possible to discern which categories of intervention lead to the outcomes measured, thus these studies will be discussed together.

Ruland et al. conducted a RCT of 325 breast and prostate cancer patients to assess the ability of “WebChoice”, an Internet-based, interactive health communication application, to influence cancer symptoms, QoL, social support, self-efficacy, and mood. The platform allows self-monitoring of symptoms and provides tailored

information and self-management support, online communication with cancer nurses, and an online forum for group discussion with other patients. Members of the control group were directed to publicly available cancer Internet sites. The primary outcome was symptom distress as measured by the Global Symptom Distress Index on the Memorial Symptom Assessment Scale, which comprises 3 subscales: Global distress index, Physical symptoms, Psychological symptoms. Over the 12 month follow up period a significant group difference was demonstrated only for the Global distress index, however there was a trend toward better scores on the other outcome measures in the intervention group. No evidence was found to support efficacy for the secondary outcomes, which included mood (The Center for Epidemiological Studies Depression Scale), health-related QoL, (15D HRQoL instrument), social support (Medical Outcomes Study Social Support Survey), or self-efficacy (Cancer Behavior Inventory version 2.0)[41].

Gustafson et al. undertook a RCT of 173 breast cancer survivors comparing high quality online educational resources and communication services (CHESS platform) with simple Internet access or paper and audiotape information controls. The five month intervention included QoL outcome measures, which were determined using a combined measure incorporating The Functional Assessment of Cancer Therapy-Breast (FACT-B), a two item Depression score and a three item Concerns About Body Image score. Social support was again a combined score incorporating a Social Support score, and a five item Bond with Other Patients score, both of which were taken from previous CHESS studies and focus groups. These were assessed pre-test, and at 2, 4 and 9 month posttest. At 2 and 4 months, those with access to the CHESS system demonstrated a QoL and social support benefit compared to controls, however 4 months after the intervention ceased this difference disappeared[35].

A smaller RCT of 53 breast cancer patients examined an online intervention of coping skills training and an online support group (OSG). The 12-week study looked at QoL (FACT-B), physiological well being (Memorial Symptoms Assessment Scale) and psychological well being (Impact of Events Scale). For all three outcome measures, no benefits were seen after this intervention. However, there was a significant interaction between baseline self-reported health status (EuroQol-5D "Feeling Thermometer") and the intervention, such that women with poorer self-perceived health status at baseline showed greater improvement over time in the treatment group[38].

Meneses et al. undertook a repeated measures study of 106 breast cancer patients, which examined the effect of participation in The Fertility and Cancer Project, an online fertility education and bulletin board discussion platform. Mood was assessed using Profile of Mood States, health status was assessed using Medical Outcomes Survey Short-Form, fertility knowledge was assessed using a Knowledge of Fertility scale and breast cancer treatment, health, and fertility status was measured by an investigator developed tool and the Breast Cancer Treatment and Health Status Questionnaire. Significant improvement was detected, with improved physical functioning, social functioning, psychological distress, vigor, vitality and fertility knowledge at the 6 month follow up[34]. However an additional six subscales for mood and four for health status were defined by Meneses et. al. in their Methods, but were not reported in the results[34]. Presumably this was because any differences in these subscales did not achieve significance at the $p < 0.05$ level. The subscales with

unreported results outnumber the reported subscales, indicating less than half of the defined outcome measures detected a positive change after the intervention.

Osei et al. undertook a RCT of 40 prostate cancer patients examining at the use of an online resource (“ustoo.com”) which incorporated a patient chat room and access to educational resources [32]. The control group received pamphlets, which included future treatment options, potential side effects, approaches to dealing with side effects, and other information. [32]. The 6 week intervention, assessed QoL using SF-12, the Extended Prostate Cancer Index Composite, the Satisfaction With Life Scale and the Relationship Satisfaction Questionnaire. QoL was found to be improved in the domains of perceived physical health, urinary irritation and obstruction health, sexual health and hormonal health life satisfaction with a decrease in spouse negative characteristics compared with controls[32]. These differences were not maintained at 8 weeks [32].

In a cluster randomized study of 184 head and neck cancer patients, van den Brink et al. determined the effect of access to an electronic health information support system that provided education, the ability to send messages to the healthcare team and access to a patient forum on QoL[33]. QoL was assessed using questionnaires developed by the researchers based on a theoretical model of coping with cancer, containing 19 validated subscales and 3 subscales not previously used. After the 6 week program QoL was improved in five of twenty-two studied parameters, however only one of these five QoL parameters remained significantly improved at 12 weeks[33].

(Insert Table 2. here)

3.8 Interventions linking patient to clinicians

Cleeland et al. undertook a RCT to assess the efficacy of an intervention linking 79 thoracotomy patients to their healthcare professionals online. Cancer-related symptoms were reported using the M.D. Anderson Symptom Inventory and an automated telephone system. In the intervention group, email alerts to the treating team were generated when symptoms exceeded a certain threshold. No alerts were generated for the control group. The alert provided the practice nurse with the severity of each symptom that had generated a symptom threshold event, so the patient could be contacted and appropriate action (including counseling, education or appointment scheduling) taken. Cancer symptoms were assessed using the M.D. Anderson Symptoms Inventory. There was a reduction in symptom threshold events for the intervention group compared to controls (19% v 8%, respectively) and a more rapid decline in symptom threshold events[31].

3.9 Interventions connecting patients with each other

This group of studies all contained elements of online communication between cancer patients. Lieberman et al. undertook a repeated measures study of 114 breast cancer patients to assess the benefit of asynchronous bulletin boards on depression, QoL growth and positive change. Depression was assessed using The Center for Epidemiological Study Depression Scale, QoL using FACT-B and growth and positive change using The Posttraumatic Growth Inventory. Improvement in all three domains as compared with baseline was demonstrated after 6 months of participation[37]. Other similar studies showed mixed results. Winzelberg et al. undertook a RCT of 72 breast cancer patients looking at the efficacy of a 12-week

Internet social support group. “Bosom Buddies” was a semi-structured moderated group, which was assessed using the outcome measures of depression (The Center for Epidemiological Study Depression Scale), posttraumatic stress disorder (Posttraumatic Stress Disorder Checklist-Civilian Version), stress (Perceived Stress Scale), anxiety (State Trait Anxiety Index), coping (Cancer Behavior Inventory) and adjustment to cancer (Mini-Mental Adjustment to Cancer Scale). Depression, posttraumatic stress disorder, and stress were reduced, however no benefit was observed for anxiety, coping or adjustment to cancer[40].

Lieberman et al. undertook a repeated measures study of 32 breast cancer patients, assessing the effects of participation in a moderated OSG. Outcome measures included depression (The Center for Epidemiologic Studies-Depression Scale), positive change (Posttraumatic Growth Inventory), suppression of affect (The Courtauld Emotional Control Scale), pain (Pain and Courtauld Emotional Control Scale), personality traits (Weinberger Adjustment Inventory), and cancer-related coping (Mini-MAC). They demonstrated that when compared with baseline scores, patients who participated in the 16-week OSG showed significantly reduced depression and reactions to pain, and a non-significant trend toward improvement on The Post-Traumatic Growth Inventory in two subscales: New Possibilities and Spirituality. Interestingly these patients also demonstrated an increase in emotional suppression[36].

A RCT of 74 breast cancer patients by Salzer et al. examined the effects of an OSG on QoL (FACT-B) and cancer symptoms (Hopkins Symptoms Checklist). Despite high levels of user satisfaction, patients undertaking the OSG intervention did worse on measures of QoL and cancer symptoms[39]. Further analysis of these primary outcome measures revealed that the between group difference was due to the experimental group failing to improve their scores in QoL and cancer symptoms from baseline, where the control group did. Although there were few further changes that reached statistical significance at the $p < 0.05$ level in the secondary measures, the results of mood, emotional self efficacy, impact of events and medical outcomes also demonstrated this trend.

Hoybye et al. undertook a cluster RCT of 794 patients undertaking weeklong rehabilitation for cancer. Both groups participated in a 6-day rehabilitation retreat which included lectures and group work related to survivorship, run by a multidisciplinary team. In addition to these activities the intervention group attended a lecture on the use of the Internet as a support and participated in an OSG. Outcome measures included psychological distress (Profile of mood states) and adjustment to cancer (Mental Adjustment to cancer). A secondary outcome measure of self-rated global health was also used. No difference between the intervention and control groups was found for most measures of mood and adjustment to cancer at any of the three time points. However the intervention group demonstrated less reduction in helplessness, and increased anxious preoccupation, confusion and depression at 6 months compared with controls[42].

3.10 Interventions providing educational resources.

Yun et al. conducted a RCT of 273 patients evaluating the efficacy of an Internet-based cancer-related fatigue education program for Korean women. The outcome measures included fatigue (Brief Fatigue Inventory and Fatigue Severity Scale), QoL (European Organization for Research and Treatment of Cancer Quality of Life

Questionnaire C30) and anxiety (Hospital Anxiety and Depression Scale). They found that the intervention group, when compared with a routine care control, had a significantly greater decrease in fatigue, improved QoL and decreased anxiety compared with controls[43].

Ritterband et al. undertook a RCT of 28 cancer patients, assessing the efficacy of a 9-week online Cognitive Behavioral Therapy (CBT) program to improve insomnia symptoms. The program delivered CBT components for treatment of insomnia including sleep restriction, stimulus control, cognitive restructuring, sleep hygiene, and relapse prevention. Outcome measures included overall insomnia severity (Insomnia Severity Index and Sleep Diary), fatigue (The Multidimensional Fatigue Symptom Inventory- Short Form), mood (The Hospital Anxiety and Depression Scale) and QoL (SF-12). It was demonstrated that patients in the Internet CBT group had significant improvements compared to a waitlist control group in overall insomnia severity and a reduction in fatigue. No significant change was found for mood or QoL.[44].

3.11 Summary of interventions

Most studies describe a single intervention, such as participation in an OSG [36, 37, 39, 42], access to online educational resources [43], or remote monitoring of vital signs or disease indicators[45]. However this is a growing area of research and there is increasing interest to broaden the approach, with the design of multipurpose interventions. A number of research protocols[45, 46] describe such interventions, however only one RCT assessing a multidimensional online intervention in cancer patients is currently present in the literature, the previously described “WebChoice” platform[41] which allows patients to monitor symptoms over time and access self-management options and has a communication area where patients can ask questions to a clinical nurse specialist and exchange experiences with other cancer patients[41]. Table 1 summarises the results of each intervention and outcome measures used.

(Insert Table 3 and 4. here)

4.1 Discussion

Only 14 studies from the vast literature relating to the Internet and cancer patients were included in this review. This reflects the small proportion of this literature that has a quantifiable and clinically meaningful evidence-base. There is ever-increasing interest in online health tools and interventions, as shown by the large number of articles screened (Figure 1). Many exciting, innovative platforms are described[5, 46-51]. The vast majority, however, report only simple qualitative analysis, or are purely descriptions of the intervention with no evaluation.

Overall, this review found a generally positive effect on cancer patients of the various types of online interventions described. However, the studies were too heterogeneous for a meta-analysis or to contribute to clinical practice guidelines or best-practice recommendations. In particular, the outcomes measures used differed markedly between studies. Some measures, such as the FACT-B, have been thoroughly

validated in the literature and were used by more than one reviewed study[35-39]. However, some studies used less validated or infrequently used measures. Two groups used unvalidated outcome measures produced uniquely for their studies. Meneses et al.[34] developed a Knowledge of Fertility questionnaire exclusively for their study and van den Brink et al.[33] assessed QoL using a questionnaire containing twenty-two subscales, of which three were created uniquely for their study. This is particularly problematic, with the potential for bias, the lack of validation and the difficulty of comparison with similar interventions. Furthermore, many clinically meaningful measures directly related to QoL, such as return to work, activities of daily living and functionality, were not assessed in any study and are therefore not discussed in this review.

Although the online interventions reviewed demonstrated mixed efficacy, no harm was seen from the majority of interventions. However, Hoybye et al.[42] and Salzer et al.[39], both studying the effects of an OSG, demonstrated that there is the potential for adverse effects. Hoybye et al.[42] showed that participants involved in the support group intervention demonstrated a transient increase in helplessness, anxious preoccupation, confusion and depression at 6 months, and Salzer et al.[39] showed that despite high levels of user satisfaction, patients undertaking the OSG tended to do worse in direct and related measures of QoL. Those participating in the OSG intervention failed to improve from baseline, whereas those in the internet-based educational control condition group did. This raises the concern that the intervention actually hampered improvement in QoL. This study also demonstrates that caution must be used when interpreting user satisfaction as a measure of intervention feasibility or success.

Although the focus of both the Salzer et al.[39] and Hoybye et al.[42] studies was an OSG, these two interventions studied different cancer populations for both type of cancer and stage of disease, and used different outcome measures to assess efficacy. The results of these two studies are important, as the benefit of online interventions is often assumed, with the investment of significant resources in implementation, but with little thought to measurement of outcome. This review shows the efficacy of many interventions to be marginal, often ~~time limited and~~ unsustained or occasionally negative.

The mixed and variable results achieved in many of the interventions may be the result of multiple factors, including the lack of a theoretical framework with a poor correlation between outcomes measured and mechanisms targeted. Interventions may target patients at the wrong time, target the wrong patients, use the wrong 'dose' of the intervention (wrong frequency or length), the wrong delivery method or mechanism. Additionally, it is essential that the patient's pre-intervention and extra-intervention Internet and social network use is taken into consideration, as this represents a potential confounding factor when assessing the efficacy of an Internet-based intervention. Interestingly, in the study by Gustafson et al.[35] study, which used two control groups, an internet information control and a book information control, to assess an online intervention for breast cancer patients, the internet control group did worse than the book control group on measures of QoL at 2 months[35]. This emphasizes that baseline, non-intervention internet usage may be a confounding factor in studying online interventions, and raises the possibility that non-directed internet use may be detrimental in the time after diagnosis. Conversely, a lack of

Internet usage skills may also hamper the effectiveness of an intervention, which may be particularly relevant in older populations.

For most studies it was impossible to precisely determine the important characteristics of the intervention to achieve the results reported. Future research requires evidence-based reasoning behind intervention design and implementation in well-defined patient groups, with appropriately justified outcome measures for that population.

The durability and longevity of benefit from interventions that demonstrated a positive outcome has yet to be clearly demonstrated. Van den Brink et al.[33] reported improvement in five QoL parameters after a six week online intervention which allowed patients to connect with each other and relevant health information, however this improvement remained significant in only one parameter at three months. Similarly Osei et al.[32] found the improvement in QoL they demonstrated for prostate cancer patients after six weeks, had waned by eight weeks.

It is, of course, possible to deduce from the studies in this review that online interventions are not useful for significantly improving health outcomes for cancer patients and survivors, and there is no substitute for face-to-face interactions with peer support groups and healthcare professionals. However, such a conclusion is likely to be premature, as the field has been inadequately studied. In particular, the significant diversity of interventions, populations and outcomes studies precludes in-depth analysis.

Absence of a quantitative outcome measure was the major criteria for exclusion of an article from this review. Some of the most promising projects used outcome measures that were associated only with the feasibility or usability of the intervention, an important first step in a complex intervention, but of little use in assessing clinical benefit [5, 23-26, 29, 30]

A study by Cathala et al. is a good example of this. User satisfaction for their potentially beneficial online education and communication platform for prostate cancer patients was high, but no clinical outcome measure was reported[5]. Similarly a multidisciplinary online research network for cancer patients, "PatientViewpoint", also failed to report a quantitative outcome[46]. This is a promising online tool, comprising a website allowing QoL assessment and patient reported outcomes to be assigned and individualized for patients, stored on a secure network, and linked with the electronic medical record, thus accessible to the clinician at the next consultation. The outcome measure used in this case was qualitative interview. These interviews revealed that patients were interested in using the "PatientViewpoint" website, and clinicians believed it would help their clinical practice[46]. However, a clinically meaningful quantitative outcome measure was not used. While the review of such reports is interesting and may inform the design of new interventions, for an online intervention to contribute to best practice it must be shown to have an impact on measurable health outcomes, whether survival, QoL or another measure.

There were two main limitations of this study. The first is the inclusion of a mixed cancer population. The paucity of included studies precluded deeper analysis of individual tumour types, which may, have significantly different needs. Common cancers, such as breast and prostate cancer, predominated in the reviewed studies, with less common cancers, such as brain tumours, which may especially benefit from

online interventions, unfortunately under-represented. Secondly, as previously discussed, there was a paucity of studies using similar well-validated outcome measures. Therefore, the ability to determine the efficacy of many interventions was limited. ~~Table 4 summarises the results of each intervention.~~

4.2 Conclusion

The overall benefit of online interventions for cancer patients is unclear. Although there is significant promise, the few interventions that have been rigorously analyzed demonstrate mixed efficacy, often of limited duration. Future studies would benefit from a more informed approach to the design of online interventions, with objective evidence to justify the creation and implementation of interventions created for specific patient populations. Furthermore the outcome measures used should be limited to those that have been well validated within the populations being studied. No single intervention has sufficient evidence to support widespread implementation for a specific cancer population.

There is particular interest in linking patients and their healthcare professionals online. However, only two such studies fulfilled the inclusion criteria for the current review[31, 41], thus limiting the extent to which the literature can inform the movement towards more integrated patient-centered online healthcare. This form of online intervention could evolve to form a network encompassing the patient and their caregivers and supports, the specialized treating team, and the local healthcare team, but is as yet poorly defined, with a scarcity of analysis in the literature, despite some promising innovations.

4.3 Practice Implications

Despite the paucity of studies, some useful data has been obtained that point to the research needs in the field. Future studies should focus on determining the affordances of online interventions and social media for cancer patients and survivors and developing an intellectual and theoretical framework for development of future interventions. This will lead to rational development of the right intervention for the appropriate patient. There should then be rigorous analysis of clinical benefit using validated outcome measures. Only then will this be a mature field of investigation and best practice will be defined and clinical practice guidelines feasible.

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Competing Interests

None declared.

Authors' contributions

HM led the analysis, and wrote the first and final drafts.

KJD led the conceptualization and critically reviewed the first and final drafts.

FM-S assisted with the conceptualization, assisted with the analysis and reviewed the final draft.

LJ assisted the conceptualization, assisted with the analysis and reviewed the final draft.

MM assisted with the formation of tables and reviewed the final draft.

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Intervention category and reference		Sample characteristics (Sample size, mean age in years & SD)		Study type	Description of intervention			Outcome measures assessed	Results	Effect size
Reference	Intervention category	Intervention	Control		Type of cancer	Intervention	Control			
Winzelberg et al.[34]	Patient to Patient	SS: 36 Age: 49.5 (6.2)*	SS: 36, Age 49.5 (6.2)*	RCT Prospective	Breast Cancer	12-week, web-based, social support group, "Bosom Buddies". Semistructured, moderated by health care professional, asynchronous newsgroup format.	Wait list control	(1) Depression assessed with CES-D (2) Post-traumatic stress disorder assessed with PLC-C (3) Stress measured with PSS. (4) Anxiety was measured using STAI.	Reduced depression*, cancer related trauma (PTSD)*, and perceived stress* in intervention group. No change in anxiety between groups	Depression = 0.54, cancer related trauma PTSD = 0.45, Perceived stress scale = 0.37, Anxiety = -0.05
Salzer et al.[24]		SS: 51 Age: (35.3% under age 50)	SS: 27 Age: (48.2% under 50y)	RCT Prospective	Breast cancer	Internet peer support. Participants subscribed to an unmoderated (no professional facilitator), closed Listserv for 12 months.	Internet-based educational control condition	Primary outcomes: (1) Symptoms assessed using HSCL-25 (2) QoL assessed using FACT-B. Secondary outcomes: (1) Distress assessed using the IES (2) Mood assessed using the POMS-SF (3) Hope assessed using the HHI (4) Self-efficacy assessed using the SESES-C (5) Social support measured using the MOS.	4 months Primary: Increased cancer symptoms and decreased QoL* in experimental group. Secondary: No difference between groups for impact of events, hope or medical outcomes in experimental. Higher level of distress* in experimental group. 12 months Primary: Increased cancer symptoms and decreased QoL* in experimental group. Secondary: Less mood problems in control*. Hope is greater in control*. Higher level of distress in experimental*. No difference between groups for impact of events or medical outcomes.	4 months Cancer symptoms = 0.40, QoL = 0.48, impact of events = not reported, mood = 0.65, hope = not reported, self efficacy 0.40, medical outcomes = not reported 12 months Cancer symptoms = 0.40, QoL = 0.55, impact of events = not reported, mood 0.67, hope 0.47, self efficacy 0.42, medical outcomes = not reported
Hoybye et al.[21]		SS: 361 Age: 53 (SD not reported)	SS: 433 Age: 55 (SD not reported)	Cluster randomisation Prospective	Various	Rehabilitation participation plus lecture on internet use/social support/information, plus internet support group participation. Follow up at 1, 6 and 12 months.	Participation in rehabilitation	Primary: (1) Psychological distress assessed using POMS-SF (2) Adjustment to cancer assessed using Mini-MAC. Secondary: (1) Self rated global health.	No difference between groups for majority of measures of mood or adjustment to cancer at any of the three time points. Intervention group had decreased reduction in helplessness, and increased anxious preoccupation, confusion and depression at 6 months	Effect size not reported
Lieberman et al. 2003[22]		SS: 32 Age: proportion in each age group 30 – 39, 12% 40 – 49 54%, 50 – 59 28%, 60 6%.		Repeated measures (Baseline vs. post intervention) Prospective	Breast Cancer	Breast cancer patients participated in 16 week electronic support group (1 session per week).	No control – results compared to pre-support group baseline.	(1) Depression assessed using CES-D. (2) Positive change assessed using PTGI. (3) Suppression of affect assessed using CECS. (4) Pain assessed using pain self ratings. (5) Personality traits, were assessed using WAI. (6) Cancer-Related Coping assessed using Mini-MAC	Reduced scores in depression* and reactions to pain* with a non-significant trend toward improvement on PTGI in two subscales: New Possibilities and Spirituality. An increase in emotional suppression was also found.	Effect size not reported
Lieberman et al. 2005[23]		SS: 114 Age: 46.2 (8.1)		Repeated measures (Baseline vs. post intervention) Prospective	Breast Cancer	Survey of breast cancer patients who joined an online bulletin board assessing depression and QoL at baseline and 6 months.	No control group. Baseline outcomes compared with outcomes after 6 months using the online support group.	(1) Depression assessed using CES-D. (2) Quality of life assessed using FACT-B. (3) Positive change assessed using PTGI.	Reduced depression*, growth and positive change*, and improved QoL*.	Effect size not reported

<i>Ritterband et al.[35]</i>	Educational	SS:14 Age: 53.7 (10.8)	SS: 14 Age: 59.6 (12.3)	RCT Prospective	Various	9 week program CBT-I program "Sleep Healthy Using The Internet" for breast cancer survivors with insomnia to improve insomnia symptoms.	Wait list control	Sleep assessed using three measures:(1) ISI (2) Sleep diary (3) The MFSI-SF Other outcome measures included (1) Mood, assessed using HADS (5) Quality of life assessed using the SF-12.	Reduced overall insomnia severity*, sleep efficiency*, sleep onset latency*, soundness of sleep*, restored feeling upon awakening* and general fatigue* No difference in total sleep time, time in bed, wake after sleep onset, number of awakenings, depression, anxiety or quality of life	Insomnia severity =1.85, total sleep time = 0.32, wake after sleep onset = 0.22, average sleep efficacy = 0.72, sleep onset latency = 0.67, soundness of sleep = 1.21, restored feeling upon waking 1.35, time in bed = 0.40, restored feelings upon awakening = 1.35, number of awakenings = 0.43, depression 0.42, anxiety 0.54, QoL 0.48
<i>Yun et al.[25]</i>		SS: 136 Age: 52.2% >45y	SS: 137 Age: 54.7% >45	RCT Prospective	Various	North Korean cancer patients with primary treatment completed in prior 24 months suffering moderate/severe fatigue undertook 12-week, Internet-based, individually tailored cancer-related fatigue education program.	Routine care	Primary outcomes: Cancer related fatigue assessed using (1) BFI and (2) FSS. Secondary outcomes: (1) Mood assessed using HADS. (2) QoL assessed using EORTC QLQ-C30 (3) Energy-conservation strategies assessed using the ECSI (4) Physical activity measured by MET (5) Nutritional status assessed with MNA (6) Severity and impact of pain assessed by BPI (7) Quality and quantity of sleep determined using MOS-SS	Primary: Reduced global fatigue*, severity of fatigue*, interference of fatigue*, total fatigue score* and improvement in QoL. Secondary: Improvement in anxiety*, nutritional status*, and the function subscale of cognition. No improvement was seen in depression, physical activity, quality of quantity of sleep (medical outcomes), pain, energy conservation, global health status.	Primary: Global fatigue = 0.29, severity of fatigue = 0.21, interference of fatigue 0.29, total fatigue score 0.27, QoL = 0.26 Secondary: Anxiety = 0.33, depression = 0.09, nutrition status 0.23 function (cognition subscale)= 0.25, physical activity = 0.09, energy conservation = 0.03, pain (severity) = 0.01, (interference) =0.13, quality of sleep - medical outcomes (quality index 1) = 0.13 (quality index 2) 0.14, global health status = 0.26
<i>Cleeland et al.[29]</i>	Patient to Doctor	SS: 38 Age: 59.2 (13.6)	SS: 41 Age: 60.9 (11.8)	RCT Prospective	Lung Cancer	Lung cancer patients post thoracotomy undertook 4 week program of symptom rating via automated telephone calls. These activated email to clinical team for response when symptoms reached severity threshold.	Same design with no alerts generated at symptom threshold.	(1) Cancer symptoms assessed using MDASI	Reduced number of threshold symptom events in both groups. The slope of the reduction of events was steeper in the intervention group * Mean symptom severity between discharge and follow-up was not significantly different. Symptom interference was less in intervention group*	For control and intervention groups together, the effect size of reduction in symptom severity was 0.72, with an effect size of 0.68 in the control group and 0.75 in the intervention group.

<i>Meneses et al.[31]</i>	Patient to Patient PLUS Educational	SS: 106, Age: 34.3 (4.38)		Repeated measures (Baseline vs. post intervention) Prospective	Breast Cancer	Breast cancer patients accessed online fertility cancer education and participated in online discussions. Changes in mood, functioning, knowledge of fertility and cancer were assessed at 6 months.	No control group. Baseline outcomes compared with outcomes after 6 months.	(1) Mood assessed using POMS-SF (2) Health status assessed using MOS-SF. (3) Fertility knowledge assessed using KF (4) Breast cancer treatment, health, and fertility status measured by investigator developed tool, the BCTHS	Mood state*, health status, fertility knowledge	Effect size not reported
<i>Owen et al.[33]</i>		SS: 26 Age: 52.5 (8.6)	SS: 27 Age: 51.3 (10.5)	RCT Prospective	Breast Cancer	Stage 1 or 2 breast cancer patients had 12 week access to website containing self guided coping skills training, a discussion board and education on symptom management.	Wait list	(1) Quality of life assessed using FACT-B, and the EQ-5D "feeling thermometer" (2) Distress measured using IES (3) Physical wellbeing measured using the MSAS	No significant effect on QoL or physical wellbeing. Psychological wellbeing improved on FACT-B emotional well being subscale*, but not IES.	Quality of life (FACT-B) = 0.30 (EQ-5D) 0.13, Psychological well being (FACT-B emotional well being subscale) = 0.38 IES (0.00), physical well being (MSAS symptoms prevalence) = 0.05 (FACT B breast specific concerns subscale) = 0.28
<i>van den Brink et al.[30]</i>		SS: 39 Age: 59 (range 38-78)	SS: 145 Age: 61 (range 29-84)	Cluster randomization Prospective	Head and Neck Cancer	6 week program for head and neck cancer patients. Included access to online support system, offering patient communication (messages and online forum), access to information, and home monitoring.	Standard care: Standard follow-up appointments, and the possibility to contact care providers if desired.	(1) QoL assessed by questionnaires developed by researchers based on their theoretical model of coping with cancer, containing 19 validated subscales and 3 subscales not previously used.	6 weeks: Reduced state anxiety*, fear related to specific head and neck problems*, physical self efficacy*, perceived abilities in swallowing and food intake*, and general physical complaints*. 3 months: Improvement in physical self efficacy* No significant improvement in fear for consequences of the illness, fear for (additional) treatment, fear for social interactions, fear related to interaction with care providers, feelings of depression, uncertainty-prospects of disease and treatment, uncertainty-access to help and problem solving, uncertainty-how to handle practical consequences of the illness, uncertainty-how to cope with one's own emotions, feelings of insecurity related to accessibility of aid, feelings of insecurity related to surveillance of the illness by care providers, loss of control, self confidence in oral presentation, perceived speech abilities, loneliness, general psychosocial complaints, head and neck specific complaints	Effect size not reported

<i>Osei et al.</i>		SS: 20 Age: 67.2 (7.6)*	SS: 20Age: 67.2 (7.6)*	RCT Prospective	Prostate Cancer	Online prostate cancer educational and support network program (ustoo.org)	Prostate cancer resource kits.	(1) QoL measured using (a) SF-12 v2 (b) EPIC-26 (c) Satisfaction with life scale (d) Relationship satisfaction questionnaire (2) Program satisfaction (investigator developed questionnaire)	6 weeks: Improvement in perceived physical health, urinary irritation and obstruction health, sexual health, hormonal health life satisfaction and decrease in spouse negative characteristics. No significant difference was seen in perceived mental health, urinary incontinence health, bowel health, or spouse positive characteristics. At 8 weeks there was no significant difference seen on any measures.	Effect size not reported.
<i>Gustafson et al.[32]</i>		SS: 90 CHESS, 79 internet (age not reported)	SS: 83 (age not reported)	Random assignment stratified by geographic site and ethnicity Prospective	Breast Cancer	(2 intervention arms) 1. CHESS arm: Access to 12 online services incl. information services, communication services and decision services. 2. Internet only arm: Links to 6 high-quality breast cancer websites	Usual care plus books or audiotape set.	(1) Combined QoL measure (0-100) incorporating FACT-B, a two item depression score and three item concerns about body image score. (2) Social support was determined by a 6 item social support score developed from previous CHESS clinical trials, and a five item bond with other patients score, developed from previous CHESS focus groups. (3) The final outcome measure of Health and Information Competence was assessed by using measures from previous CHESS studies including an eight item healthcare participation measure and a three-item scale assessing access to health information.	(CHESS vs book) 2 months: No significant improvement in QoL, social support, health and information confidence 4 Months: Improvement in social support*, no significant improvement in QoL or health and information confidence 9 months: Improvement in QoL*, social support*, No significant improvement in Health and information confidence (CHESS vs internet) 2 months: Improvement in QoL*, social support*, health and information confidence* 4 Months: Improvement in QoL*and social support*. No significant improvement in health and information confidence 9 months: No significant improvement in QoL, social support or health and information confidence	(CHESS vs book) 2 months: QoL 0.29, social support 0.16, health and information confidence 0.39. 4 months: QoL 0.18, social support 0.46, health and information confidence 0.17 9 months: QoL 0.39, social support0.38, health and information confidence 0.38 (CHESS vs internet) 2 months: QoL 0.34, social support 0.47, health and information confidence 0.44. 4 months: QoL 0.31, social support 0.35, health and information confidence 0.23 9 months: QoL 0.24, social support0.24, health and information confidence 0.24
<i>Ruland et al.[28]</i>	Patient to Doctor PLUS Patient to Patient PLUS Educational.	SS: 162 Age: 56.9 (10.7)	SS: 163, Age: 56.4 (11.5)	RCT Prospective	Various	WebChoice allowed breast and prostate cancer patients to monitor symptoms, access self-management support, communicate with cancer nurses and access an e-forum for discussion with other patients. Follow up at 3, 6, 9 and 12 months.	URLs of publicly available cancer Web sites.	(1) Symptom distress was assessed using the MSAS-SF. (2) Depression was assessed using the CES-D. (3) QoL was measured using the 15DHRQoL(4) Social support was measured using the Medical Outcomes Study Social Support Survey (5) Self efficacy/Coping was assessed using the Cancer Behavior Inventory version 2.0.	Primary: Reduction in symptom distress (MSAS-SF global symptoms distress subscale only)* No significant change in physical symptoms, psychological symptoms, distress Secondary: No significant change in self-efficacy, QoL, depression, social support	Effect size not reported.

Table 1 Summary of the included online interventions for oncology patients (N=14)

Mean age refers to combined experimental and control group; SD, standard deviation; SS, sample size; RCT, randomized controlled trial; QoL, quality of life; PLC-C, Posttraumatic Stress Disorder Checklist-Civilian Version; STAI, State-Trait Anxiety Inventory; PSS, Perceived Stress Scale; FSS, Fatigue Severity Scale; EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30; SESES-C, Stanford Emotional Self-Efficacy Scale-Cancer; HSCL-25, Hopkins Symptoms Checklist; HHI, Health Hope Index; CHES, Comprehensive Health Enhancement Support System; MOS, Medical Outcomes Survey; MOS-SF, Medical Outcomes Survey Short-Form; CECS, The Courtauld Emotional Control Scale; FACT-B, The Functional Assessment of Cancer Therapy-Breast; CES-D, The Center for Epidemiologic Studies-Depression Scale; PTGI, The Posttraumatic Growth Inventory; Mini-MAC, Mental adjustment to cancer; ISI, Insomnia Severity Index; MFSI-SF, Multidimensional Fatigue Symptom Inventory-Short Form; ECSI, energy-conservation strategies inventory; IES, Impact of Events Scale; WAI, Weinberger Adjustment Inventory; BFI, Brief Fatigue Inventory; MNA, mini-nutritional assessment; BPI, brief pain inventory; POMS-SF, profile of mood states short form; HADS, The Hospital Anxiety and Depression Scale; SF12 V2, short form health survey; BCTHS, Breast Cancer Treatment and Health Status Questionnaire; MET, metabolic equivalent of task; MOS-SS, Medical Outcome Study-Sleep Scale; EPIC-26, The Extended Prostate Cancer Index Composite; GDI, Global Depression Index, MDASI, M.D. Anderson Symptoms Inventory; MSAS, Memorial Symptom Assessment Scale; MSAS-SF, Memorial Symptom Assessment Scale Short Form; 15DHRQoL, 15-dimensional health related quality of life; KF, knowledge of fertility; EQ-5D, EuroQol-5D “feeling thermometer.” *Indicates significant at the $p < 0.05$ level. H.McAlpine et al. / Patient Education and Counseling 98(2015)283–295 289

Outcome domain	Connecting patients		Linking patient to clinician		Educational	
	RCT	non-RCT	RCT	non-RCT	RCT	non-RCT
QoL	4 (Owen[48], Salzer[49], Ruland[51]Osei[42])	2 (Lieberman[47], van den Brink[43])	2 (Gustafson[45], Ruland[51])		4 (Gustafson[45], Owen[48], Yun[53] Osei [42])	1 (van den Brink[43])
Mood	3 (Ruland[51], Salzer[49],Winzelberg[50])	4 (Hoybye[52], Lieberman[46], Lieberman[47], Meneses[44])			2 (Ruland[51], Yun[53])	2 (Meneses[44], Ritterband[54])
Cancer symptoms	3 (Owen[48], Salzer[49], Ruland[51])		2 (Cleeland[41], Ruland[51])		2 (Owen[48], Ruland[51])	
Social support	2 (Salzer[49], Ruland[51])		2 (Gustafson[45], Ruland[51])		2 (Gustafson[45], Ruland[51])	
Health competence			1 (Gustafson[45])		1 (Gustafson[45])	
Health status		1 (Meneses[44])				1 (Meneses[44])
Coping	1 (Ruland[51])	2 (Hoybye[52], Lieberman[46])	1 (Ruland[51])		1 (Ruland[51])	
Self-efficacy	1 (Salzer[49])					
Distress	2 (Owen[48], Salzer[49])				1 (Owen[48])	
Stress	1 (Winzelberg[50])					
Posttraumatic Stress disorder	1 (Winzelberg[50])					
Adjustment to cancer						
Self-rated global health		1 (Hoybye[52])				
Positive change		2 (Lieberman[46], Lieberman[47])				
Pain		1 (Lieberman[46])				
Breast cancer treatment, health, and fertility status		1 (Meneses[44])				1 (Meneses[44])

Hope	1 (Salzer[49])					
Sleep			1 (Ritterband[54])		1 (Yun[53])	1 (Ritterband[54])

Table 2. Outcome measures stratified by intervention category. QoL, Quality of Life; RCT, Randomised Controlled Trial; non-RCT, non Randomised Controlled Trial

Table 3. The web based platforms delivering online interventions addressing particular outcome domains.

QoL, Quality of Life; OSG, Online Support Group. H. McAlpine et al. / Patient Education and Counseling 98 (2015) 283–295 291

Outcome domain	Email	Online education intervention	OSG/message boards	Cancer information websites	Interactive websites
QoL	Salzer[49]	Yun[53], Osei [42]	Lieberman[47] Osei [42]		Owen[48], Ruland[51], van den Brink[43]
Mood	Salzer[49]	Ritterband[54], Yun[53]	Hoybye[52], Lieberman[46],		Meneses[44], Ruland[51]
Cancer symptoms	Cleeland[41], Salzer[49]				Owen[48], Ruland[51]
Social support	Salzer[49]			Gustafson[45]	Ruland[51], Gustafson[45]
Health competence				Gustafson[45]	Gustafson[45]
Health status					Meneses[44], Ruland[51]
Coping			Hoybye[52], Lieberman[46]		
Self-efficacy	Salzer[49]				
Distress	Salzer[49]				Owen[48]
Stress			Winzelberg[50]		
Post-traumatic Stress disorder			Winzelberg[50]		
Adjustment to cancer					
Self-rated global health			Hoybye[52]		
Positive change			Lieberman[46], Lieberman[47]		
Pain			Lieberman[46]		
Breast cancer treatment, health, and fertility status					Meneses[44]
Hope	Salzer[49]				
Sleep		Ritterband[54], Yun[53]			

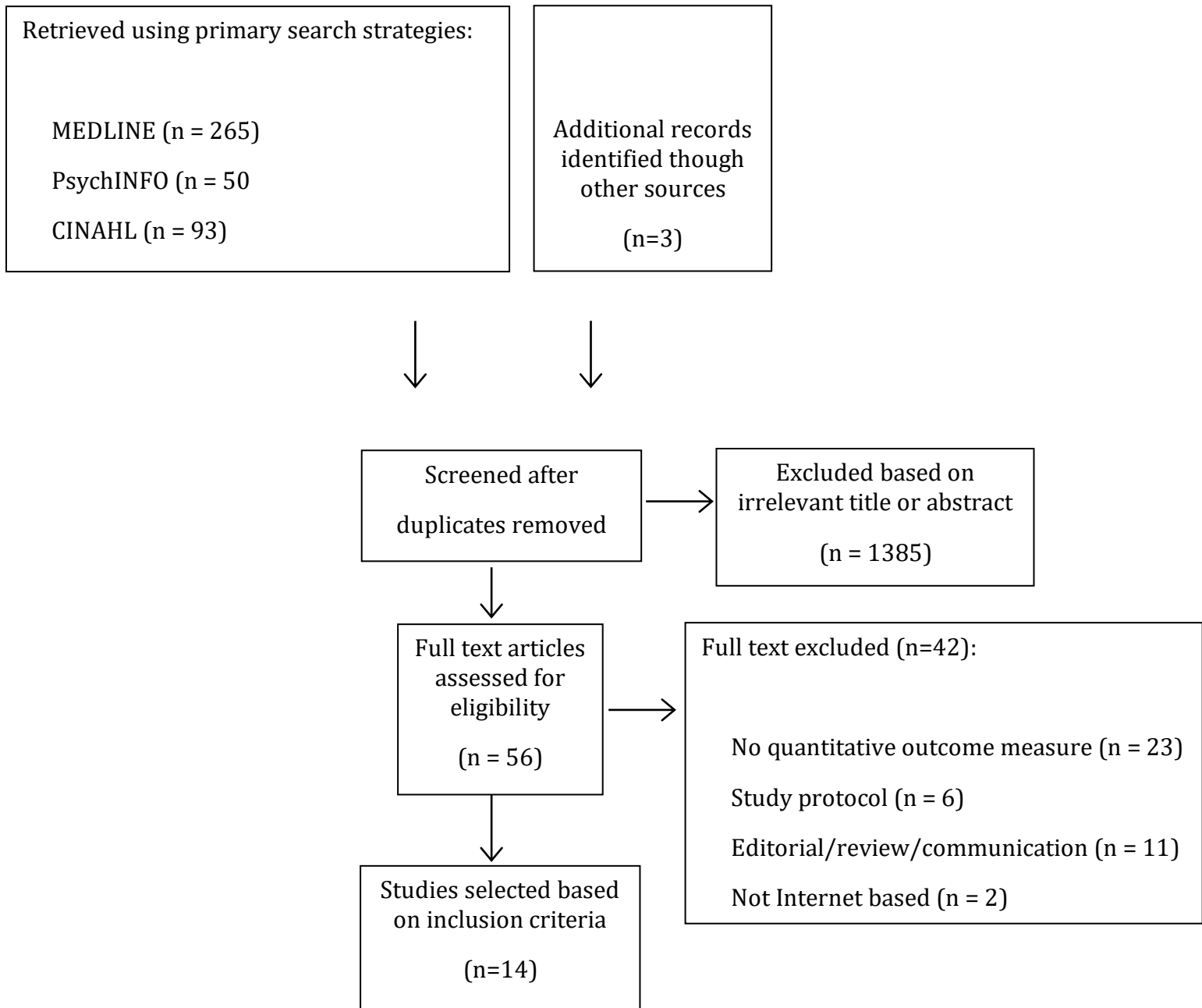


Figure 1. Flowchart of literature search based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [52]

Appendix A: Example search method - Medline

Search category	Cancer or Chronic Disease	Online community	Quality of life, survivorship
Search term used: MeSH or keyword	Neoplasm (MeSH) OR Medical Oncology (MeSH) OR Chronic Disease (MeSH) OR (keyword) Cancer	Internet (MeSH) OR Social Media (MeSH) OR Blogging (MeSH) OR Computer Communication Networks (MeSH) OR Telemedicine (MeSH)	Quality of Life (MeSH) OR Sickness Impact Profile (MeSH) OR Activities of Daily Living (MeSH) OR Health Status Indicators (MeSH) OR Outcome "and" Process Assessment Health Care (MeSH) OR Survivors (MeSH) OR Recovery of Function (MeSH) OR "Survivorship" (keyword)
Other sources	Additional searches after date of original search: Medline (note: search strategy same as original search)		

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