Understanding acceptability of and engagement with online interventions for cancer survivors- a systematic review.

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## **Abstract**

***Purpose***

Much research on online interventions to improve quality of life after cancer treatment is at an early stage. We sought to synthesise currently available literature in order to inform the development of future interventions.

***Methods***

We included a variety of study designs (qualitative research, feasibility/pilot trials, randomised trials, and process evaluations), and used thematic analysis to identify features of online interventions which might be important for intervention outcomes such as acceptability, feasibility, engagement, and effectiveness.

***Results***

Sixteen papers describing nine interventions were analysed.

Our findings suggested that cancer survivors value easy to use, accessible interventions that were delivered at the right time-point in the recovery trajectory and allow them to choose content specific to their changing needs. Social networking features did not always provide any added benefit, and behaviour change techniques such as self-monitoring and action planning needed to be designed carefully to be feasible and avoid potential negative consequences for some individuals. Participant feedback seemed useful to ensure that the intervention was appropriate for the target users.

***Conclusions***

This review provides insight into factors that appear to influence engagement outcomes in online interventions for cancer survivors, which may be useful for designing interventions for this population.. The common themes identified across the very different types of study and intervention confirm that thematic synthesis may help researchers identify key features of potential importance when there is limited definitive trial evidence available.

***Implications for Cancer Survivors***

Interventions appeared to be most successful when they recognised and addressed the unique challenges faced by cancer survivors, and were well matched to their changing needs. This review may facilitate the development of interventions that are more engaging for cancer survivors.

**Keywords**

Cancer; survivorship; digital intervention; review; online; intervention development

## **Background**

The number of cancer survivors is increasing over time as a consequence of earlier diagnoses and advances in treatment[1]. Long-term survival data reveals that there is now a life expectancy of 10 years or more for some common cancers[2]. The period following primary treatment is a critical time in the cancer trajectory, often characterised by ongoing symptoms, and poor general health [3]. Prolonged symptoms lead to ongoing challenges for post-treatment cancer survivors and delay return to normal life [4]. The Internet is increasingly being used as a resource by cancer survivors [5]. Online interventions can provide an efficient method of improving support for cancer survivors [6], as they can incorporate multiple and complex behaviour change techniques, while overcoming frequently cited obstacles to seeking support after cancer treatment such as time, mobility, and geography [7].

We sought to synthesise the growing evidence base that relates to online interventions directed at improving quality of life in cancer survivors, in order to inform the development of an acceptable and feasible new intervention. Previous reviews of interventions for cancer survivors have focused on questions of effectiveness, by reviewing controlled trials [8-10]. However, much of the literature on online interventions for cancer survivors is at an early stage, and currently consists mainly of intervention development and feasibility studies. Systematic reviews are useful to synthesise research findings [11] but are most appropriate when strong evidence bases (of homogenous datasets) exist [12, 13]. Reviews of heterogeneous, complex interventions often conclude that the evidence is ‘weak’ or ‘mixed’ [10, 14] and often fail to address intervention usability and acceptability[11]. For intervention design, it is important to understand how an intervention works in and suits a given context [13, 15]. Integrating and implementing all currently available evidence on online interventions for cancer survivors, rather than simply definitive trials, could inform decisions regarding intervention design and delivery [15].

Systematic reviews have started to incorporate a wider range of study designs (e.g. qualitative research) to address questions relating to intervention processes, and acceptability [12, 16]. Some new approaches to review such as thematic synthesis [11]and Intervention Component Analysis [17] can be used to try to interpret variations in findings of different interventions, and allow comparisons to be made across studies with similar objectives, but which may be different in many respects [17]. For example, Thematic Synthesis [11] has been used to address questions relating to intervention need, appropriateness and acceptability. The method adheres to key principles of systematic reviews[16], using rigorous and explicit methods to synthesise primary research, while incorporating the experiences and views of intervention participants. Findings from ongoing or qualitative research may not lead to firm conclusions about the effectiveness of the intervention, yet may help researchers to identify important issues relating to trial feasibility for future work [18]. Identifying components in a multicomponent intervention that are likely to be necessary for trial implementation [2] can inform a novel, composite online intervention that meets the needs of cancer survivors [19].

This review aimed to thematically synthesise findings from a range of studies with different designs in order to identify features of online interventions for cancer survivors which might be important for acceptability, feasibility, engagement, and effectiveness[11, 18].

## **Methods**

Inclusion and exclusion criteria (See Table 1) were employed to identify studies that could provide qualitative and quantitative data relating to online interventions for cancer survivors, focusing on breast, prostate and bowel cancer (or cancers considered similar in terms of quality of life issues) since these were the target population for the intervention we were developing. Studies considered included surveys, focus groups, individual interviews, and data from feasibility and pilot trials, RCTs, and process evaluations. Studies were identified in May 2016 using electronic bibliographic databases. Further details of the search strategy can be seen in Appendix A. Due to time constraints, we followed rapid review methods [20-22]**.**

**INSERT Table 1. Inclusion and Exclusion Criteria for Studies in Review**

## ***Data collection and analysis***

One review author (LP) conducted the initial searches. Two authors (LP and TC) independently screened titles and abstracts. Titles not relevant to this review were removed. TC and KS independently screened the remaining titles and abstracts for eligibility. Ineligible studies were excluded, with each author recording the reason for rejection. Full-text copies were screened when there was not sufficient information to definitively include or exclude based on the abstract. Differences between the two reviewers were resolved by discussion, with the involvement of a third reviewer if necessary (KB).

Quality Appraisal was conducted using the Critical Appraisal Skills Programme (CASP) quality assessment tools for quantitative and qualitative studies [23] and the Critical Appraisal of a Survey tool developed by the centre for Evidence-Based Management [24]. Appraisal was performed by TS and KS on each study independently and then discussed. The authors tabulated quality assessments of the studies based on the categories used in the CERQual (Confidence in the Evidence from Reviews of Qualitative research) Approach for assessing the confidence of evidence from reviews of qualitative research [25] (See Table 2.).

**Procedures**

TC and KS independently extracted all available information regarding intervention characteristics, experiences, and outcomes from the Results and Discussion sections of the papers, using a standardised data extraction form (See Appendix B). All data were electronically extracted, and synthesised as textual (qualitative) data. Authors’ interpretations in the Discussion were included, as these can be considered qualitative evidence that may provide insights about the perceived strengths and weaknesses of interventions as well as the experience of development, use and implementation[17].

The synthesis and analysis of the data was conducted in line with thematic synthesis [11]. Initially, we aimed to develop a description of the relevant features and outcomes of the interventions [11, 17, 26, 27]. TC and KS carried out the coding and analysis, with iterative in-depth discussion of emerging themes with LY and KB. We conducted line-by-line open coding of the method, findings, and discussion sections of included studies. We used one paper deemed to be of high quality (*RESTORE [28]*) to develop a coding manual and tested its reliability on two other papers. A sample paper was checked by a third co-author (KB) to ensure coding consistency. The remaining texts were coded, with authors discussing additional codes where any novel concepts were identified [11].

We grouped these codes according to similarities and organised them into descriptive themes [11]. Descriptive themes remain 'close' to the reported findings. .

Analytical themes were then generated based on identified clusters of descriptive themes. Analytical themes are used to facilitate the development of new interpretive explanations or hypotheses[11]. Our analytical themes were constructed based on their relevance to the research question that we had outlined a priori, namely “what features of online interventions for cancer survivors might be important for acceptability, feasibility, engagement, and effectiveness?”. This process allowed us to derive our outcomes of interest from the data, based on pre-specified aims of the research. Our analytical themes therefore grouped the descriptive themes into outcomes and factors that might influence outcomes. We then engaged in a process of mapping these influential factors onto the outcomes. This allowed us to explore the relationship between them, in order to identify which features of online interventions impact each of the individual outcomes.

## **Results**

### *Characteristics of papers and interventions*

Papers were excluded where: interventions targeted caregivers or partners (n=2); some or all participants were undergoing active medical treatment for cancer (n = 20); the focus was on needs associated with specific cancer types (e.g. gynaecological/ head and neck cancers) or specific problems (e.g. sleep disorders/ sexual dysfunction) rather than general quality of life issues (n = 7); not online interventions (n=6); needs assessments (with no data relating to actual intervention experience) (n=5). One intervention was excluded as it focused on a paediatric sample. Multiple papers relating to the same intervention were included, with each paper identified by the name of the intervention. Figure 1 shows the number of papers screened and reasons for inclusion/ exclusion. In total, 16 relevant papers pertaining to nine interventions fulfilled all eligibility criteria for inclusion. Further details can be seen in Table 2. We included studies regardless of study quality, but used quality assessment to assist the reader to determine the relative quality of each study included in the analysis (See Table 3.).

Three trials focused on multiple health behaviour changes; physical activity and diet. These were the *WSDEI (Health Planner)[29]*, *Survive and Thrive* [30, 31]and *Kanker Nazorg Wijzer (KNW) [32, 33]* trials*.* Two trials (*RESTORE* [28, 34, 35] and *Health Navigation[36]*) addressed fatigue in cancer survivors. *BREATH* [37, 38]and *STRIDE* [39]also specifically targeted particular outcomes (i.e. distress and physical activity). The *Oncowijzer* [40, 41] and *Prostate Cancer Education and Resources for Couples (PERC)* [42]studies focused on cancer survivors and their partners during the transition into survivorship (see Appendix B for full study descriptions).

**Insert *Table 2.* Trial Details**

**Insert *Table 3.* Quality Assessment of Included Studies**

**Insert Figure 1. *PRISMA Flow Diagram***

### Themes identified in this review

We identified 28 descriptive themes which we grouped into five analytical themes (see Fig 2). The first four themes addressed specific aspects of intervention designs and implementation of online interventions. The themes were:

1. Participant factors
2. Characteristics of the online intervention
3. Techniques used to change behaviour
4. Preferred features of online interventions

These themes were seen as key factors that appeared to potentially influence the outcomes discussed in the papers (which constituted the fifth analytical theme), i.e. uptake, adherence and attrition, engagement, feasibility, efficacy, positive behaviour change and acceptability of the interventions. To address the aims of the review, we present our analyses below in terms of how each of the first four themes appeared to relate to each of the outcomes discussed in the papers.

In reporting our findings, we have illustrated each concept using the name of the study it originated from, but also in terms of the type of information source from which the code emerged. Codes derived from statements by study authors were marked with “Au” and participant sources were identified as “Ps”. Quantitative evidence or statistic-based findings were identified with “Q” .(i.e. Au, Ps or Q).

## **Insert Figure 2. Depiction of analytical and descriptive themes, and their hypothesised relationship**

*Uptake*

Uptake included data concerning comments regarding recruitment, as well as patterns observed by the study authors. Individuals took part in the interventions due to perceived unmet care needs, personal interest, and motivation (Au) [31, 35, 39, 41, 42]. Characteristics of those who did not take up the intervention were often not recorded.

Technology was seen as a means of potentially increasing access to supportive care for those who cannot (or prefer not to) engage in traditional care, particularly those with sensitive symptoms and illness issues (Au; Ps) [28, 35, 42]. The timing of the intervention may influence uptake. The authors of the *Oncowijzer* study suggested preparing for cancer survivorship before treatment commencement and continuing soon after completion(Au)[41]. In *RESTORE* participants described the timing of participation (from 3 months post-treatment) as ‘about right’, with participants at least one year post-diagnosis indicating they would have preferred access sooner (Ps;Q)[28, 35]. One participant suggested that after a certain stage, the information may be less beneficial: “*I suppose it’s also that sense of wanting to kind of move on from it as much as possible…it would be a daily reminder”*(Ps) [38; pg. 6]

*Adherence and attrition*

This referred to participant adherence to, and drop-out of, the trial. Commonly reported reasons for attrition included being busy, and cancer recurrence [29, 36]. Family death, comorbid physical problems, and family illness were also cited as a reasons for dropout (Q;Au) [36, 42]. Demographic predictors of dropout included factors such as male gender, lower income, and higher levels of distress (Au;Q)[31, 35, 38, 42].

Higher attrition in the online intervention arms may have been due to participants struggling with the web-based nature of the trial (Au;Ps) [28, 29, 35, 40]. Some authors suggested that accessing the intervention added burden and/ or required routine adjustments (Au; Ps) [28, 35, 40]. However, some studies reported lower levels of attrition than average for online trials for cancer survivors (Q;Au) [29, 36, 42] [33]. This was attributed to participants’ motivational readiness to engage (Au) [29, 36] and the relevance of the content (Au) [29, 33, 42]. Other reasons suggested were the convenience for participants being able to access the intervention at their own pace, when it suited them (Au) [29, 33, 36, 42] and the ease of use an accessibility of the content (Au) [29, 33, 36, 42].

*Engagement*

Engagementfocused on the extent to which the user engaged with the intervention content (i.e. extent of use- duration and/or frequency). Online interventions allow researchers to identify patterns of use, and how these may be related to outcomes (Au) [28, 31, 33, 40, 43]. Additional research to better understand these processes was recommended (Au) [28, 31, 33, 40, 43]. Authors noted that lower levels of engagement may be linked to some participants experiencing an early effect, making further use of the intervention redundant (Au) [43]. However, generally, evidence suggested that participants who engaged more with the interventions appeared to get the most benefit (Q) [28, 31, 33]. Authors highlighted the importance of actively motivating participants to engage with the online intervention content, for example using prompts and reminders (Au) [31]. For example, usage in the *BREATH* intervention varied considerably and logins were on the day the weekly reminder was sent (Q)[43].

Findings indicated that participants engaged more when they reported unmet needs, lower self-esteem, and a need for social support(Au;Q) [40, 43]. Participants often chose to access information and content pertaining to physical and social consequences of cancer, returning to work, and communicating with others (Au;Ps;Q) [30, 31, 41]. Other cited factors included computer literacy and socio-economic status. High usage rates in the *PERC* trial were deemed encouraging by study authors, particularly because the intervention targeted older adults (Au) [42].

The exclusion of certain groups (limited information technology skills; elderly) was a concern for many authors (Au) [28, 29, 35, 36, 40]. Online interventions did not seem to appeal to all, and some individuals did not ever access the intervention (Au; Q)[40]. Reasons for not fully engaging included illness burden, perceiving content as irrelevant, not useful, or not required (Au; Ps)[29, 39].Barriers to using these interventions included glitches and problems with functionality (such as difficulties logging on; passwords being refused or forgotten), and screens freezing or closing unexpectedly (Au;Ps) [28, 35].

*Feasibility*

Feasibility related to descriptions by the authors about the intervention being easy or convenient to deliver and factors relating to the work required to participate. Online interventions offered a feasible approach to providing supportive care after cancer (Au)[29, 31, 33, 36, 38-40, 42] and were considered particularly beneﬁcial for those who have limited access to supportive care (Au) [31, 39, 42]. Ease of participation was an important facilitator of engagement and participants required low levels of assistance to use the interventions (Au; Q)[28, 29, 31, 33, 36, 38-40, 42]. Easy to use, interesting, informative, and comprehensible interventions were found to be feasible (Au) [28, 31, 33, 40, 42].

Accessibility was improved by involving stakeholders during intervention protocol development, and end users during usability testing (Au) [28, 32, 33, 35, 38, 40, 42].

Online interventions were designed to be incorporated into participants’ lives easily, yet some required additional work and/or routine adjustments for participants (Au) [29, 31, 32, 34, 36, 39, 40, 42]. This was particularly difficult when the participant had external burdens (e.g. competing demands such as family and work commitments, etc.) or were feeling unwell (e.g. experiencing pain or fatigue)(Au;Ps) [35, 39]. Dealing with technical difficulties, and completing fatigue diaries were sometimes cited as burdensome by participants (Au;Ps;Q) [35, 39, 42].

*Efficacy*

This referred to effectiveness of the intervention in relation to specified outcomes. In many cases, due to the exploratory nature of some of the trials, the limited data, small sample sizes, or lack of a comparator group meant that it was not possible to draw ﬁrm conclusions about the efficacy of these interventions [36, 38, 39, 42].

*Satisfaction*

Here, we refer to participant reflections on taking part in the trial, and perceived benefits directly related to the intervention(s).User feedback was sometimes used to improve the intervention, with users displaying a preference for content chosen by end users who contributed to the design of the intervention (Au;Q)[40]. (Au) [35, 42]. Participants liked convenient and readily available online interventions that had content that was clear, novel, and well organised (Au;Ps;Q) [29, 31, 35, 36, 39, 40, 42].

Participants liked being able to choose the elements of the intervention that they engaged with (Au;Ps)[33, 39, 40], which was seen as a means to reduce information overload (Au) [32, 34, 36, 39, 40, 42]. In some studies, specific content was recommended but participants could select topics that had a higher priority for them (Au)[31, 32, 40].

Findings were mixed regarding the use of in-person support. Social networking components (e.g. webmail and discussion boards etc.) were perceived as useful (Au; Q ;Ps) [30, 31, 39]. However, participants differed in the extent to which they engaged with social networking features (Au; Q)[30, 31, 39]. In some trials, participants preferred to read posts rather than to comment themselves. Others indicated that these features did not interest them (Ps) [30, 31, 39].

Many individuals considered online interventions superior to offline comparators (Ps) [28, 35]. Participants appreciated the ability to access straightforward information and valued material that addressed relevant issues such as feeling guilty, healing, achieving normality, and fears regarding recurrence (Ps; Au;Q) [28, 35, 40, 42]. However, others found the interventions impersonal, simplistic, and vague (Q)[39, 40] and suggested incorporating more detailed or cancer-specific information and practical advice, as well as signposting to resources (Au; Ps) [35, 38, 42]. Some participants showed a preference for offline media, and/or struggled with using an online intervention (Au;Ps)[28, 29, 31, 35, 39, 40, 42]. Authors recommended that online interventions should be part of a multi-modal care model, supplemented by other forms of post-treatment care (e.g. informative brochures, consults with a psychologist etc.) (Au)[29, 35, 37, 42].

*Positive behaviour change*

We also analysed the impact of behaviour change techniques on behaviour or antecedents of behaviour.

Information provision was a commonly used strategy to promote behaviour change in these interventions (Au) [28, 32, 33, 40, 42], and included signposting to existing supplementary support resources and resources intended to facilitate follow-up conversations with healthcare professionals (Au; Ps) [28, 33, 38, 42]. Established national and international guidelines informed the content of many interventions (Au) [28, 29, 31, 33, 36, 39, 42]. Other interventions were based on modified versions of pre-existing interventions (Au) [31-33].

Goal management prompted participants to prioritise activities, recognise limitations, and engage in self-reflection about lifestyle and behaviour and was widely regarded as motivating, (Au; Ps) [28, 30, 32, 33, 35, 36, 39]. *STRIDE* included step goal approach based on goal setting theory, which promoted goals that were perceived as attainable with respect to the individual’s capacity. This reduced feelings of guilt on days participants felt unwell (Au; Ps) [39].

Self-monitoring helped participants to better recognise symptom patterns, reflect on their progress, increase personal accountability, and develop self-awareness (Au;Ps) [29, 35, 36, 39]. However, diary keeping was sometimes difficult to incorporate into daily routine (Au;Ps)[28, 35]. Behaviourfeedback on progress potentially increased perceived self-efﬁcacy (Au) [29, 31, 35, 42].

Action planning was used in some studies to improve motivation and may positively influence changes in health outcomes (Au;Q) [28, 29, 31, 36], but could sometimes be problematic (see ‘Negative consequences for some users’ below).

***Negative consequences for some users***

Some authors did not consider any adverse events as attributable to the study (Au) [36] [28]. However, in the *RESTORE* trial some users considered the content of the intervention to be more suited to those undergoing treatment and therefore an unwelcome reminder of their cancer (Au;Ps) [35]. The authors of the *Survive and Thrive* trial found that attempting action planning and failing led to reduced activity levels in some cases (Q) [31]. Action planning strategies may not suit those who continually fail to complete their action plans (Au)[31]. Some couples in *PERC* reported decreased relationship satisfaction and communication about cancer (Ps; Q)[42], with some individuals reporting increased sexual dysfunction over time (Ps;Q)[42]. The authors suggest that participants may have found it difficult to adjust to novel ways of relating to each other: the intervention may have introduced concepts and ideas that were different to their long-standing relationship and communication patterns, leading to participants finding it challenging to talk about sensitive topics they may not have discussed before (Au) [42]. Finally, in the *BREATH* study one woman was admitted to a psychiatric clinic (Q)[38]. The authors considered this as a serious adverse event (Au) [38]. Further, a pattern emerged where more high-distress survivors in the intervention group showed a clinical deterioration (Q) [38]. These findings suggest that high-distress Breast cancer survivors may need a more intensive intervention than *BREATH* (Au) [38].

## **Discussion**

Sixteen papers relating to nine online interventions designed to improve outcomes in post- treatment cancer survivors were analysed in our review. Common themes were evident across the papers, suggesting that it is possible to combine, and learn from, papers reporting many different study designs, including qualitative reports and findings of early-stage interventions.

Ensuring that the intervention fits with the users’ characteristics appears to be key to the successful implementation of online interventions for cancer survivors. Interventions appeared to be most successful when they were developed and delivered in a manner that recognised the unique challenges faced by cancer survivors. The uptake of, and engagement with, online interventions for supporting cancer survivorship was influenced by the users’ motivation and need for support. Users preferred content that was specific to the needs of cancer survivors. Users appreciated being able to choose to address particular problems that had a higher priority for them. This is particularly appropriate for cancer survivors as their unique needs are likely to vary greatly during the post-treatment period [40, 44].

Further, it is crucial that the appropriate target sample is identified and recruited into the trial. Previous reviews have suggested that efficacy of online interventions is varied due to factors including the timing of the interventions, targeting the wrong patients, or using an unsuitable mode of delivery [45, 46]. In some of the studies in this review, participants perceived the intervention or its content as irrelevant or unnecessary. Online information presented could be perceived as impersonal or vague. This issue could be overcome by including more specific or tailored information regarding the unique needs of those after cancer [40]. Some participants did not perceive a need for the intervention. In particular, some engaged in the trial as a research volunteer rather than to actively seek strategies to improve quality of life[35]. In our review, some participants indicated they would have preferred this type of intervention closer to the end of treatment, raising questions about the timing of the delivery. In *RESTORE,* those who were at later stages of survivorship felt some elements were more suitable to individuals with a current diagnosis or soon after treatment[35]. Conversely, the authors of *Oncowijzer* note that their website may be more relevant to those at later stages of survivorship, with website users having ended treatment about 4 months prior to use, and non-users being on average 3 months posttreatment. It is therefore difficult to reach a conclusion about the optimal timing of an intervention [47]. Other user characteristics that may impact interventions include illness burden, competing demands, experience using computers, and ability [48]. Older age was not always a barrier to use [42]. This is encouraging and may be due to increases in the of use electronic devices in this group [49]. Some other recent reviews have concluded that online interventions are likely to have potential in an older population [50-52].

Unsurprisingly, a range of positive outcomes including adherence, engagement, feasibility, and satisfaction appeared to be related to easy to use, interesting, informative, and comprehensible interventions. However, it is not always easy to tell from the outset whether a prototype intervention will be perceived by patients as providing these features. Participant feedback facilitated the development and refinement of some interventions in the current review. User-centred approaches (such as The Person-Based Approach) can help intervention developers to identify intervention features which are likely to be most acceptable and persuasive to users [53]. It is unclear whether social networking features provide any added benefit. Online interventions are likely to function effectively without social networking components and with relatively little input from researchers or clinical staff[54].

It was also clear that in interventions for cancer survivors, particular behaviour change strategies were more successfully implemented than others. Recent reviews have suggested that self-monitoring of behaviour, planning, goal setting and review, and feedback on performance are associated with increased effectiveness in behaviour change interventions [55-57]. In our review, self-monitoring enabled participants to recognise symptom patterns, but could be difficult to incorporate into routines. Likewise, action planning was associated with positive behaviour change in many cases, but failing to complete action plans could have deleterious consequences [58]. The selection of techniques to change behaviours should be appropriate to the characteristics of those participating in the trial, in order to avoid causing inadvertent harm [59]. An unexpected benefit of this review was that by combining data from a number of early studies it was possible to collate information about rare but potentially important potential for negative consequences for some users, which is particularly valuable for intervention design.

***Strengths and limitations***

A limitation of this analysis is that the findings are largely descriptive due to the exploratory nature of this method, and the limitations of the data. It was not always possible to ascertain a complete picture of the intervention design process (particularly, how the content was developed), and some studies did not provided details of limitations and challenges faced throughout the trial process. Although we proposed an elementary model broadly linking the intervention characteristics to outcomes, we were unable to generate hypotheses about exactly how different intervention characteristics might influence different outcomes, as only partial data was available for each intervention characteristic and outcome. A further limitation of the data was that individuals with particular characteristics (i.e. in a relationship, middle aged, Caucasian, and female) were overrepresented in most of the studies, limiting the ability to establish external validity [48]. Developers must therefore be aware that it is unclear if specific subgroups would benefit from online interventions (specifically socioeconomically disadvantaged groups, low-health literacy groups, and ethnic minorities), which may impact the validity of any findings [60]. Recruitment of heterogeneous samples and analysis of usage patterns to better contextualise findings is recommended.

A strength of our method is that we were able to integrate data from a variety of study designs at an early stage of development of the literature in this field. The inclusion of both individual author and participant interpretations allowed us to go beyond intervention descriptions and explore real-world experiences of online interventions for cancer survivors [17].

***Conclusions***

The common themes identified across the very different types of study and intervention confirm that thematic synthesis of a variety of study designs can inform the development of interventions when there is limited definitive trial evidence available. The method of synthesising early stage research described in this paper may enable researchers to generate useful hypotheses about why interventions work or do not work as intended. This method may well have application in other areas, beyond cancer survivorship.

*Implications for cancer survivors*

The findings from this analysis provide detailed insights into factors that may influence the uptake, acceptability, feasibility, adherence, attrition and positive behaviour change in online interventions for cancer survivors. They also highlight numerous specific issues for consideration when designing online interventions for this group. In general, it appears important to ensure that both the content and the timing of interventions is appropriate to the particular and changing support needs of cancer survivors. Behaviour change techniques also need to be carefully designed to match users’ needs and capabilities, in order to avoid the potential for inadvertent negative consequences for some users. To minimise barriers to use, digital interventions must also be convenient and easy to use. User involvement in and feedback on the intervention during development may help to ensure that it is accessible, usable and appropriate.

**Compliance with Ethical Standards:**

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|  |  |
| --- | --- |
| Table 1. Inclusion and Exclusion Criteria of Studies in Review | |
| *Inclusion criteria* | *Exclusion criteria* |
| 1. Papers describing interventions designed to improve quality of life and related outcomes in adults who have completed primary treatment for cancer. Interventions must be generalizable to breast, colorectal or prostate cancer survivors. ; 2. Studies describing people’s experiences, views, and perceptions of usability and/or acceptability data of interventions. | 1. Papers analysing online forum groups and interventions delivered solely via social media websites (e.g. Facebook etc.); 2. Interventions delivered offline; 3. Interventions designed to treat specific target groups that were not generalizable to breast, colorectal or prostate cancer survivors (e.g. pediatric samples, rare cancers, metastatic cancers etc.); 4. Interventions which took place during primary treatment. |

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| ***Table 2. Quality Assessment of Included Studies*** | | | | | | | | | |
| **Study Quality** | *ST* | *Wsdei* | *STRIDE* | *BREATH* | *HN* | *PERC* | *KNW* | *RESTORE* | *Oncowijzer* |
| Methods, designs, and study conduct | **++** | **++** | **++** | **++** | **-** | **++** | **-** | **++** | **+** |
| Quality of data/effects achieved | **++** | **++** | **+** | **+** | **+** | **++** | **+** | **+** | **+** |
| Relevance | **++** | **++** | **- -\*** | **++** | **+** | **++** | **++** | **++** | **++** |
| *Overall study quality* | **++** | **++** | **+** | **++** | **-** | **++** | **+** | **++** | **+** |
| **Notes:** | - - = very low | | - = low | + = medium | ++ = high | | \*very specific population | |  |
|  | ST: *Survive and Thrive* | | | HN: *Health Navigation* | | |  |  |  |

Figure 1 PRISMA Flow Diagram

Records identified through database searching   
(n = 6,327)

## Screening

## Included

## Eligibility

## Identification

Records excluded   
(n =6,072 )

Full-text articles assessed for eligibility   
(n = 57)

Full-text articles excluded, with reasons   
(n = 41)

Studies included in synthesis  
(n = 9 )

Records screened after duplicates removed   
(n = 6,129)

Relevant full-text papers identified   
(n = 16)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Table 3. Trial Details | | | | | |  |
| Trial name | *Cancer type* | *Intervention target* | *Year* | *Country* | *Study type* | *N* |
| Survive and Thrive | Breast, ovarian, uterine, non-Hodgkin’s lymphoma, colorectal, lung, thyroid, oral. | Encourage changes in health behaviours post-treatment (including: dieting, exercise, depression, and fatigue). | 2015 | USA | Randomized controlled trial. | 352 |
|  |  |  |  | Exploratory analyses of engagement. | 20 |
| WSDEI (Health planner) | Breast. | Promote positive dietary and exercise change post-treatment. | 2014 | South Korea | Pilot randomized controlled trial. | 59 |
| STRIDE | Breast, prostate, non-Hodgkin’s lymphoma. | Increase walking/physical activity. | 2014 | Australia | Qualitative pilot feasibility study. | 8 |
| BREATH | Breast. | Support psychological adjustment post- treatment; reduce stress and improve empowerment. | 2015 | Netherlands | Multi-centre randomized controlled trial. | 150 |
|  |  |  |  |  | Sub-study analysis of usage. | 70 |
| Health Navigation | Breast, colon, stomach, lung, uterine, thyroid. | Online tailored education program for managing/ reducing cancer related fatigue. | 2012 | South Korea | Randomized controlled trial. | 273 |
| PERC | Prostate. | Online education and resources aimed to increase QoL for patients (e.g. symptom management etc.) and partners ( increase communication etc.). | 2015 | USA | Mixed methods feasibility and acceptability pilot study. | 26 |
| Kanker Nazorg Wijzer | Unspecified (any cancer type accepted). | Improve self-management of lifestyle (e.g. physical activity, diet, and smoking), and psychosocial challenges post-treatment | 2016 | Netherlands | Randomized controlled trial. | 432 |
| RESTORE | Breast, colorectal, head/neck, liver, and prostate. | Reducing cancer-related fatigue, increasing self-efficacy. | 2016 | UK | Multi-centre proof of concept randomised controlled trial. | 163 |
|  |  |  |  |  | Qualitative process evaluation. | 19 |
| Oncowijzer | Breast. | Provide information for survivors (various issues; physical, psychological, work/social etc.); and partners (e.g. relationships, care giving etc.). | 2014 | Belgium | Design and process evaluation. | 134 |

|  |  |  |
| --- | --- | --- |
| **Participant characteristics** | * + Preference for online materials   + Motivated to participate   + Motivated to engage with materials   + Patterns in participation identified | **Outcomes**   * + Uptake   + Adherence and attrition   + Engagement   + Feasibility of the trial   + Efficacy   + Satisfaction   + Positive behaviour change   + Negative consequences for some users |
| **Trial characteristics** | * + Participatory input in design   + Theory-based input in design   + Guideline-based input in design   + Developed based on other intervention   + Signposting to supplementary resources   + Sufficient support offered by research team   + Use of in-person support (online forum, etc.) |
| **Techniques used to change behaviour** | * + Action planning   + Autonomy/self-tailoring   + Feedback on behaviour   + Goal management   + Information provision   + Self-monitoring |
| **Preferred features of online interventions** | * + Convenient and readily available   + Ease of participation/easy to use   + Layout/content style rated positively |

## Figure 2. Depiction of analytical themes and the descriptive themes from which they emerged, and their relationship with the pre-specified outcomes