

Keywords: survivorship care plan; cancer survivorship; follow-up care; psychosocial care; quality of life

Survivorship care plans in cancer: a systematic review of care plan outcomes

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Background: Eight years after the Institute of Medicine recommended survivorship care plans (SCPs) for all cancer survivors, this study systematically reviewed the evidence for their use.

Methods: Studies evaluating outcomes after implementation of SCPs for cancer survivors were identified by searching databases (MEDLINE, EMBASE and Cochrane). Data were extracted and summarised.

Results: Ten prospective studies (2286 survivors) met inclusion criteria (5 randomised controlled trials (RCTs)). Study populations included survivors of breast, gynaecological, colorectal and childhood cancer. Several models of SCP were evaluated (paper based/on-line, oncologist/nurse/primary-care physician-delivered and different templates). No significant effect of SCPs was found on survivor distress, satisfaction with care, cancer-care coordination or oncological outcomes in RCTs. Breast cancer survivors with SCPs were better able to correctly identify the clinician responsible for their follow-up care. One study suggested a positive impact on reducing unmet needs. Levels of survivor satisfaction with, and self-reported understanding of, their SCP were very high. Feasibility was raised by health professionals as a significant barrier, as SCPs took 1–4 h of their time to develop.

Conclusions: Emerging evidence shows very few measurable benefits of SCPs. Survivors reported high levels of satisfaction with SCPs. Resource issues were identified as a significant barrier to implementation.

The many long-term challenges, unmet needs and gaps in care facing cancer survivors were highlighted in the Institute of Medicine's 2006 landmark report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt *et al*, 2006). Issues for survivors include late effects of cancer treatment, lifelong emotional effects and tumour recurrence. The report also outlined service provision issues such as poor coordination of care, lack of communication between health practitioners and patient uncertainty about who is responsible for providing long-term care (Hewitt *et al*, 2006). The 'survivorship care plan' (SCP), an individualised treatment summary and plan for ongoing care, was proposed as a solution to many of these issues. Many cancer treatment guidelines around the world now suggest or recommend that every cancer patient be provided with an SCP at the completion of treatment, and many suggest that this be delivered

in a dedicated appointment with a trained and competent health professional (Hewitt *et al*, 2006; Khatcheressian *et al*, 2006; National Breast and Ovarian Cancer Centre (NBOCC), 2010; Khatcheressian *et al*, 2013; American Society of Clinical Oncology & Cancer.Net, 2013). There is evidence that cancer survivors and their primary-care physicians are receptive to the concept of SCPs and there has also been strong support for them from consumer groups (Hewitt *et al*, 2007; Kantsiper *et al*, 2009; Brennan *et al*, 2011; Livestrong Foundation Livestrong Care Plan (<http://www.livestrongcareplan.org/>); Marbach and Griffle, 2011; Smith *et al*, 2011).

Enthusiasm for SCPs has been tempered by the realisation that their implementation is resource-intensive (Jefford *et al*, 2011; Spain *et al*, 2012; Brothers *et al*, 2013). In the context of looming shortages in the oncology professional workforce, evidence of their

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Received 8 May 2014; revised 28 July 2014; accepted 18 August 2014; published online 14 October 2014

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benefit is crucial to justify recommendations for the routine and universal implementation of SCPs (Erikson *et al*, 2007; Medical Oncology Group of Australia, 2009).

This study systematically reviewed the evidence evaluating outcomes following development and implementation of SCPs in cancer survivorship.

MATERIALS AND METHODS

Studies for this evidence review were identified by searching the literature to the end of June 2013. MEDLINE and EMBASE databases and the Cochrane Database of Systematic Reviews were searched using the keywords 'cancer' and 'care plan', 'survivorship care plan' and 'follow-up care'. Reference lists of background articles and eligible studies were searched to identify additional studies.

Eligibility criteria were as follows: original studies evaluating a standardised written care plan (defined as a structured multifaceted plan for long-term or follow-up care) in cancer survivors (defined as patients having completed treatment for early cancer with curative intent) and reporting quality of life, satisfaction with care or care plan and/or oncological outcomes. Follow-up care was defined as long-term medical care after treatment for early cancer. Studies evaluating care plans that included only one aspect of care (e.g., those evaluating a targeted dietary, psychological or exercise intervention) were not eligible, as the aim was to review the evidence relating to multifaceted care plans. Review articles and those focusing on patients with metastatic cancer were not eligible for inclusion. The screening process is summarised in Figure 1 (PRISMA flowchart) (Liberati *et al*, 2009).

Titles, abstracts and then full-text publications were assessed against the pre-determined eligibility criteria for study inclusion. Unclear cases were discussed and resolved with a second investigator. Data were extracted by two independent reviewers and were summarised in evidence tables. Discrepancies were resolved with review by a third reviewer. Extracted data included information about patient population (cancer type and demographic data), the type of care plan evaluated, outcomes evaluated and results of the study. Each included study was assessed for study quality using the 'QualSyst' tool, a standard checklist of 14 items (Kmet *et al*, 2004). This tool was developed for systematic reviews and used in previous reviews (Kmet *et al*, 2004; St Jacques *et al*, 2008; Agarwal *et al*, 2013; Laidsaar-Powell *et al*, 2013; Wassenaar *et al*, 2014). Each eligible study was given an overall quality score (Kmet *et al*, 2004), independently by two investigators. Items contributing to the quality score included study design, randomisation, outcome measures and analytic methods (Kmet *et al*, 2004). Mean quality scores were reported for each study.

RESULTS

Search results and description of eligible studies. The initial search identified 2262 studies. Of these, seven abstracts met eligibility criteria and all of these remained eligible following review of full-text articles (Oeffinger *et al*, 2010; Grunfeld *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013). Five further studies were identified from reference lists of eligible studies and referenced papers, and all of these were also eligible for inclusion in the final analysis (Grunfeld *et al*, 1996, 1999a, b, 2006; Jefford *et al*, 2011). Three of the 12 eligible studies reported different outcomes of the same randomised trial; hence, these were considered as one study for the purposes of this review (Grunfeld *et al*, 1996, 1999a, b). The findings of 10 studies are

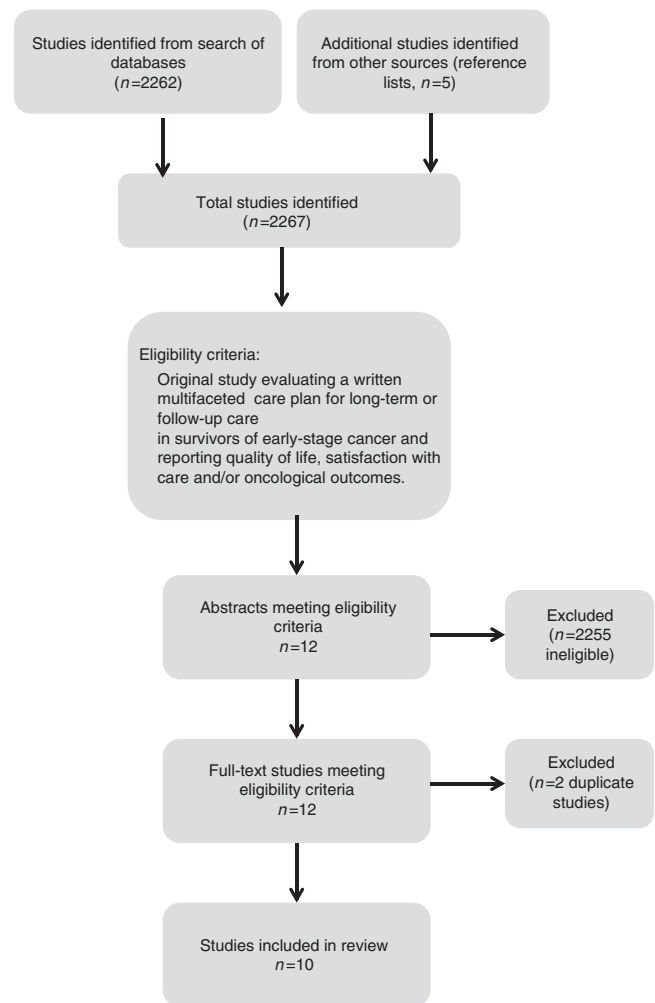


Figure 1. Prisma Flowchart (Liberati *et al*, 2009).

therefore presented (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013). These included 2286 trial participants (mean 254 participants (median 126) in each trial).

All studies were prospective studies of SCPs in cancer survivors (Table 1) (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013). All studies used predominantly quantitative methodology (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013). Five studies evaluated SCPs in survivors of breast cancer (Grunfeld *et al*, 1996, 2006, 2011; Blinder *et al*, 2013; Hershman *et al*, 2013), three in adult survivors of childhood cancers (Oeffinger *et al*, 2010; Blaauwbroek *et al*, 2012; Spain *et al*, 2012) and one each in survivors of gynaecological cancer (Brothers *et al*, 2013) and colorectal cancer (Jefford *et al*, 2011). There were five randomised controlled trials (RCTs) (Grunfeld *et al*, 1996, 2006, 2011; Brothers *et al*, 2013; Hershman *et al*, 2013), four in breast cancer (Grunfeld *et al*, 1996, 2006, 2011; Hershman *et al*, 2013) and one in gynaecological cancer (Brothers *et al*, 2013). The remaining studies were non-randomised observational studies (Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013). Four studies were conducted in the United States (Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013), two in Canada (Grunfeld *et al*, 2006, 2011), one across the

Table 1. Studies reporting outcomes following implementation of SCPs in cancer (grouped by study design and ordered by year of publication)

Author, year (country)	Tumour type	Population	N	Age (years, mean or median)	Description of trial	Description of SCP	Development/introduction of SCP	Quality score, mean ^a
Randomised controlled trials (SCP or no SCP)								
Hershman et al, 2013 (USA)	BC	<6 Weeks post treatment	126	54	Randomised (standard follow-up or standard plus SCP) Questionnaires (0, 3, 6 months) SCP template not described	Paper: 1. Treatment summary 2. Follow-up care plan 3. Late-effects information	Developed and introduced by nurse practitioner and nutritionist in specialised 1-h consultation	0.98 (0.96, 1.00)
Brothers et al, 2013 (USA)	Gynaecologic cancer	<1 Year post treatment	121	60	Randomised to standard follow-up consultation by oncologist or standard consultation plus SCP. Questionnaire after SCP consultation LiveStrong SCP template	Paper SCP: 1. Treatment summary 2. Follow-up care plan 3. Information about survivorship/follow-up	Developed by research assistant Introduced by oncologist (routine consultation)	0.88 (0.81, 0.96)
Grunfeld et al, 2011 (Canada)	BC	≥3 Months post treatment	408	62	All discharged to PCP Randomised (standard oncologist discharge consultation or standard plus SCP with nurse education) Own SCP template developed Questionnaire (12 months)	Paper: SCP plus nurse-delivered educational session: 1. Personal treatment summary 2. Copy of national follow-up guidelines (patient edition) 3. Summary table for follow-up 4. Supportive care resource kit	Developed by oncology nurse/team Introduced by nurse in with survivor	0.94 (0.88, 1.00)
Grunfeld et al, 2006 (Canada)	BC	9–15 Months post diagnosis	968	61	Randomised (standard follow up at hospital (no SCP) or PCP (with SCP)) Own SCP template Questionnaire	Paper SCP: 1. Treatment summary 2. Recommendations for follow-up care 3. Indications for investigation/indications for referral back to cancer centre	Developed by oncology team Mailed to primary-care physician	1.00 (1.00, 1.00)
Grunfeld et al, 1996 (UK)	BC	Survivors (2 hospitals)	296	59/62	Randomised (standard follow-up hospital (no SCP) or PCP (with SCP)) Own SCP template Questionnaire	Paper SCP: 1. Treatment summary 2. Individual follow-up recommendations 3. Handbook on follow-up care	Developed by oncology team Mailed to primary-care physician	1.00 (1.00, 1.00)
Non-randomised prospective studies (whole cohort received SCP)								
Blinder et al, 2013 (USA)	BC	Newly diagnosed All oncologists ASCO BCR Pilot Program Multicentre	174	58	Evaluation of 'treatment plan and summary document' Introduction of survivorship documents at start of chemo (if having chemo) or end of treatment ASCO TPS template Telephone survey after documents received	Paper SCP: 1. Treatment plan (before chemo) 2. Summary document (treatment summary/survivorship recommendations) (given separately or together depending on treatment)	Developed by oncologist Introduced by oncologist in standard treatment or follow-up consultation	0.78 (0.62, 0.94)
Spain et al, 2012 (USA)	Paediatric cancer (adult survivors)	Adult long-term follow-up clinic	111	30	SCP introduced at routine consultation Own template (MSKCC) Telephone survey (1–6 weeks after SCP)	Paper SCP: 1. Treatment summary 2. Follow-up care plan	Developed by medical team Introduced by oncologist in standard consultation	0.82 (0.69, 0.95)
Blaauwbroek et al, 2012 (Netherlands)	Paediatric cancer (adult survivors)	Survivors off-treatment ≥5 years, not in a follow-up programme	73 Survivors; 72 family doctors	38	Evaluation on-line SCP for survivors and PCPs Survivors made appointment with PCP to have care plan implemented	Written web-based plan (on-line and printed book); accessible on line to survivor and PCP) Components: 1. Treatment summary	Developed by specialist oncologist Self-administered website viewed by survivor Directed to survivorship consultation with PCP for	0.72 (0.67, 0.77)

Table 1. (Continued)

Author, year (country)	Tumour type	Population	N	Age (years, mean or median)	Description of trial	Description of SCP	Development/introduction of SCP	Quality score, mean ^a
					Own template/website developed Questionnaire for survivor and PCP	2. Follow-up care plan/late effects monitoring plan	implementation of follow-up plan	
Jefford <i>et al</i> , 2011 (Australia)	CRC	<12 Months after treatment	10	55	SCP/survivorship package introduced by nurse in educational consultation IOM template Questionnaires and interview	Paper: SCP (part of survivorship package) Survivorship package components 1. Survivorship information (DVD, information booklet, question prompt list) 2. SCP, individualised treatment summary and follow-up care plan including supportive care information 3. Nurse-led end-of-treatment consultation 4. 3 Follow-up telephone calls	Developed by oncology nurse/medical team Introduced by nurse at a specialised end-of-treatment consultation	0.61 (0.58, 0.64)
Oeffinger <i>et al</i> , 2010 (USA/Canada)	Paediatric Hodgkin lymphoma (adult survivors)	≥5-Year survivors Elevated risk BC/ cardiomyopathy (multi-institutional database)	72	37	Evaluation of mailed SCP; aim encourage late effects screening (echocardiography/mammography) via PCP Own SCP template Questionnaire (baseline) interview (6 months)	Paper format mailed SCP: 1. Treatment summary 2. Summary late effects 3. Screening recommendations Plus survivorship website	Not reported	0.76 (0.77, 0.75)

Abbreviations: ASCO = American Society of Clinical Oncology; BC = breast cancer; BCR = Breast Cancer Registry; CRC = colorectal cancer; IOM = Institute of Medicine; MSKCC = Memorial Sloan-Kettering Cancer Center; PCP = primary care physician; SCP = survivorship care plan; TPS = treatment plan and summary document.

^aQuality score assessing the scientific quality of study (Kmet *et al*, 2004); maximum score = 1.0.

United States and Canada (Oeffinger *et al*, 2010), one in the United Kingdom (Grunfeld *et al*, 1996), one in the Netherlands (Blaauwbroek *et al*, 2012) and one in Australia (Jefford *et al*, 2011). Heterogeneity was noted in the point in the survivorship trajectory that recruitment occurred. Although one study recruited survivors at diagnosis or during chemotherapy (Blinder *et al*, 2013), there were others that included survivors of breast cancer, who had completed treatment several years before entering the study (Grunfeld *et al*, 1996, 2006, 2011).

The quality scores for the studies reflected the suboptimal methodology of many studies (overall mean score = 0.85, mean for RCTs = 0.96, mean for non-RCTs = 0.74, Table 1). Maximum possible score was 1.0.

SCPs – models evaluated

SCP format and content. Of the 10 studies, 9 evaluated paper-based SCPs (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Jefford *et al*, 2011; Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013) and one evaluated a web-based document (Blaauwbroek *et al*, 2012) (Table 1).

All studies evaluated SCPs that consisted of at least two components: a treatment summary and a plan for long-term follow-up care. Nine of the 10 SCPs were accompanied by other survivorship resources such as booklets, DVDs or websites that contained information about late effects of treatment, supportive care, lifestyle/general health information or copies of follow-up care guidelines (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013).

Most of the SCPs were developed primarily as a resource for cancer survivors (Oeffinger *et al*, 2010; Grunfeld *et al*, 2011; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*,

2013; Brothers *et al*, 2013; Hershman *et al*, 2013). Copies were frequently sent to the primary-care physician, oncologist or other health professionals involved in care, and survivors were encouraged to share their SCP with family and practitioners who may not have been sent a copy.

In two studies, the SCP was developed specifically as a resource for primary-care physicians to facilitate discharge from cancer centre-based follow-up to general practice (Grunfeld *et al*, 1996, 2006). Although these 'discharge plans' may not traditionally be considered to be SCPs, they met the definition of multifaceted plans for long-term care; hence, they were included in the review. These two studies were conducted before the term 'survivorship care plan' was in common use and they are considered to be landmark studies of novel models of follow-up care after cancer treatment (Grunfeld *et al*, 1996, 2006). It should be noted, however, that the effect of the SCPs in these studies is confounded by the fact that survivors with an SCP were followed up in primary care and those without an SCP were followed up in a cancer centre, as the trials were designed to evaluate the practitioner delivering the care rather than the care plan itself (Grunfeld *et al*, 1996, 2006).

Most SCPs for survivors of adult cancers were developed at the end of treatment. The exception was a study that combined a treatment plan developed at the beginning of chemotherapy with an SCP developed separately at the end of treatment (Blinder *et al*, 2013). In the studies of survivors of childhood cancers, one focused on survivors over the age of 18 years, who were already attending a follow-up clinic (Spain *et al*, 2012). The other two included only adult survivors who were treated more than 5 years ago and who were not necessarily attending for follow-up care (Oeffinger *et al*, 2010; Blaauwbroek *et al*, 2012).

SCP development and introduction. Several different models of SCP delivery were evaluated. All SCPs were developed by the

treatment team. Some were delivered to the patient by an oncologist during a normal follow-up visit (Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013) and others were delivered during a specialised educational consultation with a specialist nurse (Grunfeld *et al*, 2011; Jefford *et al*, 2011; Hershman *et al*, 2013). Three were sent by mail, either to the patient (Oeffinger *et al*, 2010) or primary-care physician (Grunfeld *et al*, 1996, 2006), and one was a web-based SCP with log-in details sent to patient and primary-care physician (Blaauwbroek *et al*, 2012).

All SCPs were developed using standardised templates. One study used the American Society of Clinical Oncology SCP template (American Society of Clinical Oncology & Cancer.Net, 2013; Blinder *et al*, 2013), one the LiveStrong SCP template (Brothers *et al*, 2013 and Livestrong Foundation Livestrong Care Plan (<http://www.livestrongcareplan.org/>)), one adapted the Institute of Medicine template (Hewitt *et al*, 2006; Jefford *et al*, 2011) and the remaining studies developed their own template for use in the study and/or for routine institutional use (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Hershman *et al*, 2013).

Outcomes

Randomised controlled trials. There have been five RCTs of SCPs (Grunfeld *et al*, 1996, 2006, 2011; Brothers *et al*, 2013; Hershman *et al*, 2013) (Table 2). The two earliest studies evaluating breast cancer follow-up care in primary care with a standardised follow-up protocol (considered as an SCP) showed no difference in the primary outcomes of cancer recurrence and anxiety/depression, and they concluded that follow-up in primary care with the SCP (rather than in a hospital clinic) is safe (Grunfeld *et al*, 1996, 2006). One of these studies (Grunfeld *et al*, 1996) evaluated satisfaction and economic outcomes (published separately) (Grunfeld *et al*, 1999a, b) and found that patient satisfaction with health care was higher in the primary care/SCP group, and that although more diagnostic tests were ordered in the primary care group, the cost of tests overall was no different and the cost of follow-up to the patient (in the United Kingdom) was less in the primary care/SCP group compared with the hospital group (Grunfeld *et al*, 1999a, b).

A later study by the same investigators evaluated a more formal, individualised SCP, randomising breast cancer survivors receiving follow-up in primary care to receive an SCP or standard (primary) care without the SCP. They found that there was no difference in the primary outcomes of various aspects of health-related quality of life but there was a statistically significant difference in the number of women who correctly identified their primary-care physician as the clinician responsible for their follow-up care, with more women doing so in the SCP group (Grunfeld *et al*, 2011).

A further RCT, also in breast cancer survivors, also found no overall difference in the primary outcomes (Hershman *et al*, 2013). There was a transient decrease in cancer-related anxiety in women in the intervention group but this was not sustained. The study also looked for differences between Hispanic and non-Hispanic survivors, and there was no significant difference between racial groups (Hershman *et al*, 2013).

The remaining RCT was conducted in gynaecological cancer survivors (Brothers *et al*, 2013). It evaluated response to the SCP and perception of care in the consultation wherein the SCP was delivered. It was found that survivors overall were very satisfied with the care and consultation, and that there was no difference between the two groups in any of the outcomes measured (Brothers *et al*, 2013).

The remaining five (non-RCT) studies were prospective studies in which the whole cohort received an SCP (Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013).

Results for individual outcomes are reported below, across all studies.

Health-related quality of life. The effect of SCPs on health-related quality of life (HRQOL) has been assessed in five studies (Grunfeld *et al*, 1996, 2006, 2011; Jefford *et al*, 2011; Hershman *et al*, 2013). Four of these were the RCTs in breast cancer survivors, described in the previous section (Grunfeld *et al*, 1996, 2006, 2011; Hershman *et al*, 2013). No difference was found when measuring HRQOL using SF-36 (Grunfeld *et al*, 1996, 2006, 2011) and FACT-B (Hershman *et al*, 2013). The other study measuring HRQOL in detail was a small ($n=10$) non-randomised pilot study of colorectal cancer survivors receiving an SCP as part of a survivorship package (Jefford *et al*, 2011). In this study there was similar HRQOL before and after implementation, measured by the EORTC QLQ-C30 and QLQ-CR29 (Jefford *et al*, 2011). However, there were fewer unmet needs after implementation of the package using the Cancer Survivors Unmet Needs scale (Jefford *et al*, 2011). The investigators are currently conducting a randomised trial in this Australian population.

Distress/cancer-related distress. The RCTs that included the evaluation of distress in breast cancer survivors found no difference between the SCP and no-SCP groups (Grunfeld *et al*, 1996, 2006, 2011; Hershman *et al*, 2013) measured by the Hospital Anxiety and Depression Scale (Grunfeld *et al*, 1996, 2006) and the Impact of Events Scale (Grunfeld *et al*, 2011). In one of these RCTs, there was a significantly lower level of health worry (measured by the Assessment of Survivor Concerns questionnaire) in the SCP group at 3 months but this was not seen at the 6-month measurement (Hershman *et al*, 2013). There was also no difference in Profile of Mood States score before and after receiving an SCP by mail in a group of adult survivors of childhood cancer considered to be at substantially elevated risk of breast cancer or cardiomyopathy due to previous cancer treatment (Oeffinger *et al*, 2010).

A study in a cohort receiving SCPs found that distress may be lower in survivors with an SCP; 72% of breast cancer patients surveyed after receiving an SCP said it gave them greater peace of mind (measured by a Likert scale developed for the study) (Blinder *et al*, 2013).

However, other studies found that distress may be higher in survivors with an SCP (Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012). In one study, the proportion of colorectal cancer patients experiencing distress increased from 30% at baseline as measured by the Brief Symptom Inventory (BSI-18) to 37% at the second assessment point (Jefford *et al*, 2011). This study also showed a slight increase in distress at follow-up, measured by the Distress Thermometer (Jefford *et al*, 2011). In another study where all participants had an SCP, 17% reported worrying 'frequently' or 'almost constantly' about their health (assessed by one item in the Memorial Symptom Assessment Scale) (Spain *et al*, 2012). Thirty-one per cent of childhood cancer survivors surveyed 2 weeks after receiving an SCP at a routine follow-up visit said that reading the treatment summary and care plan or at least one of its individual sections had caused them distress (Spain *et al*, 2012), and in a study of childhood cancer survivors 20% of those given an on-line SCP said it triggered negative memories (Blaauwbroek *et al*, 2012) and 20% of the related primary care physicians surveyed were concerned that the SCP may trigger negative memories in their patients (Blaauwbroek *et al*, 2012). These studies had a much lower quality score than the RCTs that showed no increase in distress (Table 1).

Survivor satisfaction with care plan. All studies evaluating the overall satisfaction of survivors with their SCP showed very high levels of satisfaction. Colorectal cancer survivors expressed high levels of

Table 2. Outcomes following implementation of SCPs in cancer (grouped by study design and ordered by year of publication)

Author (year)	Description of trial and SCP	Outcomes	Measures	Results	Conclusions
Randomised controlled trials (SCP or no SCP)					
Hershman <i>et al</i> , 2013	BC; standard follow-up or standard plus SCP; <i>n</i> = 126	1.Treatment satisfaction 2.Impact of cancer 3.Health and cancer worry 4.HRQOL 5.Depression 6.Cancer symptoms 7.Ethnicity (Hispanic/non-Hispanic)	FACIT-TS-PS IOC ASC FACT-B CES-D Memorial Symptoms Assessment Scale All measures	No difference No difference Less worry in intervention group at 3 months; did not persist at 6-month evaluation No difference No difference No difference No significant persistent difference	No short-term benefit of SCP (6 months) Decrease in cancer-related worry (did not persist)
Brothers <i>et al</i> , 2013	Gynaecologic cancer; standard consultation or standard plus LiveStrong SCP; <i>n</i> = 121	1.Satisfaction (administrative services) 2.Satisfaction (clinical services) 3.Satisfaction (educational services) 4. Satisfaction (helpfulness of written materials)	Administrative services scale Clinical services scale Educational services scale Helpfulness of Written Materials scale	No difference No difference No difference No difference	No effect of SCP on rating of health services
Grunfeld <i>et al</i> , 2011	BC; usual follow-up (PCP) or usual plus SCP; <i>n</i> = 408	1. Cancer-related distress 2.General distress 3.HRQOL 4.Patient satisfaction 5.Continuity/coordination of care 6.Health service (a) Identify clinician responsible for care (b) Number of visits to oncologist	Impact of events scale POMS SF 36, PCS and MCS MOS-PSQ CCCQ New measure developed Number of visits	No difference No difference No difference No difference No difference SCP group better identified PCP as person responsible for follow-up (<i>P</i> =0.005) No difference	SCPs do not improve PROs. Patients with SCPs are significantly more aware of doctor responsible for follow-up care
Grunfeld <i>et al</i> , 2006	BC; usual follow-up (hospital clinic, no SCP or PCP with SCP); <i>n</i> = 968	1.Recurrence 2.Serious clinical event 3.Death 4.HRQOL 5.Distress	Recurrence rate Event rate Death rate SF-36 HADS	No difference No difference No difference No difference No difference	Serious events rare; equal frequency in both groups BC patients can safely be followed-up by PCP
Grunfeld <i>et al</i> , 1996	BC; randomised to usual follow-up at hospital clinic (no SCP) or follow-up with PCP (with SCP); <i>n</i> = 296	1.Recurrence 2.Time to diagnosis recurrence 3.HRQOL 4.Distress 5.Economic evaluation 6.Satisfaction with care	Recurrence rate Time to recurrence EORTC symptom scale SF-36 HADS Cost calculation UK College of Health	No difference No difference No difference No difference No difference PCP follow-up visits less costly than hospital follow-up; cost of diagnostic tests no diff PCP follow-up higher level of patient satisfaction than hospital follow-up	PCP follow-up no increase in time to diagnosis. No difference in anxiety, or deterioration in HRQOL PCP less costly to patient; no difference in cost of tests PCP follow-up higher satisfaction
Non-randomised prospective studies (whole cohort received SCP)					
Blinder <i>et al</i> , 2013	BC; ASCO template treatment plan and summary document given at consultation; <i>n</i> = 174	1. Perception about communication with and between physicians 2. Perception about peace of mind 3. Perception about using documents in future 4. Perceptions about support 5. Perceptions about preparedness for treatment	Likert scale Likert scale Likert scale Likert scale Likert scale	94% Said helps communication between patient and doctor; 82% between health professionals 72% Greater peace of mind 56% Likely to use again 70% Right amount of support from health professionals; 69% right amount of information about cancer and treatment 96% Understood planned treatment; 96% felt prepared for what to expect from their treatment	Survivors react favourably when treatment plans are personalised and implemented as part of their oncologic care.

Table 2. (Continued)

Author (year)	Description of trial and SCP	Outcomes	Measures	Results	Conclusions
Spain <i>et al</i> , 2012	Paediatric cancer (adult survivors); SCP introduced in consultation; <i>n</i> = 111	1. Retention of documents 2. Understanding of SCP 3. Value of SCP 4. Dissemination of document 5. Concern raised by receiving SCP 6. Worry about health 7. Preferences for format of SCP	Single item Single item Likert scale Single item Single item Memorial Symptom Assessment Scale Preferences for paper form vs wallet card, online, e-mail	95% Retention 95% Reported understanding 93% Moderately or extremely valuable 44% Shared with others in personal circle 14% Caused concern; 86% not 17% Frequent or almost constant worry about health 95% interest in an online or wallet-card version of the treatment summary and care plan	Survivors retain, understand, and value the treatment summary and care plan in a real-world clinic setting Receipt of SCP did not cause worry or concern in majority
Blaauwbroek <i>et al</i> , 2012	Paediatric cancer (adult survivors); web-based SCP for survivor and PCP; <i>n</i> = 73	1. User friendliness (website) 2. Satisfaction (SCP information) 3. Negative memories triggered? 4. Confidence in PCP	Survey Survey Survey Survey	95% Survivors/97% PCPs said user friendly 89% Survivors/100% PCP said info is sufficient 20% Survivors negative memories 82% Survivors/93% PCPs confident	The availability of a web-based personalised SCP facilitates follow-up care in shared-care model (late effect outpatient clinic and PCP) SCP appreciated by survivors
Jefford <i>et al</i> , 2011	CRC; nurse-delivered survivorship package with SCP; <i>n</i> = 10	1. Unmet needs 2. Distress 3. HRQOL 4. Satisfaction 5. Feasibility	CASUN scale BSI-18 EORTC QOL questionnaire QLQ-C30/QLQ-CR29 Survey developed for study Survey developed for study	7 Unmet needs at baseline, 4 at follow-up 30% Distress (baseline); 37% (follow-up) Mean 71 (baseline), 69 (follow-up) High level of survivor satisfaction Feasible but resource intensive	Feasibility confirmed Acceptability confirmed Participants valued all intervention components Resource intensive for health professionals
Oeffinger <i>et al</i> , 2010	Paediatric Hodgkin lymphoma (adult survivors); paper-based SCP mailed to random sample from multi-institutional database; <i>n</i> = 72	1. Use of SCP 2. Screening Practices 3. PCP interest in study	Survey Survey Survey	78% Remembered receiving SCP; half had shared plan with PCP 41% Women had mammogram within 6 months; 20% had recommended echocardiogram; additional 1/3 planned to have recommended testing in the next 6 months Only 19% of PCPs approached by survivors agreed to participate in survey	Feasibility demonstrated Increase screening rates; SCP favorably received. Website did not add value to mailed materials

Abbreviations: ASC = Assessment of Survivor Concerns; BC = breast cancer; BSI = Brief Symptom Inventory; CASUN = Cancer Survivors Unmet Needs; CES-D = Center for Epidemiologic Studies Depression Scale; CCCQ = Continuity/coordination of care; CRC = colorectal cancer; EORTC = European Organisation for Research and Treatment of Cancer; FACT-B = functional assessment of cancer therapy-breast; FACIT-TS-PS = functional assessment of chronic illness therapy-treatment satisfaction patient-satisfaction; HADS = Hospital Anxiety and Depression Scale; HRQOL = health-related quality of life; IOC = Impact of Cancer Scale; MOS-PSQ = Medical Outcomes Study-Patient Satisfaction Questionnaire; PCP = primary care physician; POMS = profile of mood states; PRO = patient reported outcome; SCP = survivorship care plan.

satisfaction in interviews after receiving an SCP in a nurse-led consultation; it was used as part of a survivorship package (including DVD and face-to-face educational session and follow-up phone calls) and participants valued all components of the intervention (Jefford *et al*, 2011). Positive feelings about the SCP were reported in a group of adult survivors of childhood cancer considered to be at substantially elevated risk of breast cancer or cardiomyopathy due to previous cancer treatment (Oeffinger *et al*, 2010).

In one of the RCTs, gynaecological cancer survivors were asked about the helpfulness of written materials that were given at

consultation (including in the intervention arm, the LiveStrong SCP) and there was no difference between the groups in rating of helpfulness (Brothers *et al*, 2013).

In the two studies that asked survivors to rate the amount of information contained in the SCP (Blaauwbroek *et al*, 2012; Spain *et al*, 2012), over 80% of survivors thought the amount of information was right (Blaauwbroek *et al*, 2012; Spain *et al*, 2012); in one of the studies, the primary-care physicians were also asked and 100% were satisfied with the SCP (Blaauwbroek *et al*, 2012).

Understanding of information in the SCP. Survivor understanding of SCP content was assessed in two studies (Spain *et al*, 2012; Blinder *et al*, 2013). In all of these, survivors were asked whether they understood the document, and all reported a high level of perceived understanding. This included self-reported understanding of SCP content in 98% (Blinder *et al*, 2013) of breast cancer survivors and in 95% of childhood cancer survivors (Spain *et al*, 2012).

Patient satisfaction with medical care. In two RCTs in breast cancer survivors, higher levels of satisfaction with many aspects of the overall care and the consultation were seen in women having follow-up in primary care with an SCP compared with those having follow-up care without an SCP at a hospital clinic (Grunfeld *et al*, 1996, 2006). The follow-on study to this showed no difference in these outcomes in the SCP compared with the no-SCP group when all were followed-up in primary care (Grunfeld *et al*, 2011). The other RCTs (in gynaecological cancer and breast cancer survivors) also showed no difference in perception of care evaluated following a single consultation where the SCP or standard care was delivered (Brothers *et al*, 2013) or in satisfaction with care over a 6-month period (Hershman *et al*, 2013). Another study evaluating satisfaction with care found that 70% of breast cancer survivors (all receiving a SCP) surveyed after receiving the plan felt they got the right amount of general support from health professionals; 69% felt they received the right amount of information about cancer and treatment (Blinder *et al*, 2013).

Uptake of recommended screening. One study was designed primarily to assess whether an SCP received by mail would increase uptake of recommended screening for late effects in a group of adult survivors of childhood cancer considered to be at substantially elevated risk of breast cancer or cardiomyopathy due to previous cancer treatment (Oeffinger *et al*, 2010). In this study (where all participants received an SCP), 41% of women had a mammogram within 6 months of receiving the care plan; 20% of survivors had a recommended echocardiogram; and an additional one-third of the group planned to have testing in the next 6 months (Oeffinger *et al*, 2010). It is not clear whether this was an improvement on the screening rate in a similar population without an SCP. No long-term data were provided in any studies; thus, it is unknown whether this will translate to improved survival.

Feasibility. Feasibility and provider time factors were reported in five studies (Grunfeld *et al*, 1999b; Jefford *et al*, 2011; Spain *et al*, 2012; Brothers *et al*, 2013; Hershman *et al*, 2013).

In a pilot study of colorectal cancer survivors, SCP use was considered feasible but resource intensive; it was estimated that 1–1.5 h was required for an oncology nurse to complete SCPs and, in addition, staff with clinical experience had to verify the accuracy of the SCP (Jefford *et al*, 2011). In another study, an SCP developed for adult survivors of childhood cancer was estimated to take the medical team 1–4 h to develop (Spain *et al*, 2012). In the RCT in gynaecological cancer survivors, it took a research assistant an average of 1.5 h (range 1–2) to prepare the SCP (Brothers *et al*, 2013). A further study commented that development of the SCP had a significant cost related to use of health resources but did not quantify this (Hershman *et al*, 2013).

Other outcomes

- **Oncological outcomes:** There was no difference in recurrence (Grunfeld *et al*, 1996, 2006) or serious clinical events (Grunfeld *et al*, 2006) in two RCTs of breast cancer survivors having follow-up with SCP implemented by primary-care physician vs survivors having follow-up in a hospital clinic without SCP (Grunfeld *et al*, 1996, 2006).
- **Survivor perception of care coordination:** There was no difference in an RCT of primary care follow-up with SCP or

no SCP (measured by Continuity/coordination of care questionnaire (Grunfeld *et al*, 2011)).

- **Survivor perception of communication role of SCP:** 94% of breast cancer survivors surveyed after receiving an SCP thought it would be useful for communication between patient and doctor; 82% thought it would improve communication between health professionals (measured by a Likert scale developed for the study) (Blinder *et al*, 2013).
- **Sharing of SCP:** In studies of adult survivors of childhood cancer, 44% (Spain *et al*, 2012) and 50% (Oeffinger *et al*, 2010) said they had shared their SCP with other people in their personal circle, and breast cancer survivors reported using the SCP to facilitate discussions with family members (Blinder *et al*, 2013).

None of the studies included in the review reports long-term outcomes following the implementation of an SCP. This includes an absence of data regarding quality of life/psychosocial outcomes, adherence to recommended screening regimens and long-term recurrence and survival data.

DISCUSSION

This systematic review identified 10 studies (5 of them were RCTs) that met inclusion criteria. Study populations included survivors of breast, gynaecological, colorectal and childhood cancer, and several different models of SCP were evaluated. Although levels of survivor satisfaction with SCPs were very high, no significant effect was found on survivor distress, satisfaction with care, cancer-care coordination or oncological outcomes in the RCTs. One study suggested a positive impact on reducing unmet needs (Jefford *et al*, 2011). Potential harm (increase in distress) was suggested in some non-randomised studies. Resource issues were identified as a significant barrier to implementation.

Two questions arose from the IOM report (Hewitt *et al*, 2006): (1) will treatment summaries and SCPs improve care for cancer survivors and (2) what is the ideal model for implementation of SCPs and their incorporation into routine practice?

In 2006 when the IOM recommended the development of a treatment summary and SCP for every cancer survivor (Hewitt *et al*, 2006), only two of the studies identified in this review (evaluating outcomes of models of survivorship care similar to that proposed by the report) had been published (Grunfeld *et al*, 1996, 2006). Since then, there have been many studies showing that survivors are very enthusiastic about the concept of an SCP (Hewitt *et al*, 2007; Kantsiper *et al*, 2009; Brennan *et al*, 2011; Marbach and Griffle, 2011; Smith *et al*, 2011); this is accompanied by cautious interest from many oncology health professionals (Hewitt *et al*, 2007; Brennan *et al*, 2010) and some concerns from other professionals (Hewitt *et al*, 2007; Kantsiper *et al*, 2009). Many models and methods of delivery have been proposed, and survivor and health provider preferences have been assessed (de Bock *et al*, 2004; Cox *et al*, 2006; Ganz and Hahn, 2008; Greenfield *et al*, 2009; Marbach and Griffle, 2011).

Research has progressed from exploring preferences to focusing on evaluating different models of survivorship care planning.

Despite this burgeoning interest, only 10 studies were identified for inclusion in the current review (Grunfeld *et al*, 1996, 2006, 2011; Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Blinder *et al*, 2013; Brothers *et al*, 2013; Hershman *et al*, 2013). None of the five randomised studies identified found a significant or sustained benefit to quality of life, distress, quality of care/care coordination or oncological outcomes from the SCP. It is unclear from detailed evaluation of these studies whether the failure to detect benefits is due to these SCPs actually not being beneficial, or whether it is related to other factors. Some of these studies may fail to identify the most appropriate outcomes

to evaluate, use of insensitive outcome measures, or fail to include or identify a subgroup of cancer survivors who may benefit from SCPs more than others. Using the example of breast cancer, it is possible that one outcome of an SCP may be better compliance with adjuvant endocrine therapy but this has not been measured. It is also possible, for example, that breast cancer survivors, a group that is overrepresented in the RCTs of SCPs, and a group that is already relatively well informed and well supported, may not be the survivors most likely to benefit from SCPs.

Many of the studies in the review asked survivors for feedback on the SCP they were given (Oeffinger *et al*, 2010; Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012; Brothers *et al*, 2013). The feedback was extremely positive, consistent with the previous background survivorship research showing great enthusiasm for SCPs from cancer survivors. In the studies in this review, survivors reported having a good understanding of the content of the SCP (Spain *et al*, 2012; Blinder *et al*, 2013), valuing and sharing the information with clinicians and family members. These studies suggest that despite having no measureable benefit in RCTs, SCPs appear to be highly valued by survivors. However, as patients and survivors are often very positive about elements of their care, these data are not sufficient to warrant routine use of SCPs.

Several studies have raised the possibility that there may be some harm from SCPs; they may increase distress in some survivors (Jefford *et al*, 2011; Blaauwbroek *et al*, 2012; Spain *et al*, 2012). This must be considered when SCPs are being developed and implemented. It is likely that there are some survivors (possibly 'information-seeking' survivors) more suited to SCP use than others. It also highlights the need for flexibility and survivor input in determining the appropriateness and the content of an SCP.

A 2011 study evaluating the uptake and quality of treatment summaries and SCPs in 13 LiveStrong Centers of Excellence in Cancer Survivorship Network showed relatively poor adherence to IOM recommendations even in dedicated cancer institutes and their affiliated community-based treatment centres (Stricker *et al*, 2011). Less than half of IOM content recommendations for treatment summaries were met (mean 46%) and less than two-thirds of the recommendations for SCPs were met (mean 59%). This suggests that there are significant barriers to the implementation of SCPs even when there is extremely strong commitment to the concept (Stricker *et al*, 2011). Barriers to quality survivorship care were hypothesised to include reimbursement issues, limited institutional resources including personnel, time and information/communications systems (Stricker *et al*, 2011).

The current review has also highlighted resource issues (particularly time) (Grunfeld *et al*, 1999b; Jefford *et al*, 2011; Spain *et al*, 2012; Brothers *et al*, 2013). It was estimated in these studies that the development of an SCP takes at least 1 h (and up to 4 h) regardless of whether it is developed by a doctor, a nurse or a research assistant (Grunfeld *et al*, 1999b; Jefford *et al*, 2011; Spain *et al*, 2012; Brothers *et al*, 2013). Current health-care funding models do not allow for remuneration for this considerable time. The studies in this review suggest that outcomes following delivery of the SCP by nurses (Grunfeld *et al*, 2011; Jefford *et al*, 2011; Hershman *et al*, 2013) and primary-care physicians (Grunfeld *et al*, 1996, 2006, 2011; Blaauwbroek *et al*, 2012) (rather than specialist oncologists), and by mail (Grunfeld *et al*, 1996, 2006; Oeffinger *et al*, 2010) or on-line (Blaauwbroek *et al*, 2012) (rather than in a face-to-face consultation) are similar. This means that it is possible to reduce the burden of SCP development and implementation by oncologists (a scarce resource in many nations) if there are other available and trained health professionals to share the workload.

There is great heterogeneity in the content of SCPs. Assessment of content of care plans, with reference to the IOM recommendations, is an area for further research. This would be aided by a recently published 'score card' for SCP content evaluation (Palmer *et al*, 2014).

At present, there exists a lack of long-term outcome data about the impact of SCPs. It is unknown whether there may be significant benefits later in the survivorship phase of care and it is unknown whether SCPs will change long-term oncological outcomes (recurrence and survival). None of the studies used has an impact on recurrence and/or survival as an aim or an outcome, as SCPs have been developed primarily as a tool to improve psychosocial and care coordination (rather than oncological) outcomes.

This study has several limitations. There is a small body of extremely heterogeneous literature on which to base conclusions and few randomised trials. This has been noted in previous discussions about interpretation of the evidence (Parry *et al*, 2013). The populations represented in the studies have survivors of different tumour types at different stages of survivorship represented. A number of different models of care have been presented, including different SCP templates, formats and methods of delivery. Different outcomes have been evaluated using different measurement tools and it is unclear which tools are most appropriate. The 'ceiling effect' is an additional challenge; for example, in these studies, survivors reported high levels of satisfaction with care before an SCP was introduced, making it difficult to detect an improvement if it existed (Grunfeld *et al*, 1996, 2011; Hershman *et al*, 2013). However, given the diverse needs of cancer survivors and the large spectrum of health environments in which survivors are treated, this heterogeneity also reflects the necessity for survivorship care planning to be adapted to local needs and resources. Reviewing these varied models will aid this process. This would be enhanced by consistency in the approach to planning trials (distinguishing the physical SCP document from the context of its delivery/implementation), consistency in measurement tools and consistency in the description of results (Parry *et al*, 2013).

CONCLUSION

This study has identified and evaluated 10 studies reporting outcomes after implementation of SCPs for cancer survivors. The emerging evidence has shown few measureable benefits to support the use of SCPs (i.e., making survivors more aware of who the clinician responsible for their care is, and possibly reducing unmet needs of some survivors). High levels of survivor satisfaction with SCPs was reported and self-reported levels of understanding were very high. Suggestion of potential harm was found, with some (non-randomised) studies reporting an increase in cancer-related distress. Significant barriers to the implementation of SCPs were identified, including the intense resources required. Further studies of innovative SCP models, evaluating a range of outcomes in various survivor populations and using different outcome measures are required. The long-term effect of SCPs on psychosocial, oncological and resource outcomes should be evaluated. It is unlikely that one model will suit all survivors, cancer centres or tumour types (e.g., younger patients may prefer electronic care plans, and the content may need to focus more on managing endocrine symptoms when treatment-induced premature menopause occurs). Research addressing these variables in a consistent manner is needed.

ACKNOWLEDGEMENTS

This study was supported in part by The Friends of The Mater Foundation, North Sydney, Australia.

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