Self-guided interventions for managing psychological distress in people with cancer - a systematic review

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Review article

Self-guided interventions for managing psychological distress in people with cancer – A systematic review

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A B S T R A C T

Objective: People with cancer can experience psychological distress but do not always desire, or engage with, professional support to assist with managing distress. Interventions that are self-directed or guided by patients may hold promise as they allow patients to engage with interventions as they need. The objective of this review is to describe and appraise the evidence for effectiveness of self-guided interventions that aim to manage psychological distress in people with cancer.

Methods: A systematic search of Medline, PsycINFO and CINAHL identified 15 relevant papers, reporting on 14 studies.

Results: Of the interventions, three studies comprised hard-copy workbooks, six studies used resource packs, four were online resources and one was a brief multimedia resource. One study was adequately powered and demonstrated a positive effect. Almost all interventions required some level of facilitation. Distressed participants may benefit more from interventions.

Conclusion: Self-guided interventions represent a potentially efficient way of delivering support for people affected by cancer, however evidence supporting them is lacking.

Practice implications: There is a need to generate evidence to understand the impact of self-guided interventions for: i) the ideal delivery point in the disease trajectory, ii) patient groups, iii) intervention content and iv) type and mode of delivery.

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1. Introduction

A diagnosis of cancer is a stressful event, and psychological distress in people diagnosed with cancer is common. Approximately one-third of all cancer patients will experience psychological distress, although this can vary depending on clinical characteristics (e.g., disease type, stage) and demographic variables (e.g., gender, age) [1,2]. Furthermore, cancer survivors can experience high levels of psychological distress up to 12 months post-diagnosis [3]. Psychological distress has been defined as: ‘a multifactorial unpleasant emotional experience of psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment’ [4] and is internationally recognised by psychosocial oncology clinicians and researchers as the sixth vital sign in cancer care along with body temperature, heart rate, blood pressure, respiratory rate and pain [5].

People with cancer who have high levels of psychological distress do not always engage with support services or supportive interventions aimed at reducing distress [6]. A UK study found that only one-third of distressed patients with emotional or psychological difficulties were willing to be referred for help [7]. Similarly, an Australian study found that 70% of distressed cancer patients did not want formalised supportive intervention to assist with their distress, and of those, the majority (59%) of patients with a distress score of 10/10 indicated they did not want help with distress [8].

There are a variety of reasons why people do not seek or engage in psychological services when they are experiencing psychological distress. One reason is poor identification of psychological distress by professionals and the patients themselves, [9], or patients many not feel comfortable raising emotional issues with their oncologists [10]. Other reasons patients may not engage with supports for psychological distress when offered by professionals is that they are receiving it elsewhere, or have a preference for managing their emotional and psychological difficulties on their own [6,7]. Additionally, stigma about seeking psychological support may be another reason that patients avoid accessing services or refuse referral if offered [11]. Consequently, interventions that are self-guided rather than delivered by a clinician may show some promise in allowing patients to access supports without these barriers.

Self-management is defined as an individual’s ability to manage symptoms, physical and psychosocial consequences of treatment and lifestyle changes inherent in living with a chronic condition [12]. In people with cancer, self-administered stress management training has been shown to result in better quality of life compared to both a control group and the professionally managed stress management training group [13]. Although the focus of this intervention was a self-managed program, the self-administered intervention consisted of a one-hour orientation that was facilitated and delivered by a health professional; requiring resources for delivery. A further literature review of self-management programs in cancer identified 16 papers; finding there was evidence for self-management to improve patient outcomes during treatment, post-treatment and at the end of life; however these interventions required facilitation which could be resource-intensive [14]. More recently, reviews that focus on internet interventions which can be delivered without facilitation have demonstrated some efficacy in chronic conditions [15]. In clinical practice, interventions which have substantial facilitation components may be more difficult to incorporate into usual care given the required resources, while interventions that are directed or guided by participants rather than requiring professional facilitation may hold promise as they may be cost-effective to deliver, allow the patient to engage with the intervention as they are ready and may also overcome geographical barriers.

This systematic review aimed to describe and appraise the literature for self-guided interventions that sought to manage psychological distress in people with cancer.

2. Methods

The reporting of this systematic review is consistent with the PRISMA statement [16]. A narrative synthesis of results was used, rather than meta-analytic procedures, due to the heterogeneity of study design, population, type of intervention and outcomes [17]. This protocol was registered on the Prospero database http://www.crd.york.ac.uk/PROSPERO on 31 July 2015 with reference number CRD42015024401.

2.1. Eligibility criteria

The focus was on interventions that targeted psychological functioning in people with cancer and were self-guided or self-delivered. Eligibility criteria are presented according to the PICOS framework [18]:

**Participants** were adults (aged 18 years and over), diagnosed with cancer regardless of type (solid or haematologic) or disease stage. Studies with participants who had not been diagnosed with cancer, such as those with a genetic predisposition, or those undergoing screening for cancer, were excluded.

**Interventions** were self-guided, to promote management of psychological wellbeing. To be self-guided the intervention needed to be largely not facilitated by a health professional and delivered by the patient. Interventions with minimal involvement of a facilitator or health professional were included, for example, a brief introduction to an intervention, brief reminders, or minimal monitoring of online postings. The content needed to target
psychological functioning in a substantial part of the intervention. Interventions that were self-guided but were not specifically psychological in intent were excluded e.g. interventions to alleviate treatment side effects. Interventions had to have interactive components such as diaries or relaxation exercises. Passive interventions, such as information sheets, were excluded.

Control groups could be of any type including active controls, wait list controls or no treatment (i.e. treatment as usual or usual care). The comparison needed to be able to establish evidence for the self-guided intervention; studies that were self-guided intervention +/- another intervention (e.g. peer support), were excluded.

There were no restrictions on the types of Outcomes.

Studies needed to compare at least two groups (randomised controlled trials or other study designs that include a comparison group). Multiple arm randomised controlled trials with different interventions were included, if a self-guided intervention was one of the arms, and could be compared to a control group.

2.2. Study selection

The search was conducted in June 2015. Three electronic databases (Medline, PsycInfo and CINAHL) were searched for relevant papers published between January 2000 to June 2015 using the following search terms: cancer and (“self help” OR “self care” OR “self guided” OR “self managed” OR “self administered” OR “self directed” OR “unguided”) and (anxiety OR depression OR distress).

Terms were searched within the abstract, title, keywords and subject headings. Only articles published in English were included.

Reference lists of identified papers were examined to identify additional potentially eligible studies. Key review papers on similar topics were also reviewed and their reference lists searched [15,19–21].

2.3. Review process

All identified titles and abstracts were screened by one reviewer (KH) against the inclusion criteria. Papers clearly not meeting inclusion criteria were excluded at this stage. Abstract and full texts of potentially eligible studies were read by two reviewers (KH and AU) to confirm eligibility. There was 100% agreement on classification of the selected review articles.

2.3.1. Data extraction

For the studies meeting the full inclusion criteria, data were extracted to a standardized coding sheet. The data extraction form documented the authors, publication year, country, sample size and characteristics, research design, intervention description, outcome measures and key results. Given the nature of these interventions in being self-delivered by the patient, consent rate and engagement with the intervention rate were also examined as indicators of acceptability.

Fig. 1. PRISMA diagram.
<table>
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<tr>
<th>First Author, Year, Country</th>
<th>Participants</th>
<th>Research design</th>
<th>Self-directed component</th>
<th>Facilitated component</th>
<th>Duration of Intervention</th>
<th>Outcome measures</th>
<th>Results</th>
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<tbody>
<tr>
<td>Aguado Loi 2012 [25] USA</td>
<td>220 adults recently diagnosed with cancer and scheduled to undergo chemotherapy</td>
<td>RCT. Groups: 1. Usual care 2. Stress management Kit</td>
<td>Stress management training kit for self-administration, comprising a DVD and booklet about relaxation techniques, plus patient testimonials</td>
<td>5 min introduction Training kit presented to participants to complete in their own time</td>
<td>Measured at baseline, before cycles 2 and 3 of chemotherapy and before cycle 4. Primary outcome: Quality of Life. Secondary outcomes: Quality of life, depression, anxiety. Use and usefulness of stress management techniques was also collected.</td>
<td>No improvement in mental quality of life, depression or anxiety in intervention group, compared with control. However intervention group had improved emotional adjustment scores, demonstrated a stabilizing effect on the functional adjustment scores and reported greater use of relaxation techniques throughout treatment.</td>
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<tr>
<td>Beatty 2010a Australia [30] (Supportive Care in Cancer)</td>
<td>40 women who had completed treatment for breast cancer in the past 3 months</td>
<td>RCT. Groups: 1. Treatment as usual 2. Workbook intervention</td>
<td>A workbook-journal with education on medical and psychosocial issues, suggestions and activities to address the issues. Chapters addressed: maintaining the medical partnership, physical well-being, feeling alone, family and friends, emotional recovery, spirituality, seeking closure, moving forward, living the life you want and resources. It also included a relaxation and meditation tape</td>
<td>Treatment compliance was assessed by phone at 1 and 2 months Participants encouraged to work through Workbook at their own time over three months</td>
<td>Measured at baseline, 3 and 6 months. Primary outcome: coping (planning, restraint coping, seeking social support, turning to religion, venting emotions). Secondary outcomes: traumatic stress and QOL.</td>
<td>No significant group x time interactions on primary or secondary outcomes. However workbook participants experienced a positive effect in venting coping, and a benefit compared to controls in cognitive functioning. Trend toward a protective effect across all coping measures for participants. Feedback from participants suggested they would prefer to receive the workbook during treatment.</td>
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<tr>
<td>Beatty 2010b Australia [31] (Medical Journal of Australia)</td>
<td>49 women diagnosed with breast cancer in the previous month</td>
<td>RCT. Groups: 1. Controls received booklets but no suggestions, worksheets or relaxation and meditation CDs 2. Workbook intervention</td>
<td>Self-help workbook, with information on medical and psychosocial issues; suggestions and exercises to address the issues and survivors' quotes. Chapters dealt with relaxation and meditation; coping with side effects; emotional adjustment; body image and identity; social support; and survivorship.</td>
<td>None</td>
<td>Participants encouraged to work through Workbook at their own pace over three months</td>
<td>Measured at baseline, 3 and 6 months. Primary outcome: distress (depression, anxiety, traumatic stress). Secondary outcome: QOL, body image and coping (cognitive avoidance, helplessness/ hopelessness and anxious preoccupation)</td>
<td>No significant group x time interactions on primary or secondary outcomes. However workbook participants had lower levels of traumatic stress, helplessness/ hopelessness, cognitive avoidance than control group. More effective for women with higher levels of distress. However intervention group had poorer body image than control which was still significant at 6 months.</td>
</tr>
<tr>
<td>Carpenter 2014 [32] USA</td>
<td>135 women within 18 months of diagnosis of breast cancer and reporting at least moderate distress</td>
<td>RCT. Wait list controls. Participants paid for phone calls and assessments</td>
<td>10 chapter online workbook comprising cognitive and behavioural coping strategies, relaxation training, guided expressive writing exercises and weekly homework activities. Video was used to guide users through the workbook and Biweekly phone calls for 10 weeks to monitor participants' distress (using the Distress Thermometer) and keep them engaged. Weekly emails of encouragement. Workbook included a discussion board moderated by health professionals.</td>
<td>None</td>
<td>Participants were encouraged to complete one chapter a week over a ten week period, although all the intervention was made available</td>
<td>Measured at baseline, week 10 and week 20. Primary outcomes: self-efficacy for coping with cancer, self-efficacy for coping with negative mood, and finding benefit in the cancer experience. Secondary outcomes: cancer-related post-traumatic symptoms.</td>
<td>At 10 weeks intervention participants showed improved self-efficacy for coping with their cancer and self-efficacy for regulating negative mood and lower levels of cancer-related post-traumatic symptoms.</td>
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<td>David 2013 [36] Germany</td>
<td>186 adults with haematological cancer</td>
<td>RCT. Groups: 1. Waiting list control 2. Online program</td>
<td>Four week online cognitive behavioural program. The modules comprised: Information on stress and behavioural assessment, techniques for coping with acute stress and upcoming stressful situations, and an expressive writing module.</td>
<td>Psychologists sent an introductory email and provided support on request</td>
<td>One module was made available each week for four weeks</td>
<td>traumatic symptoms, social well-being, functional well-being, and positive affect</td>
<td>compared to controls</td>
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<tr>
<td>Jacobsen 2013 [23] USA And Phillips 2012 [24]</td>
<td>286 adults receiving chemotherapy (Jacobsen) 391 adults receiving chemotherapy (Phillips)</td>
<td>RCT. Groups: 1. Usual care 2. Stress management 3. Home-based exercise 4. Stress management and exercise</td>
<td>Stress management group given video and audio recordings, and booklet with information and instructions for relaxation techniques for use during chemotherapy. The exercise group received a video, booklet and pedometer. The booklet included information and instructions on engaging in exercise while undergoing chemotherapy. The combined self-management and exercise group received both types of information and materials.</td>
<td>Short phone call at week 1. Intervention group given materials prior to first chemotherapy session</td>
<td>Participants could work through materials at their own pace</td>
<td>Measured at 6 and 12 weeks. Primary outcome: Physical and Mental Quality of Life. Secondary outcomes: depression, anxiety, exercise and stress reduction activity Phillips (2014) reported on ability to enact several self-management skills, which included relaxation, awareness of tension, getting needs met and coping confidence</td>
<td>There was no effect for the stress management intervention on primary outcomes of quality of life or quality of life or depression or anxiety. Those in the stress management group also reported an increase in the ability to relax; those in both the exercise group and combined stress management/exercise group reported awareness of tension, those in combined group reported increased ability to get their needs met.</td>
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<tr>
<td>Jacobsen 2014 [37] USA</td>
<td>711 adults with haematopoietic cell transplant (HCT) planned within 6 weeks</td>
<td>RCT. Groups: 1. Usual care 2. Stress management 3. Home-based exercise 4. Stress management and exercise</td>
<td>Same as Jacobsen 2013/Phillips 2014</td>
<td>20 min introduction to program prior to HCT. Patients contacted at 30 and 60 days post HCT to review training goals and provide encouragement</td>
<td>Participants could work through materials at their own time</td>
<td>Measured at baseline, 30, 60, 100 and 180 days after HCT. Primary endpoints: Physical and Mental Quality of Life Secondary endpoints: cancer and treatment distress, sleep quality and nausea</td>
<td>No differences in physical and mental quality of life, treatment related distress, sleep quality, pain or nausea at day +100 among the groups</td>
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<td>Krischer 2007 [26] USA</td>
<td>310 adults undergoing radiotherapy</td>
<td>RCT. Groups: 1. Usual care 2. Self-administered stress management training</td>
<td>Instructional materials comprised a videotape and booklet on stress management, relaxation techniques, and positive thinking. A relaxation audiotape was also provided.</td>
<td>Intervention group each met briefly with a clinician for an explanation of the program and provision of study materials</td>
<td>Participants could work through materials at their own time</td>
<td>Measured at baseline, 1, 2 and 3 weeks after initiation of radiotherapy. Primary Endpoints: Mental Quality of Life Secondary Endpoints: depressive symptoms and state anxiety Measured at baseline and 3 weeks</td>
<td>Overall, no difference in mental quality of life, or depressive symptoms and state anxiety. However patients with higher levels of distress after first radiotherapy treatment reported improvements.</td>
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<td>Lee 2014 [27] Korea</td>
<td>36 adults receiving</td>
<td>Quasi-randomised control trial. Groups:</td>
<td>The psychoeducational</td>
<td>Both groups were given PC tablets at</td>
<td>20 min video clip</td>
<td>Compared with controls, the</td>
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<td>Owen 2005 [33] USA</td>
<td>62 women with breast cancer</td>
<td>RCT. Groups: 1. Waiting list control 2. Internet based discussion group</td>
<td>Website included a bulletin board for group discussion, a dictionary of medical terms, breast cancer resources, information and coping advice for management of common physical symptoms, a forum for sharing artwork and poetry, and 6 structured coping skills training exercises. 39 automated email prompts were sent at regular intervals, providing information and encouragement to post messages to the group</td>
<td>The investigators monitored online discussions</td>
<td>Six structured coping exercises administered over a 12 week period.</td>
<td>Health related quality of life, distress, physical well-being, satisfaction with the website and quality of participation.</td>
<td>No effects for treatment were observed at 12 weeks. However women with baseline poorer self-perceived health status in the intervention group showed greater improvement in perceived health over time.</td>
</tr>
<tr>
<td>Ramachandra 2009 [34] UK</td>
<td>46 adults with stable metastatic breast or prostate cancer</td>
<td>RCT. Groups: 1. Waiting list control 2. Self-administered psychosocial intervention</td>
<td>The intervention had three components: Patients were encouraged to use the diary, plan pleasurable activities and practice mindfulness using the CD provided.</td>
<td>Participants were encouraged to engage in the intervention daily. Duration of intervention engagement not specified</td>
<td>Measured at baseline, 6, 12 and 18 weeks. Primary outcomes were Quality of life and psychological distress (depression and anxiety combined). Other outcomes were Social and Occupational Functioning, optimism/ pessimism and a personality inventory.</td>
<td>Compared to controls, there was an improvement in quality of life in the intervention group. No effect on psychological distress. Feedback from participants was generally positive</td>
<td></td>
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<tr>
<td>Stiegels 2004 [28] Netherlands</td>
<td>109 patients with curative tumour. Two groups: 1. Usual Intervention was a booklet with three main levels. Level 1 A ‘manipulation check’ whereby intervention was “successful” if the patient was not able to answer any questions and encourage participation</td>
<td>Participants who received IC with 20 min of psychoeducational material</td>
<td>1. Control group who received tablet PC with 20 min movie, containing scenic images and relaxing music. 2. Intervention group who received tablet PC with 20 min of psychoeducational material</td>
<td>The commencement of chemotherapy infusion. When the researchers retrieved the tablet PCs, they informed participants about how to access psychosocial services</td>
<td>Measured at baseline (one week prior to beginning of intervention group showed improved depression, QOL, insomnia and avoidant tendency following cancer related traumatic events at 3 weeks. There was no difference in use of psychosocial services</td>
<td>The experimental group had higher fighting spirit and self-care behaviours. No differences for helplessness/ hopelessness, anxiety or depression.</td>
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Table 1 (Continued)

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<tr>
<td>Wootten 2014 [35] Australia</td>
<td>142 men with localised prostate cancer</td>
<td>RCT. Groups: 1. My Road Ahead (MRA) alone 2. MRA plus access to online forum 3. Online forum alone</td>
<td>MRA was a 10 week self-guided online intervention which consists of six modules designed to facilitate improved emotional well-being. It provided psycho-education (though text, video, audio and graphics), interactive exercises and regular automated feedback.</td>
<td>The online forum component was moderated. Weekly email reminders were sent.</td>
<td>Six-module intervention delivered at participants own pace over a 10 week period</td>
<td>depression when they received the intervention.</td>
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2.3.2. Assessment of bias  
Risk of bias was assessed with the tool developed by the Cochrane collaboration. There were seven items: 1) random sequence generation; 2) allocation concealment; 3) blinding of participants/personnel; 4) blinding of outcome assessment; 5) Incomplete outcome data; 6) Selective reporting; 7) Other bias [22]. Reviewers assessed study bias independently. Scores were compared and discrepancies discussed until agreement was reached.

3. Results

Fig. 1 provides a description of the paper selection process. 1081 papers (766 after removal of duplicates) were identified in the search which resulted in 15 papers identified for inclusion in the review. Two papers reported on findings from the same trial; with one reporting primary results on efficacy of the intervention in improving psychological outcomes, [23] and the other reporting on behaviour changes as a result of the intervention [24]. Both are included, but the methodology and findings are presented as the one study. This results section presents findings of the 14 included studies.

3.1. Overview of included studies

Table 1 reports on the characteristics of the 14 included studies. Studies were conducted in USA (n = 6), Australia (n = 3), Korea (n = 2) Netherlands (n = 1), Germany (n = 1) and UK (N = 1). Six studies reported on various cancer types, [23,25–29] four reported on breast cancer, [30–33] one targeted breast or prostate, [34] one targeted prostate cancer only, [35] and two papers included haematology patients, [36] including one study which reported on patients scheduled for hematopoietic cell transplantation [37]. People with early stage cancer were the focus of many of the studies. Six of the 12 studies that recruited people with solid tumours, excluded stage IV patients [29–33,35]. Of the other six papers, stage IV patients were specifically targeted in one study [34], they made up the majority of the sample in another study [27]; a minority in two studies [23,28] and for two papers, stage was not reported in either eligibility criteria or the description of the sample [25,26].

Nine studies were two-arm randomised controlled trials. Five used wait list control, [30,32–34,36], three had treatment-as-usual controls [25,26,29] and one had an active control [31]. One study was a three arm RCT, with arms consisting of an active control (an online forum); the self-guided intervention (a website) and a combination of both [35]. Two studies were four-arm RCTs, consisting of the self-guided intervention, an exercise intervention, both interventions and a treatment-as-usual control [23,37]. Two studies had a control group but were not RCTs. One was a quasi-experimental study, with data collected from a wait-list control group before data collection from the experimental arm, [28] and another allocated to intervention arm according to date of consent [27].

In one RCT study [29] different measures were assessed pre- and post-intervention; measuring control and illness uncertainty at baseline, and psychological distress at follow-up. Consequently, this study focused more on the capacity of the intervention to mediate the relationship between baseline variables (control and illness uncertainty) with the follow up variable (distress).

3.2. Study bias

Study bias is presented in Table 2. The fourteen studies showed various levels of bias.

3.3. Sample sizes and power

Sample sizes were generally small and/or the study lacked power to achieve outcomes. Across the studies, samples ranged
from 36 to 711. Several studies were underpowered [23,28,30,31,35,36]. The sample size was not justified in four studies [26,27,33,34] and power analysis appeared to be retrospective in another study [29]. Power was justified and achieved in one study [32]. One study, the largest sample size in the review, had a requirement of 700 patients at baseline, and while this was achieved, the required numbers of participants at follow up were not clearly reported and it was not clear if the study was adequately powered [37]. Often, sample sizes were noted as limitations [28,30,31,33,34]. For most studies, justification of power calculations lacked detail and the data to inform the power calculation was rarely specified.

3.4. Acceptability

Acceptability was examined with study consent rates and engagement with the intervention. Study consent rates were often not reported [25,26,28,34,37] or were not clearly specified but could be calculated from data provided by study authors [23,27,30,32]. For some studies, consent rates were not possible as participants opted in [35,36]. Consent rates appeared to range from 24% [27] to 93% [32] (both figures calculated by authors of this review). Only three studies clearly reported consent rates: 61% [31], 65% [33] and 71% [29].

Engagement with the intervention was often not reported. When it was presented, adherence and compliance to the intervention was presented in various ways; such as the percentage of content accessed, or a percentage of patients who completed a certain amount of the intervention. Beauty and colleagues (2010A) reported that 88% of participants read all the information, and 81% completed at least a quarter of suggestions and exercises. The other study led by this author found that compliance with the workbook decreased over time [31]. Another study reported that 57% of content was accessed [35]. Participants completing all of the content were reported as 29% in one study [32]; 20% in two studies [29,36], and 46% in a further study [34]. Another study reported adherence to the intervention was good (94.5%), although this study also reported high study attrition (calculated as 41% [28]. Overall, studies showed diverse levels of engagement with the intervention and there were inconsistencies in the presentation of these data.

3.5. Overview of interventions

Of the interventions, three studies tested hard-copy workbooks or booklets, [29–31], six studies used resource packs consisting of stress management resources or CDs with other materials such as diaries or booklets, [23,25,26,28,34,37], four were online resources [32,33,35,36]; and one was a brief audio or visual resources presented on a tablet [27].

Despite being self-guided, most studies required some level of facilitation. This facilitation had several purposes: as an orientation to the intervention, to troubleshoot, monitor or encourage engagement or adherence, answer questions or provide support, or supplement the self-guided component. Studies often had brief face to face sessions to meet several of these purposes. For all online interventions, facilitation was required to monitor the online forum or discussion board and respond to requests for support [32,33,35,36]. Only one study appeared to have no facilitated component or requirements for intervention delivery [31]. The included studies presented in Table 1 differentiates between the self-guided and facilitated intervention components, and details the time frames for the various interventions.

3.6. Efficacy of interventions

Interventions were considered effective when statistically significant improvements were found in the intervention group when compared with the control group. While several studies found some expected statistically significant improvements in the intervention group compared with the control group, these outcomes were often not for the primary endpoint. Often, there were multiple study measures, each with several subscales.

Three studies found improvements in primary outcome measures when compared to the control group in those provided with the self-guided intervention. The online workbook intervention for distressed patients by Carpenter and colleagues found improvements for the primary outcomes of self-efficacy for coping with cancer and self-efficacy for regulating negative mood, though a third primary outcome of benefit finding did not reach significance [32]. Another study had two primary outcomes (quality of life and psychological distress), finding that only quality of life was significantly improved over time; although the sample was small at follow up (n = 27) so the data from the active intervention phase were combined across the two groups, with a
short follow up of six weeks [34]. The other study to demonstrate improvements also had a small sample size (n = 36) and short follow up (three weeks), with intervention participants reporting improvements in depression, insomnia, avoidant tendency and quality of life scores [27].

A further study concluded that the intervention introduced was effective, [29] however, with different measures used pre- and post-intervention; this study focused on the mediating role of the intervention between the two measures.

The majority of studies did not have significant results for primary outcome/s for the self-guided intervention [23,25,26,33,35,37]. Some were able to demonstrate support for some subscale measures but not others (e.g. one of five subscales of the primary outcome measure [36]; one of six subscales of the primary outcome [30]; one of three primary outcomes [31]; two of five primary outcome subscales [28]. Improvements across secondary measures or subscales were found for a variety of outcomes, including emotional adjustment [25], venting coping [30], traumatic stress [31], helplessness/hopelessness [31], cognitive avoidance [31]. There were no apparent patterns to the secondary measures or subscales across these studies as a result of self-guided interventions.

Of the studies that adopted four or three arm RCT designs [23,35,37], two reported better outcomes for the combined intervention [23,35] and the other found no differences across the study arms [37].

Some studies assessed whether interventions promoted engagement in positive behaviours. One study found that those who received the intervention were more likely to use deep breathing and relaxation throughout treatment [25]. Similarly, another reported that those provided a self-guided intervention promoting exercise and stress management were more likely to use those techniques; though physical activity only increased in the combined exercise and stress management arm [23,24]. Data on patient satisfaction with the intervention were collected in several studies, and was often high [25,29–32,34,36].

The amount of intervention received did not appear to indicate whether an improvement was evident in the intervention group. Two studies that showed statistically significant improvements in the intervention group when compared to the control group were very brief; [27,34] albeit with small sample sizes and short follow ups. Similarly, another study reported that engagement in the intervention was not predictive of outcomes [30].

3.7. Follow up time points

Seven studies had short term follow up points (defined as three months or less): three weeks, [26,27], four weeks, [36], ten weeks, [35], or twelve weeks/three months [23,29,33]. One study that showed positive effects of the intervention had an 18-week follow up, but only reported on six-week follow up data, noting high levels of attrition [34]. Another study, also one that showed efficacy of the intervention, had a 20-week follow up, but employed a wait list control whereby the control arm had access to the intervention at 10-weeks. This resulted in comparable data between intervention and control patients at 10-week follow up only and data at 20-weeks for the intervention arm only [32]. Of those that had a longer follow up, data were collected at 180 days [37] or six months [30,31].

The three studies that reported stronger support for the intervention had follow up periods of three weeks [27], six weeks [34], and ten weeks (although due to the waitlist-controlled design; there is a 20-week follow up for the intervention arm, but no comparison data were available for this time point) [32].

Two studies defined follow-up in terms of treatment; such as final follow-up at cycle four of chemotherapy [25], or three-months post completion of radiotherapy [29]. One study did not define the follow-up data collection point; describing the data collection as pre- and post-intervention [28].

3.8. Study endpoints

Most studies had psychological distress or quality of life including psychological subscales as a study endpoint (e.g. anxiety, depression, quality of life) [23,25–29,31,33–35,37]. Mental adjustment was the primary outcome for one study (measured with the Mental Adjustment to Cancer scale; with five subscales: fighting spirit; helplessness/hopelessness; anxious preoccupation; fatalism and avoidance) [36] and two subscales (fighting spirit; helplessness/hopelessness) appeared to be the primary outcome for another study with psychological outcomes (although primary outcome measures were not clearly identified) [28]. Coping was used as the primary endpoint for one study [30], and self-efficacy was the primary endpoint for another study [32]. The most promising intervention that was adequately powered with significant results showed improvements to self-efficacy in the intervention arm, rather than improvements to a distress or quality of life measure [32].

One study measured psychosocial service use after six-months post intervention; finding no effect [27]. No other studies reported on endpoints that were not patient reported.

3.9. Targeting distressed participants

Two of the three papers that reported significant improvements for the primary outcome specifically targeted people with psychological distress. Both studies screened for distress levels with established measures prior to study enrolment [27,32].

Two studies reported that people with high distress may respond better to the intervention, [26,31] and a further study reported that people with poor self-perceived health status had greater improvement in perceived health after intervention [33]. Conversely, one study performed a subgroup analysis on distressed participants but found no treatment effect, however only 17% (n = 37) of the sample indicated they were distressed [25]. However, investigating the efficacy of the intervention on distressed participants was not the primary aim of these studies, and they were not sufficiently powered for this subgroup analysis.

4. Discussion and conclusion

4.1. Discussion

This review aimed to assess the efficacy of self-guided interventions to manage psychological distress in people with cancer and found limited evidence for their effectiveness. Only one study was adequately powered and showed improvements for two of the three primary outcomes (self-efficacy for coping with cancer and self-efficacy for regulating mood) at ten-weeks post intervention [32] however this study had a high risk of bias. There was stronger evidence for short-term outcomes following self-guided interventions, with little evidence for longer-term benefits. A range of self-guided intervention types were reviewed, with little evidence to recommend one type of intervention over another. There is a need to generate evidence to understand how self-guided interventions can be optimised; including a) the ideal point in the disease and treatment trajectory (e.g. diagnosis, commencement of treatment, post-treatment period); b) key patient groups (e.g. cancer type, level of distress); c) intervention content and type (e.g. stress management, coping strategies, relaxation training) and d) mode of delivery (e.g. online, workbook format, kit of resources).
There is some evidence from this review that self-guided interventions could be more effective when targeted to those with the greatest level of need such as higher distressed patient groups. However, the lack of pre-planned sub-analysis or a-priori defined primary endpoints for these subgroup limits the strength of this evidence; but it is suggested that future research should take pre-planned sub-analyses into account. Despite all studies reviewed here focussing on the management of psychological distress, studies generally did not recruit participants who were formally assessed as being distressed, and two studies noted that their samples had relatively low levels of distress, potentially reducing the study’s ability to detect an intervention effect [25,35]. Further research into the optimal patient group, including exploration of whether distressed samples benefit from self-guided interventions, is warranted.

Successful management of chronic illnesses, including cancer, are highly dependent on individual factors, including responsibility for self-care outside the healthcare system. Patient-driven interventions require high levels of acceptability to foster use by the targeted population. This review found that briefer interventions had potential to do improve patient outcomes. Consequently, the length of intervention may not equate to greater effect. Additionally, a study reviewed found that engagement with the intervention was not predictive of greater effect [30]. There is a need to understand more about the processes, and patient motivation factors, that contribute to successful self-guided interventions.

In the studies reviewed, patients’ engagement with and adherence to the self-guided interventions was often difficult to ascertain; this may be due to the nature of these interventions. There were examples of poor or reduced adherence, with less than half the participants completing study requirements in some studies [34]. Adherence also varied across different components of the intervention; e.g. engagement was low for the modules but many read the workbook [30]. Poor reporting of compliance to different sections of the intervention and a lack of qualitative research means it is difficult to ascertain preferred aspects of programs, or what was considered helpful. Because of gaps in evidence, the effects of systems-based factors to promote adherence, such as clinician endorsement are not known, but are worthy of further investigation. As uptake, compliance and adherence was variable or poorly reported, future research on self-guided interventions requires improved reporting such as clearly described consent rates and intervention adherence.

The level of professional facilitation used varied across the studies, ranging from provision of the intervention, introductions, orientations, email communication or follow up phone calls. Understanding optimal facilitation to best promote adherence to self-guided interventions is an important avenue for research and a completely self-guided intervention may not be possible. A small facilitated component, such as enquiring about compliance with two phone calls, [30] an introductory email [36] or a 20-min introduction to the program [23] may be helpful in encouraging engagement and promoting adherence, but further research on the optimal role of facilitation is needed. Furthermore, for interventions which often involve presentation of a resource to people with cancer, studies need to clearly identify the involvement from researchers or clinicians as a part of a data collection process, and differentiate it from involvement to support intervention delivery. For example, Carpenter et al. (2014) noted that all participants received biweekly phone calls from a research assistant to monitor distress and keep participants engaged. If a high level of distress was registered, the researchers agreed and relented, the researcher stated this would have prompted further intervention. Whether this was part of the intervention, or part of the data collection procedures, was not entirely clear.

The majority of papers focused on psychological functioning or quality of life (encompassing psychological functioning) as a primary endpoint, however the most promising intervention showed improvements to self-efficacy [32]. All studies focused on patient self-reported measures. Only one study collected data to explore whether different levels of psycho-oncology service use were evident at six-months post intervention [27]. Given that the evaluation of self-guided interventions for psychological distress in cancer patients is in its infancy, and there is limited evidence for benefits on patient reported outcomes, there was no evidence for self-guided interventions having any impact on measures of adherence to treatment, indices of health or survival, comorbidity, or hospital admissions. Future research should expand the data collection from patient reported outcomes to include clinical or systems data to understand whether these interventions have capacity to reduce health service use. Several studies used multiple measures and often multiple primary endpoints, which is concerning in the context of small sample sizes [38,39] and one study was limited because psychological distress was not measured prior to administration of the intervention [29].

The majority of papers in this review were recent publications. Of 14 included studies, seven were published in or after 2012. Although not targeted within our search, several recent and related protocol studies were identified, [40–45] and it is anticipated that evidence for self-guided interventions or interventions that are conducted within a translatable framework will continue to develop.

The current review has several limitations. First, although this review focused on self-guided interventions, it was found that all except one intervention had some degree of facilitation. The process of identifying included and excluded studies was challenging and understanding whether an intervention met the criteria for “self-guided” was difficult due to reporting. Some studies included self-guided components in conjunction with facilitated components, and these were excluded if the delivery was extensive. Due to variable reporting and different types of facilitation, having a fixed cut-off for facilitation time was not possible. The focus of this review was interventions that could be readily adopted in practice with minimal cost to community services. A landmark paper on self-guided interventions in cancer was excluded as it required a one-hour facilitated component, [13] which was considered too intensive. Although no studies in our review reported requiring an hour of health professional’s time to be delivered, studies reported the requirements of the facilitated components of the intervention, but rarely reported how long this took in practice. Monitoring of emails, for example, may have required extensive staff commitments which were not recorded, reported or known. Extensive discussion in regards to the included papers took place in developing the criteria, and 100% agreement for included papers was found. Although this is a study limitation, it is also an important finding that self-guided interventions are likely to require some facilitation or support in approaching and engaging participants and users. Potentially, developing definitions of self-guided interventions, or establishing standard descriptors of these interventions may assist in future appraisal of this body of literature. It is a limitation that a meta-analysis was not conducted, as there was substantial variety in participants, interventions, control groups and outcomes across these studies; and consequently, it was not considered appropriate [17,46].

4.2. Conclusion

Self-guided interventions represent a potentially efficient way of delivering support for people affected by cancer, however
evidence for their effectiveness in reducing psychological distress is lacking. This is a developing field and there are several important lessons gained from this analysis of the methodologies of existing studies. There is a need to generate evidence to understand the impact of self-guided interventions, and the role of the facilitator requires further understanding.

4.3. Practice implications

Implementation of self-guided interventions is in its infancy. Monitoring of people who use these interventions may be particularly relevant given that they may have levels of psychological distress. It is important to develop protocols for responding to high levels of distress of self-harm. Training of staff, triaging according to risk and having oversight of the interventions may be important in ensuring patient safety. These interventions should be delivered with options for further support, contact details for help, and monitoring.

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References


