

# Cancer survivors' perspectives on adjustment-focused self-management interventions: a qualitative meta-synthesis

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## Abstract

**Purpose** Self-management interventions improve patient outcomes across a range of long-term conditions but are often limited by low uptake and completion rates. The aim of this paper was to conduct a meta-synthesis of qualitative studies exploring cancer survivors' views and experiences of engaging with adjustment-focused self-management interventions in order to inform the development of future interventions targeting this population.

**Methods** Four electronic databases were systematically searched. Studies that used qualitative methods to explore cancer survivors' views and experiences of engaging with adjustment-focused self-management interventions were included. A meta-ethnographic approach was used to synthesize the findings.

**Results** Thirteen studies met the inclusion criteria. Engaging with adjustment-focused self-management interventions enabled cancer survivors to gain emotional and informational support from peers and/or facilitators in an open, non-judgemental environment, become empowered through

enhancing knowledge and skills and regaining confidence and control, and move beyond cancer by accepting illness experiences, reprioritising goals and adopting a positive outlook. However, the extent to which they engaged with, and benefited from, such interventions was mitigated by diverse preferences regarding intervention design, content and delivery. Personal obstacles to engagement included low perceived need, reticence to discuss cancer-related experiences and various practical issues.

**Conclusions** Cancer survivors derive a range of benefits from participating in adjustment-focused self-management interventions; potential barriers to engagement should be addressed more comprehensively in intervention marketing, design and delivery.

**Implications for Cancer Survivors** The findings suggest some key considerations for the development and implementation of future adjustment-focused self-management interventions that may help to optimize their appeal and effectiveness among cancer survivors.

**Keywords** Meta-synthesis · Qualitative research · Self-management · Cancer · Survivorship

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## Introduction

Self-management refers to an 'individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' [1, p. 178] and represents an ideological shift in healthcare from viewing patients as passive recipients of care to empowered partners in managing their own health [2]. Self-management interventions focus on enhancing patients' ability and confidence to manage their condition effectively by providing education, training and support to develop their

knowledge, skills and both internal and external resources [3]. They have been developed for a range of different long-term conditions and can take a variety of forms (e.g. lay or professionally led, generic or disease-specific, group or individually delivered) [1]. They typically incorporate multiple components targeting core skills such as problem solving, action planning/goal setting, communicating with healthcare providers and making effective use of available resources [4].

A large body of research suggests that self-management interventions have the potential to improve a range of clinical and psychosocial outcomes [1, 5, 6] and reduce healthcare use [7] among people with long-term conditions, including cancer [8, 9]. Despite these potential benefits, significant gaps remain in understanding which aspects of self-management interventions work best, in what circumstances, and for whom [3, 10]. A substantial proportion of patients do not engage with self-management interventions, as indicated by low uptake and high attrition rates observed in research and clinical practice [2, 10, 11]. Given that the impact and cost-effectiveness of self-management interventions are dependent on the extent to which individuals in the target population are willing to engage with them, patients' perspectives should be taken into consideration and integrated into their design and delivery.

The promotion of self-management has gained increasing recognition as an important aspect of cancer survivorship care [8, 12]. Although cancer survivors may wish to take an active role in dealing with challenges related to their condition and its treatment, they often need specific support in learning how to do this [13]. Despite growing calls for the development of self-management interventions for cancer survivors, it remains unclear how best to design such interventions to engage this diverse population and address their needs and preferences [9]. Qualitative research conducted among cancer survivors who have experience of engaging with self-management interventions offers an opportunity to explore their perspectives; this information may, in turn, be valuable in determining how to optimise the appeal—and effectiveness—of future interventions targeting this population. Meta-synthesis involves drawing together the findings of qualitative studies in order to build a more in-depth understanding of a specific phenomenon, and is being increasingly employed to inform health-related policy and practice [14]. The aim of the present study was to conduct a meta-synthesis of qualitative research examining cancer survivors' views and experiences of engaging with self-management interventions in order to inform the development of future interventions.

## Method

There are a number of evolving methods for synthesising qualitative research [14]. In the present study, a meta-ethnographic approach was employed based on methods

described by Noblit and Hare [15, 16]. Meta-ethnography is an interpretative rather than aggregative approach, which involves the reciprocal translation of qualitative findings (i.e. comparing each study's concepts and their interrelationships with those of other studies, while preserving the meanings and context of the primary data) to develop new theoretical insights that give a better understanding of the 'whole...based on selective studies of the parts' [15, p. 62]. This approach was chosen for the present synthesis as it is widely used in research on healthcare and is suited to exploring patient experiences [17]; it has also been recommended for synthesising smaller numbers of papers [18]. The Enhancing Transparency of Reporting the Synthesis of Qualitative Research (ENTREQ) statement was followed [18].

## Search strategy

A systematic search of four electronic databases (Medline, PsycINFO, CINAHL and Web of Science) from 1990 to November 2015 was conducted. A search strategy combining controlled vocabulary and free-text search terms was created and adapted to each database (an example is provided in the [Appendix](#)). This strategy was supplemented by manually searching the reference lists of papers selected for inclusion in the meta-synthesis for further potentially relevant material. Due to time and budgetary constraints, results were limited to English language publications.

## Selection of eligible papers

Following the removal of duplicates, all titles and abstracts were independently screened by two authors (LC and OM). Articles identified as potentially eligible for inclusion were obtained in full and reviewed independently by LC and OM. Differences in opinion were discussed and brought to a third reviewer (PG) if consensus could not be reached.

Papers were selected for inclusion if they (i) included cancer survivors (defined as individuals from point of diagnosis onward) who were aged 18 years or over when diagnosed and (ii) presented analysis of qualitative data that explored their views and experiences of engaging with a self-management intervention (mixed methods papers were eligible if qualitative data were reported separately and in detail). Based on previous reviews of this topic [19, 20], self-management interventions were defined for the purposes of the present meta-synthesis as structured, multi-component interventions of limited duration that provide education, training and support in self-management and teach core self-management skills, such as goal setting and problem solving, through a process of interactive and participatory learning. Interventions covered by this definition were eligible, irrespective of their design (e.g. lay or professionally led, individual or group-based, delivered face-to-face or via Internet/telephone). Interventions

that included carers or relatives were considered eligible if they were primarily targeted towards cancer survivors. This meta-synthesis concentrated on adjustment-focused (i.e. facilitating overall transition to survivorship) rather than problem-focused (i.e. enhancing skills for managing specific problems or symptoms) self-management interventions, in line with Davies and Bateup [20]. Papers were ineligible if interventions: (i) involved provision of information alone (i.e. no training in self-management skills); (ii) were not delivered by some form of organised content delivery and/or were open-ended in duration (e.g. informal cancer support groups); (iii) focused on a specific aspect of cancer survivorship (e.g. diet/exercise, return to work, side effects of specific treatments or specific symptoms); (iv) focused specifically on end-of-life concerns for advanced cancer/palliative care patients; or (v) were mindfulness-based stress reduction or life coaching interventions.

### Quality appraisal

The quality of eligible papers was appraised independently by two authors (LC and OM) using the Critical Appraisal Skills Programme (CASP) qualitative research checklist [21], which considers rigour and credibility of relevant studies under eight headings (research design, recruitment, data collection, researcher-participant relationship, ethical issues, data analysis, findings and value of the research). The reviewers used a three-point system to rate each paper on how it explained each of the eight areas (weak = 1, moderate = 2, strong = 3) [22]. Any differences between reviewers' scores were resolved through discussion and, if needed, reference to a third reviewer (PG). Scores were then summed for each paper, giving a possible score of 8–24. This quality review was conducted to aid readers' critical consideration of the credibility of the included papers' findings, and as such papers were not excluded on the basis of their scores. Furthermore, ratings on CASP criteria tend to reflect the quality of reporting rather than that of the research undertaken and do not necessarily indicate the robustness, trustworthiness or transferability of findings [17, 18].

### Data extraction and synthesis

Meta-ethnography involves three levels of construct: first-order constructs (participants' interpretations of their experiences as reported in direct quotations), second-order constructs (study authors' interpretations of participants' accounts) and third-order constructs (the synthesis team's interpretations of the first- and second-order constructs) [23]. Two reviewers (LC and OM) read and re-read the papers in alphabetical order and independently compiled tables of second-order constructs extracted from each paper, illustrating them with first-order constructs. These tables were compared to

identify and develop working definitions for key concepts. A grid was created, in which each row represented a paper and each column represented a key concept. Cells were populated by the first- and second-order constructs extracted previously. By reading off the grid and checking that the content of each cell was accurately represented by the column label, it was possible to write a translation of these key concepts across papers while ensuring that they fully encompassed the first- and second-order constructs identified from the primary data, with labels retaining the authors' original wording wherever possible. These translations were further developed and synthesised into third-order constructs using a 'lines of argument' approach. This involves constructing a new overarching interpretation that can be applied across studies, which integrates their similarities and differences [15, 24]. LC led the synthesis; the third-order constructs were independently confirmed by OM.

### Results

The initial searches yielded 5016 articles excluding duplicates (Fig. 1). Thirteen papers were eligible for inclusion in the meta-synthesis [25–37]. The study and intervention characteristics of each paper are provided in Tables 1 and 2, respectively.

#### Study characteristics

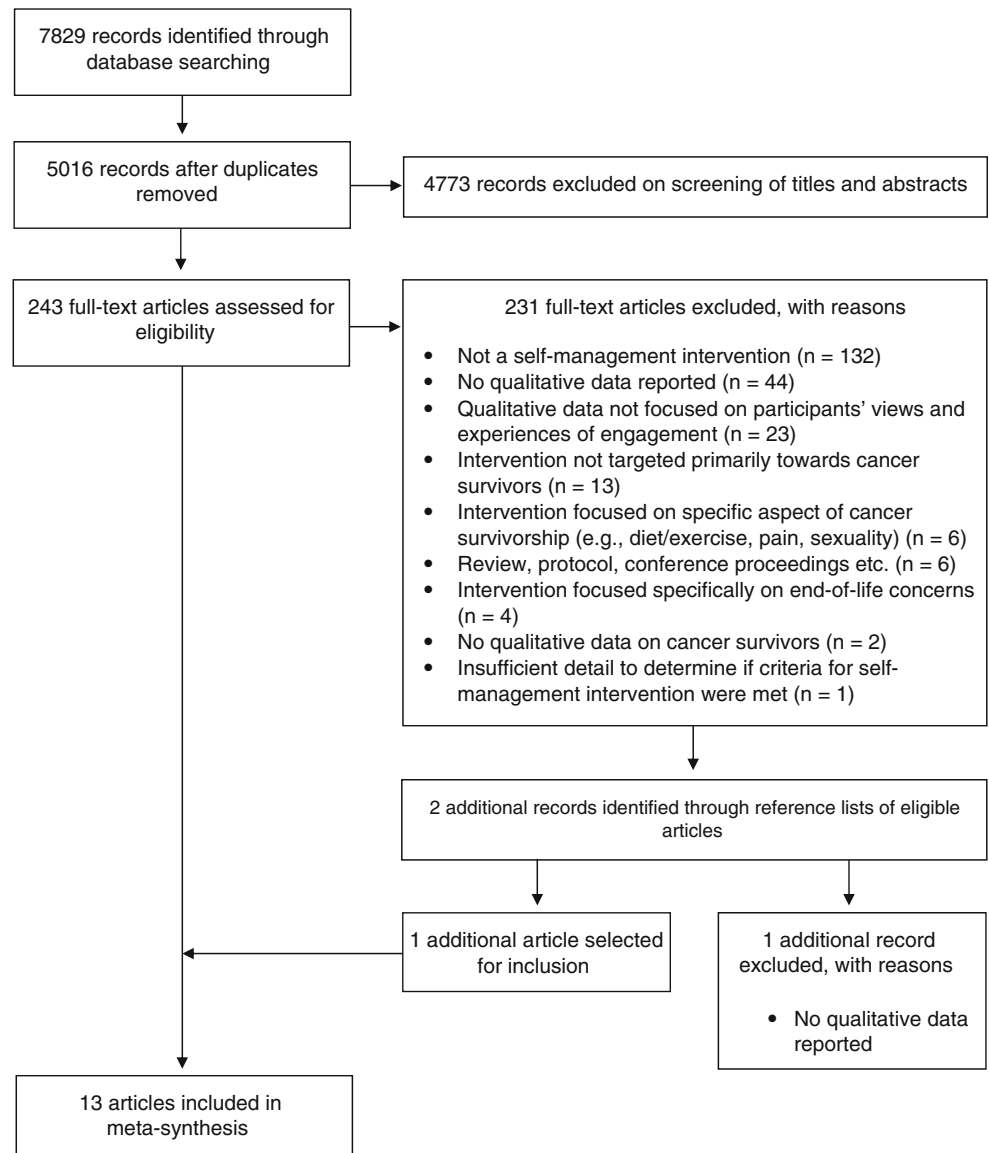
Papers were published between 1998 and 2015 and originated from the UK ( $n=4$ ), USA ( $n=3$ ), Australia ( $n=2$ ), Canada ( $n=2$ ), Hong Kong ( $n=1$ ) and Malaysia ( $n=1$ ). Qualitative data were collected using interviews ( $n=9$ ), open-ended questions ( $n=5$ ) and/or focus groups ( $n=2$ ). In five studies, the sample comprised survivors with different types of cancer; eight studies had samples limited to one type of cancer [breast ( $n=3$ ), ovarian ( $n=1$ ), colorectal ( $n=1$ ), head and neck ( $n=1$ ), lung ( $n=1$ ), testicular ( $n=1$ )] (Table 1).

Interventions were delivered to participants face-to-face ( $n=9$ ), by telephone ( $n=2$ ) or through a combination of these methods ( $n=2$ ) in either a group format ( $n=8$ ), individually ( $n=3$ ) or both ( $n=2$ ). Interventions targeted individuals newly diagnosed with cancer ( $n=5$ ), those who had completed primary treatment ( $n=4$ ) or were open to individuals at any stage of their cancer journey ( $n=4$ ) (Table 2).

#### Quality appraisal

CASP scores for the 13 included papers ranged from 10 to 19 out of a possible 24 (Table 1), with a mean value of 15.31 (median = 17). Many scored poorly (i.e. a score of one) in the areas of the researcher-participant relationship, ethical issues and data analysis.

**Fig. 1** Flow diagram of article selection process



**Synthesis findings**

Synthesis of the included papers’ findings resulted in five third-order constructs associated with cancer survivors’ experiences and perceptions of engaging with self-management interventions: (1) gaining support (sharing experiences with peers, interacting with intervention facilitators, having a safe space to talk); (2) becoming empowered (increasing knowledge, learning new skills, regaining confidence and control); (3) moving beyond cancer; (4) issues around intervention design—one size does not fit all (preferences about group composition, intervention delivery and intervention content); and (5) personal obstacles to engagement. Table 3 presents these constructs along with illustrative quotations from participants and shows which papers contributed to their development.

*Gaining support*

Gaining support from fellow cancer survivors and/or intervention facilitators in an open and non-judgemental environment was highlighted by study participants as an important aspect of their intervention experience.

**Sharing experiences with peers**

Participants in group-based interventions valued their supportive and empathic interactions with fellow cancer survivors highly [25, 26, 29–31, 34–37]. Many experienced feelings of isolation as a result of their illness and having the opportunity to meet others ‘in the same boat’ [26, p. 27] made them feel less alone [25, 26, 31, 37]. Participants were keen to share

**Table 1** Overview of included studies

First author (year of publication)	Country	Recruitment setting	Sample (qualitative component)	Data collection (qualitative component)	Analytical approach	Aim (qualitative component)	Methodological quality using CASP (24)
Beckmann (2007)	Australia	Local media, support group networks	29 cancer patients (20 participated in cancer-specific programme, 9 participated in mixed-condition programme), 11 carers and one person with another chronic condition  Characteristics for participants who were cancer patients ( $n = 29$ ): Type of cancer: breast ( $n = 8$ ); myeloma/leukaemia ( $n = 5$ ); bowel ( $n = 4$ ); prostate ( $n = 3$ ); ovarian ( $n = 2$ ); renal ( $n = 2$ ); other ( $n = 4$ ); not reported ( $n = 1$ ). Currently receiving treatment: yes ( $n = 9$ ); no ( $n = 20$ ). Time since diagnosis: <12 months ( $n = 8$ ); 1–4 years ( $n = 14$ ); 5+ years ( $n = 4$ ); unknown ( $n = 3$ )	Semi-structured interview completed via telephone 4–6 weeks post-intervention	Constant comparative method	To determine whether people affected by cancer and their carers found the programme useful in addressing some of the longer-term impacts of the disease, and whether it was more beneficial to offer the programme as one exclusively for people diagnosed with cancer (and their carers) or to refer people affected by cancer to a general programme incorporating participants with various chronic diseases.	15
Bottomley (1998)	UK	Two district general hospitals	7 newly diagnosed cancer patients identified as psychologically distressed (HADS $\geq 10$ for anxiety or $\geq 8$ for depression) Age: $M = 50.4$ years. Gender: female ( $n = 7$ ). Marital status: married and living with partner ( $n = 5$ ); widowed ( $n = 2$ ). Social class (using OPCS 1984 classification method): 1 ( $n = 1$ ); 3 or 4 ( $n = 6$ ). Type of cancer: breast ( $n = 6$ ); ovarian ( $n = 1$ ). Disease stage: local disease ( $n = 4$ ); local disease and regional spread ( $n = 3$ ). Treatment received: surgery and chemotherapy ( $n = 6$ ); radiotherapy ( $n = 2$ ); prescribed Tamoxifen ( $n = 5$ )	Semi-structured interview within 3 weeks of completing intervention	Thematic analysis	To examine and qualitatively report on the experiences of participants in a group cognitive behavioural therapy (GCBT) programme in order to give health workers the patients' perspectives on the most useful components of the programme to inform the development and evaluation of future programmes.	17
Chambers (2015)	Australia	Local cancer support networks	31 lung cancer survivors (22 participants, 9 nonparticipants)  Characteristics for subset of participants who took part in interviews not reported	Semi-structured interview at 3-month follow-up	Thematic analysis (based on an interpretative phenomenological framework)	To test the acceptability of an acceptance-focused cognitive behavioural intervention targeting stigma in people with lung cancer—to examine how helpful the intervention was; what aspects of the intervention were	17

**Table 1** (continued)

First author (year of publication)	Country	Recruitment setting	Sample (qualitative component)	Data collection (qualitative component)	Analytical approach	Aim (qualitative component)	Methodological quality using CASP (24)
Chow (2014)	Hong Kong	Obstetrics and gynaecology department of teaching hospital	12 newly diagnosed gynaecological cancer patients Characteristics for subset of participants who took part in interviews not reported	Semi-structured group interview (2–3 participants) 4 weeks post-operation	Content analysis	unhelpful or could have been improved, and for patients who did not commence the intervention the reasons for this were explored. To investigate the acceptability of a psychoeducational intervention program for gynaecological cancer patients in the Hong Kong Chinese context—“How do you feel about the interventions?”; “What is the usefulness of the interventions?”; and “Any suggestions for the interventions?”	19
Cimprich (2005)	USA	Clinical settings (academic cancer treatment centre, community oncology treatment clinics) and affiliated private physician practices	22 women aged 25 years or older who had completed treatment for newly diagnosed, early stage I or II breast cancer Age: 34–66 years ( $M=48$ years, $SD=8$ years). Marital status: currently married/living with partner (78 %). Ethnicity: white (92 %). Education: college/advanced degree (48 %). Employment status: working full-time (36 %); working part-time (32 %); unemployed/retired (32 %). Family income: <\$30,000 (8 %); \$30,000–\$69,000 (40 %); \$70,000+ (52 %). Disease stage: stage II (52 %). Treatment: combination of lumpectomy, radiation therapy and adjuvant chemotherapy (46 %)	Process evaluation questionnaire (including open-ended questions) self-completed at end of final session	Not reported	To obtain systematic information from intervention group women about their participation in the intervention and the relevance and usefulness of the self-regulation approach, informational aspects and program delivery.	13
Edgar (2004)	Canada	Volunteer peer support organisation	19 oncology patients and one close friend of a patient Characteristics for subset of participants who took part in focus group ( $n=10$ ): Gender: male ( $n=2$ ); female ( $n=8$ )	Evaluation questionnaire (including open-ended questions) completed via telephone 2–4 months post-intervention ( $n=20$ ) Focus group 3–5 months post-intervention ( $n=10$ )	Evaluation questionnaire: not reported Focus group: content analysis	To examine patients’ participation in a psychoeducational coping skills training programme, called Nuicare—to examine the benefits of, and the barriers to, the helpfulness of the intervention.	11



Table 1 (continued)

First author (year of publication)	Country	Recruitment setting	Sample (qualitative component)	Data collection (qualitative component)	Analytical approach	Aim (qualitative component)	Methodological quality using CASP (24)
Fitch (2011)	Canada	Ovarian Cancer Canada publications and stakeholder mailings	97 women who had been diagnosed with and treated for ovarian cancer, 6 caregivers/family members Age 27–74 years ( $M = 54$ years, median = 55 years). Type of cancer (cancer survivors only): ovarian ( $n = 83$ ), other ( $n = 14$ ). Time since treatment (cancer survivors only): 0–300 months ( $M = 23$ months). Characteristics for subset of participants who took part in interviews ( $n = 15$ ) not reported	Evaluation survey (including open-ended questions) self-completed at end of workshop ( $n = 103$ ) Semi-structured interview completed via telephone 6 months post-intervention ( $n = 15$ )	Evaluation survey: content from open-ended items was collated and organized on the basis of similarities in perspectives Interviews: content analysis	To describe women's perspectives about the workshop and determine how they made use of the information they received and skills they developed—to examine women's recollections about the workshop experience, what had been inspiring about the workshop, what had been challenging in attending the workshop, how the workshop learning had been applied, and suggestions for improving any future workshops.	13
Gray (2013)	UK	Colorectal oncology clinics	12 newly diagnosed colorectal cancer patients Characteristics for subset of participants who took part in interviews not reported	Semi-structured interview 4–8 weeks after home visit	Not reported	To explore patients' experiences of and attitudes towards the intervention.	10
Kilbourn (2013)	USA	Radiation oncology clinic	11 newly diagnosed head and neck cancer patients undergoing treatment including radiotherapy Characteristics for subset of participants who took part in interviews not reported	Process evaluation interview completed via telephone 1 month post-intervention ( $n = 11$ ) Exit interview ( $n = 8$ )	Constant comparative method	To test the feasibility and acceptability of the intervention and provide a preliminary assessment of the intervention benefits among participants—questions regarding recruitment procedures, intervention process (timing, content, and use of telephone), overall impressions of the program, and suggestions for improvement.	13
Loh (2011)	Malaysia	Not reported	21 breast cancer survivors who had participated in programme when newly diagnosed Age 30–64 years ( $M = 50.67$ years). Education level: Grade 6-tertiary education. Employment status: employed outside home ( $n = 14$ ); housewife ( $n = 5$ ); retired ( $n = 2$ ). Marital status: married ( $n = 16$ ); divorced ( $n = 1$ ); single ( $n = 4$ ). Ethnicity: Chinese ( $n = 17$ ); Malay ( $n = 2$ ); Indian ( $n = 2$ ).	Focus group 2 years post-intervention	Thematic analysis	To explore women's perceptions of, and experiences after, attending a self-management programme for breast cancer survivors, and whether or not it had any bearing on their post-treatment phase.	18

**Table 1** (continued)

First author (year of publication)	Country	Recruitment setting	Sample (qualitative component)	Data collection (qualitative component)	Analytical approach	Aim (qualitative component)	Methodological quality using CASP (24)
Martin (2013)	UK	Cancer services at a general hospital	<p>Body mass index: 17–31 (<math>M = 22.1</math>)</p> <p>6 testicular cancer survivors who had completed primary treatment 5–12 months prior to the intervention</p> <p>Age 29–45 years (<math>M = 35</math>)</p>	Semi-structured interview completed via telephone 6 weeks post-intervention	Framework analysis	To explore the experience of participation in a workshop for testicular cancer survivors; the interview schedule focused on process evaluation concerning the most and least helpful aspects of the workshop, perceptions of relevance, and usefulness of activities and suggested changes.	17
Risendal (2014)	USA	Community, healthcare and regional/community cancer centres	<p>113 individuals aged over 21 years diagnosed with cancer that required radiation, surgical or adjuvant chemotherapy who were not in active treatment</p> <p>Characteristics for subset of participants who completed open-ended questions not reported</p>	Impact evaluation questionnaire (including open-ended questions) self-completed 6 weeks post-intervention	Thematic analysis	To evaluate the feasibility and acceptability of the delivery of an adaptation of the Chronic Disease Self-Management Program (Cancer Thriving and Surviving) to cancer survivors.	17
Thompson (2014)	UK	Not reported	<p>31 stage I–III breast cancer survivors at least 2 years post-diagnosis in routine hospital follow-up without signs/symptoms of recurrence</p> <p>Characteristics for subset of participants who took part in interviews (<math>n = 9</math>):</p> <p>Age 46–75 years (<math>M = 58</math> years). Time since diagnosis: 3.3–9.5 years (<math>M = 5.1</math> years)</p>	Semi-structured course evaluation questionnaire (including open-ended questions) self-completed at end of final session/returned by post within two weeks of course ending ( $n = 31$ )	<p>Evaluation questionnaire: thematic analysis</p> <p>Interviews: framework analysis</p>	To evaluate an intervention which supports the transition from cancer patient to cancer survivor for breast cancer patients being discharged to primary care.	19



**Table 2** Description of interventions in included studies

First author (year of publication)	Intervention	Intended audience	Mode of delivery	Intervention facilitator(s)	Format	Details
Beckmann (2007)	Chronic Disease Self-Management Programme (CDSMP)	People directly affected by cancer and their carers	Group-based, face-to-face	Two trained facilitators, one of whom was a lay person who experienced the condition themselves	Six weekly sessions	Programme that aims to reinforce knowledge and skills around managing physical symptoms, continuing with usual daily activities, and coping with emotional demands of a chronic condition. Topics covered include dealing with anger, fear, frustration and depression, relaxation and cognitive symptom management, fitness/exercise, fatigue, medications, communication, working with health care professionals, problem solving and making action plans.
Bottomley (1998)	Group cognitive behavioural therapy (GCBT) programme	Newly diagnosed cancer patients identified as psychologically distressed (HADS $\geq 10$ for anxiety or $\geq 8$ for depression)	Group-based, face-to-face	A research psychologist and a counsellor	Eight 90-min weekly sessions	Highly structured intervention based closely on CBT approach of Adjuvant Psychological Therapy. It has a cancer specific orientation and includes homework review and setting, lectures, feedback, relaxation. Sessions 1–3 focus on introductions and teaching behavioural exercises (e.g., relaxation, activity scheduling). Session 4 focuses on the CBT model and concepts. Sessions 5–8 deal with challenging dysfunctional thinking and learning coping skills. Booklets and leaflets relating to cancer and CBT and relaxation tapes are distributed to participants.
Chambers (2015)	Psychological Wellness intervention	Lung cancer survivors	Individual, telephone-delivered	Not reported	Six weekly 50–55 minute sessions	Acceptance-focused cognitive behavioural intervention that includes psycho-education, skills in stress reduction, problem-solving, cognitive challenging and enhancing relationship support. Participants receive tip sheets matching each weekly session, self-help materials including Jon Kabat-Zinn's book 'Full Catastrophe Living' and a meditation CD.
Chow (2014)	Psychoeducational intervention programme	Newly diagnosed gynaecological cancer patients	Individual, face-to-face (sessions 1–2); individual, telephone-delivered (session 3); group-based, face-to-face (session 4)	Registered nurse	Four 30–60-min sessions (1 pretreatment, 3 post-surgery)	Based on a thematic counselling model. Different topics are covered in each session. Session 1: Information on gynaecological cancer and its treatment, common side-effects, and impact on body image and sexuality. Session 2: Post-operative wound management, diet, breathing and relaxation,

**Table 2** (continued)

First author (year of publication)	Intervention	Intended audience	Mode of delivery	Intervention facilitator(s)	Format	Details
Cimprich (2005)	Taking CHARGE	Women who completed primary treatment for early stage I or II breast cancer	Group-based, face-to-face (sessions 1 and 4); individual, telephone-delivered (sessions 2 and 3)	Oncology nurse practitioner and health educator	Four sessions delivered at 2-week intervals	<p>Session 3: Issues post-treatment and preparation for discharge.</p> <p>Session 4: Communication, sexuality, social support, social role changes.</p> <p>Self-management intervention designed to facilitate successful transitions to survivorship after breast cancer treatment. Involves a two-pronged approach building on self-regulation principles to (1) equip women with self-management skills to address concerns following breast cancer treatment, and (2) provide information about common survivorship topics. Session 1: enhancing psychological wellbeing. Session 2: managing physical symptoms and side-effects. Session 3: achieving functional wellness through a healthy lifestyle. Session 4: promoting functional adjustment in family, work, and social roles. Each participant received an intervention workbook that served as a ‘road map’ for each session and guided women through the steps of the self-regulation process and the breast cancer-specific content areas.</p>
Edgar (2004)	Nuicare coping skills training intervention	Cancer patients	Group-based, face-to-face	Not reported	Three 2-h sessions	<p>Psychosocial educational intervention offered to cancer patients and their families to help them develop skills helpful in coping with cancer. There are seven specific components: (1) problem solving techniques; (2) goal setting; (3) cognitive reappraisal; (4) relaxation training; (5) effective use of social support; (6) communication; (7) components of a healthy lifestyle. Each participant receives a comprehensive workbook with simple instructions, exercises and notes of encouragement.</p>
Fitch (2011)	Picking up the Pieces workshop for survivors	Women diagnosed and treated for ovarian cancer	Group-based, face-to-face	Not reported	One 6-h workshop	<p>The intervention focuses on providing practical approaches to recovery after ovarian cancer. The content and activities are based on four phases of recovery: inquiry (recovering sense of self); discovery (recovering sense of</p>

**Table 2** (continued)

First author (year of publication)	Intervention	Intended audience	Mode of delivery	Intervention facilitator(s)	Format	Details
Gray (2013)	Community-based intervention to improve quality of life in people with colorectal cancer	Newly diagnosed colorectal cancer patients	Individual, face-to-face (home visit) and telephone-delivered (follow-up)	Nurse	1-h home visit 6–12 weeks after diagnosis and telephone follow-up 1 week later	control); growth (recovering sense of meaning); and reflection (recovering sense of future). Intervention content includes presentations, large and small group discussions, experiential exercises, active learning and practice around foundational skills (five-question check-in and attentive walking). Evidence-based intervention informed by Control Theory to help participants identify personally important symptoms and activities; set appropriate goals; use action planning to progress towards goals; self-monitor progress; and identify (and tackle) barriers limiting progress. Participants receive factsheets on different symptoms/activities.
Kilbourn (2013)	The Easing and Alleviating Symptoms during Treatment (EASE) psychosocial programme	Newly diagnosed head and neck cancer patients undergoing treatment including radiotherapy	Individual, telephone-delivered	Not reported	Up to 8 sessions to correspond with key phases in treatment (e.g. time of diagnosis, active treatment, end of treatment)	Psychosocial intervention based on the Transactional Model of Stress and Coping, which involves (1) an ongoing systematic assessment of physical, psychosocial and functional needs; (2) a psychoeducational component geared toward the management of treatment side effects; and (3) coping skills training to facilitate adaptive coping and improve self-care and symptom management.
Loh (2011)	Staying Abreast, Moving Ahead (SAMA) self-management programme	Newly diagnosed breast cancer patients	Group-based, face-to-face	Not reported	Four weekly sessions	Guided by social cognitive theory, this programme is designed to provide self-management education, via core self-management skills, learn generic skills that can be applied to new problems as they arise, to practice new health behaviours and support via a patient-provider partnership. Core self-management skills taught include problem solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring. Participants are given a workbook with group and individual exercises on medical task management, emotional management, health and role

**Table 2** (continued)

First author (year of publication)	Intervention	Intended audience	Mode of delivery	Intervention facilitator(s)	Format	Details
Martin (2013)	Self-management workshop for testicular cancer survivors	Testicular cancer survivors who had completed primary treatment	Group-based, face-to-face	An experienced self-management tutor and a male specialist cancer nurse	One 4-h workshop	management, according to the themes of each week. Participants have to work out an action plan for each week. Three intervention targets: moving forward, psychological health, and providing information. Workshop schedule: overview and ground rules; what is self-management?; information on testicular cancer; managing fatigue; finding a meaning; cancer survivor-led discussion; open forum/question and answer session; moving forward with hope.
Risendal (2014)	Cancer Thriving and Surviving Program	Adult cancer survivors not in active treatment; support persons/caregivers were also allowed to attend	Group-based, face-to-face	Two certified CDSMP facilitators who are also cancer survivors	Six weekly sessions	Modified version of CDSMP (see Beckmann above) for cancer survivors. Adapted to include restoration of self-confidence, adjustment to changed self, and confidence to self-manage cancer-related problems to promote successful coping and recovery of wellbeing following a cancer diagnosis.
Thompson (2014)	Preparing Breast Cancer Patients for Survivorship (PREP)	Breast cancer survivors at least 2 years post-diagnosis	Group-based, face-to-face	A cancer support centre staff member and a counsellor	Four weekly 2-h sessions	Supportive patient-focused group visit intervention to facilitate the transition from cancer patient to cancer survivor. Each meeting has a specific theme. Week 1: experience of follow-up. Week 2: living with having cancer. Week 3: the threat of recurrence, signs and symptoms. Week 4: moving on from follow-up.

**Table 3** Qualitative synthesis: themes, subthemes and inclusion in papers

Themes (third-order constructs)	Subthemes	Key concepts (translated second-order constructs)	Illustrative quotations from participants (first-order constructs)	Studies that included themes/subthemes
Gaining support	Sharing experiences with peers	Reduced sense of isolation	“It was good to meet others and to realize you are not alone. Sometimes I think ‘Yes, I have cancer’ but meeting others made me feel not so alone.” (Beckmann et al., 2007, p. 40)	[25, 26, 29–31, 34–37]
		Validation/normalisation of cancer experiences	“When she said ‘I’ve got a pain here and there’ and then I said, ‘Yeah! Me too!’ Then you don’t feel like you’re so abnormal, or something is wrong with you, or that you will get a recurrence...” (Loh et al., 2011, p. 1494)	
	Being inspired by others		“...those that were in the same workshop whose conditions had been dramatically worse than mine and how they’ve, you know, responded to that actually put it back into perspective again.” (Martin et al., 2013, p. E20)	
		Sense of connection	“You are all bonded together, all going through the same emotional things and life, death, chemotherapy and whatever else it is and you just bond together because you’re all doing the same thing.” (Bottomley, 1998, p. 27)	
	More discussion time needed		“Sometimes it would have been nice to talk more as a group, but it was difficult as we had to cover so much, we liked to talk together, particularly at first. We wanted to see each others’ problems and share them.” (Bottomley, 1998, p. 28)	
		Knowledge and understanding of cancer survivorship	“The facilitator is very comfortable with the material; she understands what survivors want and need.” (Fitch et al., 2011, p. 142)	[26–29, 31, 33–37]
	Role in managing group discussions		“Leaders did a great job of keeping on topic and keeping people from dominating conversations.” (Risendal et al., 2014, p. 767)	
		Provision of emotional support	“I think the [facilitator] listening to me, offering support, encouragement; you know just having someone you can talk to was a great thing.” (Kilbourn et al., 2013, p. 198)	
	Having a safe space to talk		“I don’t know how to explain it. It really satisfied me to talk like that, you know, to somebody....Open, like really really open. Yes and somebody that understood.” (Chambers et al., 2015, p. 67)	[26–28, 34, 35, 37]
		Need for support independent of loved ones	“Even your own family, although they care about me, they, not being in the same boat, don’t know how I feel. So people that are in the sessions know how you feel, they have been through the same trauma. That was very helpful, being able to talk.” (Bottomley, 1998, p. 27)	
Becoming empowered	Increasing knowledge	Limited information prior to intervention	“In that workshop... I found out more than I have done in the last probably six years of going through this.” (Martin et al., 2013, p. E19)	[28, 31, 34, 35, 37]
		Information on cancer allays fears	“I know more about the disease and impending treatment. I am not so worried about the side effects now...” (Chow et al., 2014, p. 390)	
	Information on available resources provides reassurance		“The feeling of not being the only one and reassurance of the facilities available, even after discharge.” (Thompson et al., 2014, p. 13)	
		Information provided incrementally	“[T]he information over the four weeks was so helpful and no, there was no information overloaded (sic) – it was given in tolerable dose[s] over the weeks...” (Loh et al., 2011, p. 1493)	
Learning new skills	Goal setting	“[This exercise] actually meant I got off my backside and set myself a goal and said, ‘Right, I’ll try and achieve that.’” (Beckmann et al., 2007, p. 40)	[25–32, 34–36]	

**Table 3** (continued)

Themes (third-order constructs)	Subthemes	Key concepts (translated second-order constructs)	Illustrative quotations from participants (first-order constructs)	Studies that included themes/subthemes
Moving beyond cancer	Regaining confidence and control	Managing negative thoughts	“Thinking a negative thought, I could push it around the other way and think something positive. So it made me train my mind more to not think on the negative aspects of things.” (Bottomley, 1998, p. 27)	[25, 27, 29–31, 34, 35, 37]
		Relaxation techniques	“Whenever I can’t get to sleep, I remember what you taught me. For example, deep breathing exercises help me sleep better... (Chow et al., 2014, p. 390)	
		Diet and exercise	“I’m a non-exercise person actually... but I find that I am now more aware and conscious about exercise and diet...” (Loh et al., 2011, p. 1494)	
		Ongoing practice of self-management skills	“[The intervention] gave me the initiative to do the exercises and breathing and all that, which I still do now.” (Beckmann et al., 2007, p. 40)	
		Take-home materials support skills use	“[The workbook is] one of the greatest gifts I have received, it is my second bible. It has been so helpful, and I will be referring to it often. I feel the workbook was written just for me.” (Cimprich et al., 2005, p. 712)	
		Enhanced self-efficacy	“[A]fter each session I really felt uplifted. I really felt ok we can, I can, step forward. I can move forward and deal with what’s coming at me, or being thrown at me.” (Chambers et al., 2015, p. 66)	
		Greater sense of responsibility	“I have taken responsibility back for my life and am no longer a cancer patient but now a survivor, living a healthy full life.” (Beckmann et al., 2007, p. 40)	
		More proactive	“I’ve learnt to sort of not be so, to procrastinate about things and you know, not let things go and don’t self-diagnose.” (Chambers et al., 2015, p. 66)	
		Improved communication with health professionals	“I was able to refer back to the surgeon during my checkup... like, ‘Ok you removed my lymph nodes? May I know how many you removed? How many was cancerous? Do I have this oestrogen hormone positive, what about my hereceptin status’... things like that you know, which I am now more confident and able to ask...” (Loh et al., 2011, p. 1493)	
		Issues around intervention design - one size does not fit all	Preferences about group composition	
Desire to live life to the fullest	“That is where I was at – where you don’t want to do anything else because your thoughts were always there. ‘What is the point of going on? Why would I do that? There is going to be no tomorrow’. Whereas now I think we are not going to worry too much about tomorrow, we are just going to have a good time today.” (Beckmann et al., 2007, p. 40)			
Reprioritisation	“Without SAMA, I most probably would go into depression. I was crying all the time because of the diagnosis and everything including my marriage was falling apart. Joining SAMA at the right time save[d] my life and I could be independent for my children. I have even gone into advocacy work.” (Loh et al., 2011, p.)			
Positivity and hope	“Knowing others have been hit by this disease and come more or less through it. Confidence in the ‘go forward and enjoy each day’ philosophy.” (Thompson et al., 2014, p. 13)			
Lack of similarity hinders engagement	“The other people were quite nice but I just felt I had nothing in common with them, so I only really went to the one session, because it didn’t seem relevant at all.” (Beckmann et al., 2007, p. 40)			



**Table 3** (continued)

Themes (third-order constructs)	Subthemes	Key concepts (translated second-order constructs)	Illustrative quotations from participants (first-order constructs)	Studies that included themes/subthemes
Personal obstacles to engagement	Preferences about intervention delivery	Desire for closer match between participants	“The first group meeting was a little awkward. It might have been nice to have a closer “match” to other members of the group, i.e. lumpectomy or mastectomy, age and whether they had children or not.” (Cimprich et al., 2005, p. 712)	[25, 29, 33–36]
		Value of diversity in group composition	“I think having longer term survivors...as well as those still undergoing treatment was very helpful... Attendees hung on their every word.” (Risendal et al., 2014, p. 767)	
		Need for support before or during treatment	“That might be a good idea [starting the intervention prior to treatment] because obviously many people would feel apprehensive when you learn you’ve been diagnosed with cancer.” (Kilbourn et al., 2013, p. 197)	
		Need for support immediately post-treatment	“Being a nine-plus year survivor, much of this I learned in the beginning years. I think this would have benefited me more at the front end of survivorship.” (Risendal et al., 2014, p. 767)	
Personal obstacles to engagement	Preferences about intervention content	Preference for face-to-face contacts	“I had a little better understanding and feel; I could relate and communicate better because I had seen my counsellor at least once and she was a persona and not a voice over the phone.” (Kilbourn et al., 2013, p. 197)	[25, 28, 34–36]
		Need for cancer-specific content	“Probably most of the things they talked about I had already looked into and I felt the course wasn’t in enough depth for what I wanted to know... To be helpful for me I needed more specific things.” (Beckmann et al., 2007, p. 40)	
		Need for cancer-specific materials	“I’d have liked to have read about someone my own age who goes down the pub, you know, whose gone through it, you know, typical lad or bloke.” (Martin et al., 2013, p. E20)	
		Desire for coverage of specific cancer-related topics	“I want to know more. For example, the healing time for the abdominal wound, the duration of vaginal bleeding after the operation, and the feelings when stitches removal (sic). These can help to relieve me of doubt and worries.” (Chow et al., 2014, p. 390).	
Personal obstacles to engagement	Practical issues	Low perceived need	“Cause I’ve got great family support. Look, I’ve got a friend that’s going through cancer at the moment, I’m talking with her and I’ve got a friend who survived lung cancer and I talk to her when I wanna talk to someone that’s been there.” (Chambers et al., 2015, p. 67)	[25–27, 31–33, 35–37]
		Reluctance to talk about cancer	“I think I was worried about talking about the diagnosis of cancer and opening up to people and not really knowing what to expect to get out of it, if I were or if I wasn’t, whether I’d be better to stay at home and not get involved in something like that.” (Bottomley, 1998, p. 27)	
		Practical issues	“I have trouble on the phone, I have dreadful trouble with the mobile. Just mainly because of the complications with the hearing.” (Chambers et al., 2015, p. 67)	

their stories with each other and compare their experiences [25, 26, 31, 34–37]. Finding out that they faced similar issues—such as pain, fear of recurrence, altered body image [34], anxiety [37], depression, fatigue or feeling hopeless [25]—was reassuring, as it validated their own experiences of survivorship and helped to normalise what they had been through [25, 26, 31, 34, 35, 37]. These reciprocal exchanges also allowed participants to learn from each others' experiences [31, 34–37]. Hearing about how other people dealt successfully with their cancer, especially those who had more traumatic experiences [35] or were further along in their cancer journey [35, 36], provided them with inspiration to overcome the challenges they faced [31, 34, 35, 37]. For example, Loh and colleagues [34] described how observing the healthy behaviours and upbeat attitude of other participants encouraged breast cancer survivors who took part in their intervention to make positive changes in their own lives. Participants often felt a deep sense of connection and 'togetherness' [37, p. 13] with their fellow cancer survivors as a result of their shared experiences [25, 26, 29–31, 34, 37], and were an important source of companionship and support to each other during the intervention [25, 26, 30, 31, 34] and beyond in some cases [34]. Many expressed a desire for more group discussion time in their interventions [25, 26, 31] in order to facilitate 'a greater degree of social attachment, support and the sharing of experiences' [26, p. 28].

### Interacting with intervention facilitators

Facilitators were an important source of emotional and informational support for participants in both one-on-one [27, 28] and group-based [26, 29, 31, 34–37] interventions. Their knowledge of cancer survivorship and understanding of the various challenges it poses were positively received by participants [27, 28, 31, 37], who valued having the opportunity to ask questions about their illness and its consequences [26, 35, 37] and appreciated their ability to convey information in everyday language [35, 37]. Some commented that they were especially skilled at managing group discussions and ensuring that everyone's voice was heard [35, 36]. Facilitators' empathic interactions with participants helped them to open up about their cancer-related experiences [26–28, 35, 37]. The support and encouragement provided by facilitators in these exchanges had a positive influence on participants' emotional well-being [26–29, 31, 37].

### Having a safe space to talk

Participants noted how the support and understanding provided by peers and/or facilitators helped to foster an open and 'non-stigmatised' [34, p. 1494] environment in which sensitive issues relating to their experiences of cancer—such as recurrence [37], death [27], sexuality [28] or stigma (of lung

cancer) [27]—could be discussed freely and without self-censorship [25–28, 34, 35, 37]. Testicular cancer survivors in Martin and colleagues' [35] study remarked that men rarely talked openly about their experiences, which made this aspect of their intervention particularly important to them. Some participants talked about how their loved ones had trouble understanding or accepting what they were going through [26, 27]; having a 'neutral' [27, p. 66] audience, independent from other sources of support in their lives, with whom they could talk about their experiences was greatly valued.

### *Becoming empowered*

Participants described how engaging with self-management interventions enabled them to become empowered in managing the consequences of their condition and its treatment by equipping them with knowledge and skills and allowing them to regain their confidence and control.

### Increasing knowledge

Participants were often critical of the limited amount of information they received about cancer and its consequences prior to taking part in an intervention [28, 34, 35]; acquiring greater knowledge of their condition was considered an important aspect of their participation [28, 31, 34, 35, 37]. The information they were provided with helped to dispel unhelpful myths about cancer [34] and allay fears about what lay ahead [28, 31, 35, 37], which appeared to reduce anxiety and facilitate a greater sense of control. For participants in two studies [28, 37], finding out more about resources available in the community provided reassurance. Some participants expressed their satisfaction at how information was delivered incrementally over the course of their intervention, which prevented them from becoming overwhelmed [34, 35].

### Learning new skills

Across studies, participants reported receiving education and training in the use of various skills and practices that enhanced their ability to self-manage the consequences of cancer and its treatment [25–32, 34–36]. Goal setting (or action planning) was a central component of several interventions [25, 29, 30, 32, 35, 36]. Learning how to set and monitor progress towards valued goals provided motivation and focus, which was reinforced by feedback received from peers and/or facilitators [32, 35, 36]. Striving towards and successfully attaining goals, no matter how small, boosted participants' confidence and gave them a real sense of achievement [25, 30, 35]. Learning how to manage negative thoughts was another common intervention component [26, 27, 30]. Participants found this practice useful in reframing their illness experiences and putting things into perspective, which helped them to cope better with

challenges [26, 30] and manage their distress more effectively [27]. Self-monitoring of daily activities using observation logs or activity scheduling helped participants to identify any negative patterns in their own thoughts or behaviour and enact changes to break this cycle [26, 29]. Training in relaxation and breathing exercises, which were considered effective in aiding sleep [27, 28], improving mood [27] and providing distraction in potentially stressful situations [26], was also frequently included [25–28, 30, 31]. Advice about diet and exercise was helpful in increasing participants' motivation to maintain a healthy lifestyle [34, 35]. Both breast and testicular cancer survivors commented on the value of receiving training in physical self-examination to detect recurrence [34, 35]. Practicing these self-management skills regularly helped participants to gain confidence in their use and integrate them into their everyday lives [30, 34], while teaching them to friends and family members appeared to further enhance their expertise [30, 31, 34]. Many participants continued to employ the skills learned during their intervention long after its completion [25, 30, 31, 34, 35]. Participants noted that take-home materials such as manuals, factsheets and relaxation tapes were helpful in encouraging and supporting their ongoing use [26, 29, 30, 32, 37].

### Regaining confidence and control

Providing participants with the knowledge and tools to self-manage the impact of cancer more effectively allowed them to regain their confidence and sense of control over their lives [25, 27, 29–31, 34, 35, 37]. Participants found that engaging with a self-management intervention had increased their self-efficacy [27, 30, 34] and given them the motivation and confidence to take responsibility for their own well-being [25, 37] and deal with challenges more proactively [27, 34]. Some participants talked about how they were more confident in communicating with health professionals [34, 37] and making treatment decisions [34] as a result of taking part.

### *Moving beyond cancer*

Taking part in a self-management intervention often acted as a 'major catalyst or turning point' [25, p. 40], giving cancer survivors the impetus needed to move on with their lives [25, 27, 29–31, 34–37]. Having the opportunity to reflect on their experiences in a supportive environment helped them to reach a sense of acceptance about their illness [25, 27, 34, 35]. Rather than remaining focused on cancer, participants were determined to live life to the full [25, 37]. For many, this involved reprioritising their goals and devoting more time to enjoyable activities [26, 30, 31, 34], such as hobbies and interests [30, 31] or volunteering [30, 34], without feeling guilty [30]. Participating in a self-management intervention also

helped survivors to develop a more positive outlook [29, 31, 34, 35, 37] and imbued them with a sense of hope [31, 36].

### *Issues around intervention design—one size does not fit all*

Although study participants were generally very positive about their experiences of taking part in a self-management intervention, certain issues regarding group composition and intervention design, content and delivery appeared to hinder their engagement.

### Preferences about group composition

Cancer survivors' engagement with group-based interventions appeared to be influenced significantly by their preferences regarding group composition [25, 29, 35–37]. Although having the opportunity to share with and learn from others was considered valuable, for some participants the quality of those interactions was contingent upon their perceived similarity to, and ability to identify with, the rest of the group [25, 29, 37]. For example, cancer survivors who attended groups comprising people with different long-term conditions talked about how they struggled to bond with fellow participants whom they perceived not to share the same problems as them [25]. Even within cancer-only groups, factors such as age [29, 37], stage of illness [25] and type of treatment received [29] sometimes impinged on participants' sense of connection with each other. In Beckmann and colleagues' study [25], for example, several participants with positive prognoses disclosed that they felt uncomfortable discussing their problems in front of those whom they perceived to have a worse prognosis. A participant in Cimprich and colleagues' [29] study recommended having a closer 'match' between group members in order to circumvent such discomfort. Conversely, participants in other studies responded well to having a mix of people in their groups. For example, some commented favourably on the presence of people who had completed their treatment several years previously, as they were a source of hope and inspiration [35, 36], with one participant suggesting that 'future classes would benefit by planning for such diversity' [36, p. 767].

### Preferences about intervention delivery

Participants differed in their preferences for the mode and timing of intervention delivery [25, 29, 33–36]. With respect to the most appropriate point in the cancer trajectory at which to offer a self-management intervention, some believed that either before [33–35] or during treatment [34] would be most helpful, as people would be apprehensive at this time [33] and in need of support [34]. Conversely, participants in Beckmann and colleagues' [25] study felt that the information and skills provided by their intervention would be less beneficial for

individuals who were still in the ‘acute’ treatment phase compared with those who were recovering and beginning to move on with their lives. Participants who had completed their primary treatment some time ago appreciated the social aspect of their interventions but felt that the support and education provided would have been more beneficial ‘at the front end of survivorship’ [36, p. 767], when they were less equipped for what lay ahead of them [25, 35, 36]. Conflicting views on mode of delivery were also observed. For example, although the majority of participants in Kilbourn and colleagues’ [33] study were in favour of telephone counselling, some were dissatisfied with its impersonal nature and suggested that meeting their facilitator in person prior to commencement would help them to develop a rapport and improve their overall experience. Similarly, participants in Cimprich and colleagues’ [29] study expressed a preference for face-to-face group sessions over their telephone-based contacts with facilitators.

### Preferences about intervention content

Participants’ observations and suggestions regarding intervention content indicated that it needed to be tailored to their needs as cancer survivors in order to engage them fully [25, 28, 34–36]. In Beckmann and colleagues’ study, for example, the most common reason participants gave for not being completely satisfied with the generic Chronic Disease Self-Management Programme [CDSMP: 38] was that it was ‘not detailed or specific enough’ [25, p. 40] to cancer survivorship. Even those who received a version of the CDSMP adapted for cancer survivors requested more cancer-specific content [36]. This desire for specificity extended to the materials used in interventions [35, 36]. For example, testicular cancer survivors from England who participated in Martin and colleagues’ [35] study stated that the cancer survivors’ stories they were provided with as part of their intervention were ‘too American’ (p. E20) and requested examples they could relate to more easily. In several studies, participants identified additional cancer-related topics they would have liked to have been covered in their interventions, including post-operative care [28], fatigue [36], fear of recurrence [34, 36], cancer-specific dietary advice, complementary therapies, dealing with mortality [25] and the death of fellow participants [34], and coping with late and long-term side effects of treatment [33, 36].

### *Personal obstacles to engagement*

Participants across studies described a number of personal obstacles to engaging fully with self-management interventions [25–27, 31–33, 35–37]. Firstly, some survivors indicated that they were not especially motivated to engage with their interventions as they felt that they received enough support

from family and friends [27, 33] or were already managing the impact of their illness successfully [27, 32, 33]. Others felt apprehensive about discussing their personal experiences of cancer [25, 27, 31], especially in a group setting [26, 35, 37]. Some participants found discussion of topics such as death and dying [26, 37] particularly anxiety-provoking. Participants in Fitch and colleagues’ study [31] asked for greater sensitivity regarding how challenging it could be for cancer survivors to relive their experiences. In Martin and colleagues’ [35] study, participants suggested allowing the opportunity to submit questions to the facilitator anonymously for those who were uncomfortable speaking to the group. Practical issues that participants faced such as hearing difficulties [27], treatment-related side effects, competing activities (e.g. treatment sessions) [33] and travel-related restrictions (e.g. parking, commute time) [36] also curtailed their engagement.

### Discussion

To the authors’ knowledge, this is the first meta-synthesis to explore cancer survivors’ views and experiences of engaging with adjustment-focused self-management interventions. The findings offer further evidence for the benefits of providing education and training in self-management to cancer survivors [8, 9], including gaining support, becoming empowered and moving beyond cancer. Importantly, we have also identified potential barriers to survivors’ engagement with such interventions, which relate to their preferences regarding various aspects of intervention design and personal obstacles such as low perceived need and reticence to talk about cancer experiences. Addressing these in the development and marketing of self-management interventions targeting this population could help increase uptake and improve completion rates.

Overall, our findings provide qualitative support for the effectiveness of adjustment-focused self-management interventions in enhancing important outcomes such as self-efficacy, mood and quality of life among cancer survivors [8, 20]. Participants’ perceived benefits of engaging with such interventions align closely with Foster and Fenlon’s [13] conceptual framework on recovery of health and wellbeing in cancer survivorship. This framework postulates that sources of self-management support (i.e. healthcare workers, family and friends, accessing information, networking with other cancer survivors) and personal strategies for self-managing psychological, physical and social difficulties facilitate the resolution of problems associated with cancer survivorship, thereby enhancing wellbeing. The findings of the present meta-synthesis suggest that engaging with an adjustment-focused self-management intervention may facilitate the process of adaptation through the provision of additional emotional and informational support as well as training in specific self-



management skills. Focusing exclusively on outcomes such as reductions in healthcare costs in evaluations of self-management interventions may disregard their effectiveness in yielding other such benefits in participants' lives [39]. The selection of outcome measures in future trials of interventions should thus reflect what matters to cancer survivors themselves as well as broader economic concerns. Furthermore, including qualitative as well as quantitative components in future evaluations may allow us to discover not only *if*, but also *how*, such interventions and their 'active ingredients' work [10, 40].

Despite these benefits, participants held conflicting views on various intervention characteristics, which appeared to pose potential barriers to their engagement. Indeed, our findings provide further evidence for the limitations of a 'one size fits all' approach to self-management support [10, 40, 41], and demonstrate the need for tailoring the design, content and delivery of self-management interventions to the needs and preferences of specific groups of cancer survivors in order to optimise their 'reach'. Firstly, although participants' views on the value of sharing their experiences with fellow cancer survivors lends further support to the benefits of peer support in this cohort [42, 43], perceived similarity with others (e.g. in terms of age or time since diagnosis) was a key influence on the acceptability of group-based interventions. This corresponds with findings in other long-term conditions [44] and indicates that greater attention should be paid to the influence of group composition and dynamics.

Secondly, conflicting views on the timing of adjustment-focused self-management interventions for cancer survivors as well as their mode of delivery suggest that flexibility and choice is required to optimise engagement. Given that cancer survivors' needs change across the cancer trajectory [45], access to tailored support may need to be available from diagnosis throughout survivorship, for whenever survivors need or are ready to avail of these. Indeed, low perceived need for participation in such an intervention represented a personal obstacle to engagement; the timely availability of the intervention will critically impact such decision making. With regard to mode of delivery, face-to-face group-based intervention designs were the most commonly represented in the present meta-synthesis; little qualitative data was available on perceptions of other delivery modes, although initial evidence suggests that telephone-based interventions were felt to be impersonal by some [29, 33]. Many cancer survivors viewed the opportunity for gaining support as a benefit of taking part in self-management interventions, yet some expressed discomfort in sharing their experiences of cancer with others, particularly in a group setting. Participants in individually delivered interventions appeared to be highly satisfied overall with their experiences, which was aided by facilitators' depth of knowledge regarding cancer survivorship and ability to foster a close therapeutic relationship. This suggests that

well-trained, empathetic facilitators may be able compensate for the absence of peer interaction and provide similar benefits to group-based interventions in terms of emotional and informational support. Given the considerable costs and personnel requirements involved, however, alternative means of delivering self-management support may need to be explored. Given the apparent benefits of eHealth and mHealth interventions in terms of accessibility, health service burden and cost-effectiveness [46], further qualitative research should examine the feasibility and acceptability of online self-management interventions in this cohort; preliminary findings are promising [47].

Thirdly, cancer survivors were keen to receive information specific to their condition, indicating the importance of specificity in intervention content and suggesting that generic self-management programmes might not satisfy their needs. Furthermore, participants across studies highlighted additional issues they would like addressed, suggesting that interventions should allow scope in their design for responding to participants' individual concerns. This could be achieved through the inclusion of open question and answer sessions, for example, or by scheduling sessions in which participants nominate topics to be covered.

Finally, it was found that some participants did not engage with self-management interventions, as they felt that they were receiving enough support from family and friends or were successfully managing the impact of their illness themselves. This points towards the risk inherent in predominant orthodoxies around self-management of assuming that cancer survivors' existing self-management strategies are 'maladaptive' and require external intervention to be deemed 'effective' [48]. Indeed, many individuals with long-term illness develop their own strategies and supports that enable them to manage the consequences of their illness capably on their own, and it should not be assumed that all cancer survivors need to attend, or will necessarily benefit from, formal self-management interventions. The autonomy of people with long-term illness to determine how they should live their own lives must be respected, regardless of any prescribed notions of what constitutes adaptive behaviour [49]. Moreover, it should be acknowledged that responsibility for cancer survivors' wellbeing does not start and end with the individual. Self-management is to a large extent dependent on the supports, work and skills that are mobilized in the process of self-care, especially when it takes place within the home, and is not always possible or appropriate. For example, significant functional disability may inhibit people's ability to self-manage and necessitate their reliance on family members in order to successfully deal with long-term illness and its consequences. Furthermore, self-management occurs in a broader social, political and economic context, and the experience of illness is 'embedded in family, community and societal conditions that shape and influence—and may constrain—the choices people

make, or can make' [50, p. 15]. For example, women tend to carry out the majority of unpaid work in the home (e.g. housework, childcare), which significantly constrains their available free time [51]; this could negatively affect their ability not only to attend such interventions but also to self-manage the consequences of their illness effectively. This may be further complicated by the association of gender with other factors such as age, income, and geographic location, all of which can make it more difficult for people to successfully self-manage. Focusing exclusively on change at an individual level runs the risk of 'blaming the victim' and ignoring larger socio-economic inequalities [52].

### Strengths and limitations

A number of factors relating to the literature on self-management posed difficulties in conducting this meta-synthesis. Firstly, the lack of a 'gold standard' definition for self-management [1] and divergence in the literature around what constitutes a self-management intervention made the study selection process difficult; this was further exacerbated by the fact that interventions promoting self-management are often not referred to explicitly as such [3]. Another factor that hindered our literature search was the poor labelling of qualitative studies in research databases [53]. This was compounded in the present meta-synthesis, as qualitative research on self-management interventions often comprised part of a larger evaluation and therefore did not always feature in the keywords. We overcame these issues by keeping our search terms relating to self-management broad and incorporating a comprehensive qualitative filter combining controlled vocabulary and free-text search terms, resulting in the identification of over 5000 studies for screening.

Despite the large number of studies screened, only 13 met our eligibility criteria. Certain shortcomings of the included studies placed limits on the conclusions we could draw from our synthesis. For example, few reported participants' education levels and cultural background, factors considered to have substantial influence on self-management intervention uptake and effectiveness [54, 55]. It should also be acknowledged that participants in these self-management interventions were inevitably self-recruited to a certain extent, and their views may not be representative of the entire target population. Indeed, previous research indicates that individuals who take part in self-management interventions tend to be younger, white and married, and those who complete their interventions tend to be employed and have fewer depressive symptoms at baseline than those who do not [20]. Our findings should therefore be interpreted with caution, as it is possible that individuals with less positive experiences of the included interventions chose not to participate in the qualitative component of the research or dropped out at an earlier stage. Finally, the majority of included studies were conducted in developed

countries, and the constructs we derived from our synthesis may not be applicable outside of this context. Further qualitative research with more diverse groups is required to explore the influence of factors such as culture and education on cancer survivors' experiences of engaging with self-management interventions.

### Implications for practice

Our findings provide further evidence for the need to develop evidence-based self-management interventions that take into account the specific needs and preferences of a particular target population in their design, delivery and selection of measures by which their effectiveness is evaluated. However, this must be balanced against more practical concerns such as cost-effectiveness, availability of resources and demand for services. It is also critical that self-management interventions are compatible with existing resource infrastructure so that they can be integrated into existing clinical services [56]. Guidelines on the development of self-management interventions for cancer survivors recommend engaging patients and other stakeholders in an iterative process of design, testing and feedback to ensure interventions are effective, clinically feasible and sustainable [20, 56]. The views expressed in the present meta-synthesis about intervention design, delivery and content reinforce the need to take such a 'bottom-up' approach.

Our findings also highlight potential barriers to engagement that should be taken into account in the marketing of self-management interventions. Low uptake of psychosocial or supportive care services is frequently observed among cancer survivors, who often opt to manage their own distress [56]. Careful consideration of how self-management interventions are 'pitched' to cancer survivors is required to overcome such barriers, where possible. For example, a recent synthesis of research on self-management support for men with long-term conditions suggested that marketing interventions as practical and solution-focused may appeal to a broader base [3]. Process evaluations of self-management interventions should seek the views of individuals who choose not to participate in addition to those who do so that we can learn more about potential barriers to engagement for 'hard-to reach' groups and adapt interventions and recruitment strategies accordingly [57, 58].

### Conclusion

Despite growing calls for the development of self-management support for cancer survivors, the existing evidence base has not yet provided much insight into how best to design and deliver interventions to address their distinct needs and preferences. This meta-synthesis found that



participation in adjustment-focused self-management interventions was highly valued by many cancer survivors. Engaging with such interventions offered the opportunity to gain support independent of loved ones in an open, non-judgemental environment, to become empowered by enhancing their knowledge and skills and regaining confidence and control, and to move beyond cancer by accepting their illness experiences, reprioritising their goals and adopting a more positive outlook. Potential barriers to engagement, including issues around intervention design, content and delivery and personal obstacles such as low perceived need and reticence to discuss personal experiences of cancer, were also identified. The findings point towards some key considerations in relation to the development of future self-management interventions for cancer survivors, which may be important in helping to optimize their acceptability.

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#### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** This article does not contain any studies with human participants performed by any of the authors.

#### Appendix. Example of a search strategy (Medline)

Limiters:

- English language
- Humans
- Publication date 1990–current

1. exp neoplasms/
2. (neoplas\* or cancer\* or tumo?r\* or carcino\* or malignan\* or adenocarcinoma\* or lymphoma\* or leuk?emia\* or onco\* or metastat\*).tw
3. 1 or 2
4. exp Self Care/
5. (self adj (care or help or manag\* or direct\* or monitor\* or efficacy)).tw
6. (selfcare or selfhelp or selfmanag\* or selfdirect\* or selfmonitor\* or selfefficacy).tw
7. ((symptom or stress) adj1 manag\*).tw
8. Patient Education as Topic/
9. exp Consumer Participation/
10. ((health or patient\*) adj2 (educat\* or information)).tw
11. ((patient\* or consumer\*) adj (focus\* or cent\* or part\*)).tw
12. exp Behavior Therapy/

13. exp Cognitive Therapy/
14. (cbt).tw
15. exp Adaptation, Psychological/
16. ((psychologic\* or behavio?r\*) adj1 (adjust\* or adapt\*)).tw
17. Social Support/
18. Self-Help Groups/
19. (peer or patient or emotional or social or psychosocial) adj1 (support or group\*).tw
20. (cope\* or coping or psychoeducation\*).tw
21. Holistic Health/
22. (holistic or wholistic).tw
23. Self Efficacy/
24. “Power (Psychology)”/
25. (empower\*).tw
26. ((behavio?r\* or cognitive or psychological or psychosocial or interpersonal or relaxation) adj3 (therap\* or program\* or train\* or instruct\* or workshop)).tw
27. 4–26
28. Interviews as topic/ or interview/ or focus groups/ or narration/ or exp qualitative research/
29. (qualitative or ethnograph\* or phenomenol\* or ethnons\* or grounded theor\* or purposive sample or hermeneutic\* or heuristic\* or semiotics or lived experience\* or narrative\* or life experience\* or cluster sample or action research or observational method or content analysis or thematic analysis or constant comparative method or field stud\* or fieldwork or field work or key informant or theoretical sample or discourse analysis or focus group\* or interview\* or discussion\* or ethnological research or ethnomethodolog\* or mixed model\* or mixed design\* or multiple method\* or multimethod\* or triangulat\*).tw
30. 28 or 29
31. Intervention Studies/ or evaluation studies/ or evaluation studies as topic/ or program evaluation/ or validation studies as topic/ or pilot projects/ or feasibility studies/
32. (pre- adj5 post-).tw
33. (pretest adj5 posttest).tw
34. (program\* adj6 evaluat\*).tw
35. (effectiveness or intervention or pilot or feasibility or process evaluation).tw
36. 31–35
37. 3 and 27 and 30 and 36

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