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REVIEW

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The impact of cancer survivorship care plans on patient and health care provider outcomes: a current perspective

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ABSTRACT

Background: To help the growing number of cancer survivors deal with the challenges of cancer survivorship, survivorship care plans (SCPs) were recommended by the Institute of Medicine (IOM) in 2006. The SCP is a formal document that contains both a tailored treatment summary and a follow-up care plan. Since the IOM recommendation 10 years ago, the implementation in daily clinical practice is minimal. Several studies have investigated the effects of SCPs on patient-reported outcomes and oncology and primary care providers (PCPs), but the quantity and quality of these studies are limited.

Results: The first four randomized trials comparing SCP delivery with usual care failed to show a positive effect on satisfaction with information provision, satisfaction with care, distress or quality of life. SCPs did improve the amount of information provided and communication of PCPs with medical specialists and patients. A recent small trial that changed the focus from SCP as primarily an information delivery intervention to a behavioral intervention did observe positive effects on self-reported health, lower social role limitations and a trend towards greater self-efficacy. Gaps in knowledge about SCPs include uncertainty about content and length of the SCP; whether it should be delivered online or on paper; the timing and frequency of delivery; which health care provide should deliver SCP care. Finally, cost-effectiveness of SCP interventions has received limited attention.

Conclusion: Currently, there is not enough evidence to warrant large-scale implementation of SCPs, or to abandon SCPs altogether. Emphasis on the SCP process and survivor engagement, supporting self-management may be an important way forward in SCP delivery. Whether this is beneficial and cost-effective on the long term and among different groups of cancer survivors needs further investigation.

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As a result of improved early detection, improved treatments and the ageing of the population, the number of cancer survivors is rapidly increasing in developed countries. As many of these cancer survivors continue to live with long-term or late physical and psychosocial effects of their cancer and treatment, it is important to address their specific health care needs [1,2].

Providing tailored information that corresponds to patients' needs is a key factor in the support for cancer survivors during follow-up care [3–5], but unmet information needs are frequently found among cancer survivors [6]. Unmet information needs have been associated with more psychological complaints, and higher levels of anxiety and depression [5].

To help the growing number of cancer survivors deal with the challenges of cancer survivorship, survivorship care plans (SCPs) were recommended by the Institute of Medicine (IOM) in 2006 [2]. The SCP is a formal document that contains both a tailored treatment summary (including information on diagnostic tests, type of cancer, stage, grade, treatment, and contact details of the hospital and specialists), and a follow-up care plan (including information on possible short-term and long-term effects, effects on social and sexual life, signs of recurrence and secondary tumors, rehabilitation, psychosocial support, and supportive care services). SCPs are expected to meet cancer survivors' information needs, to facilitate follow-up care for cancer survivors, and to enable better communication between the health care providers involved in the follow-up care. Based on their face validity, the IOM advised that SCPs should be implemented for all cancer survivors [2].

Since the IOM recommendation 10 years ago, several studies have investigated the effects of SCPs on patient-reported outcomes. In 2015, Mayer and colleagues conducted an integrative review (to summarize evidence from studies with diverse methodologies) that included studies focusing on SCP content, implementation and impact on outcomes [7]. They conclude that although SCP use is endorsed, implementation is not yet widespread and evidence of improved outcomes is limited. Mayer et al. give a comprehensive overview of the current evidence and finally summarize areas for future research that will answer open questions like 'When, how, which, what, whom' to use SCP care. In this current perspective we aim to further the field of SCP care by bringing focus in these areas for future research. Based our own experience of barriers and facilitators in implementing SCP care in the

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pragmatic cluster randomized ROGY Care trial [8], Mayer's review outcomes, and new evidence from the recently published POSTCARE trial [9] we suggest which specific aspects of SCP content and dissemination deserve further investigation. We discuss highest level evidence studies when possible, meaning that we only discuss results of randomized controlled trials (RCTs) if available, and only include outcomes of level II or III evidence studies if RCTs are not available.

Impact of survivorship care plans on patient-reported outcomes

Three early randomized studies [10–12] did not find any differences in satisfaction with care [10–12], distress [12] and quality of life [12] between patients who did or did not receive an SCP. Although these studies provided important first insights into the impact of SCPs, there were limitations in the study designs, including the timing of the intervention and outcomes assessment [13].

The recently published outcomes of our pragmatic cluster randomized ROGY Care trial among 221 endometrial cancer patients revealed that patients in the SCP care arm reported receiving more information about their treatment, other services and different places of care than patients in the usual care arm. However, there were no differences regarding satisfaction with the received information or care. In addition, patients in the SCP care arm experienced more symptoms, were more concerned about their illness, more affected emotionally, and reported more cancer-related contact with their PCP than patients in the usual care arm [8]. A secondary analyses evaluated the impact of an automatically generated paper SCP in patients who searched for disease-related information on the internet and those who did not [14]. Paper SCPs appeared to improve the amount of received information about the disease and medical tests, the helpfulness of the information, and the understanding of the illness for patients who did not search for disease-related information on the internet themselves (n = 141; 64%). In contrast, paper SCPs did not seem beneficial for patients who did search for disease-related information on the internet.

In contrast to the first four SCP trials that failed to have shown impact on patient-reported outcomes, the 2016 published POSTCARE trial among 79 breast cancer patients appeared to have a positive impact on self-reported health, lower social role limitations and a trend towards greater self-efficacy [9]. The POSTCARE trial placed priority on the SCP process and survivor engagement rather than the SCP document. The intervention included a single coaching encounter using motivational interviewing to engage patients in the development of their own SCP. Patients were assisted by a coach to set individual health goals and strategies related to cancer follow-up, surveillance, symptom management and health behavior.

Experiences of survivorship care plan use among oncology providers

Previous studies investigating the views of oncology providers (i.e. medical specialists and oncology nurses) who deliver the SCPs, have found that oncology providers' views regarding SCPs are generally positive [15,16], but implementation of SCPs has been limited [17,18]. Oncology providers experience substantial barriers to SCP use, including finding the time, reimbursement, personnel and resources necessary to create SCPs [18–20]. It has therefore been proposed that automatic generation of SCPs may ease some of the burden on oncology providers [15,21].

Longitudinal evaluation of expectations and experiences of oncology providers in the ROGY Care trial revealed that oncology providers were generally satisfied with the automatically generated SCP [22]. They believed the SCP affected patients positively, and were also motivated to keep using the SCP. Automatic generation of the SCP appeared to improve resources necessary to create SCPs. Nevertheless, most oncology providers (64%) still encountered barriers in providing SCP care in daily clinical practice. The most frequently reported practical barrier was finding the time to discuss the SCP.

Experiences of survivorship care plan use among primary care providers

Transferring routine follow-up care from the medical specialist to the PCP has also been suggested as an important strategy to meet the growing demand for oncology resources [23]. This would require effective sharing of information between medical specialists, PCPs and patients. In the first SCP trial by Grunfeld et al. among 408 breast cancer survivors the SCP did not contribute beyond the control condition in transferring routine follow-up care to primary care [12], although more patients in the intervention arm identified the PCP as primarily responsible for their follow-up care. In the ROGY Care trial SCP care improved the frequency and quality of the communication between the medical specialist and the PCP, and supported the contact of PCPs with patients [24]. This suggests that SCPs may be a useful tool to enable this transition, although in the ROGY Care trial only one third of the PCPs in the SCP care arm indicated having received an SCP. In the POSTCARE trial a greater percentage of the participants in the intervention arm reported an office-confirmed PCP visit and discussion of the SCP with their PCP than the control arm [9]. However, potentially related to the small sample size of this study, the findings did not reach statistical significance.

Should survivorship care plans be implemented for all cancer survivors?

In the US, in order to earn accreditation, the Commission on Cancer (CoC) requires Cancer Programs to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment [25]. However, at present for those in the field who have a choice, we would not recommend to start implementing SCPs for all cancer survivors, based on several considerations. First of all, there is no substantial evidence of a benefit of SCPs. Except for the first positive impact on patient outcomes in the

recently published small POSTCARE trial [9], no differences in satisfaction with information provision [8], satisfaction with care [10–12], distress [12], and quality of life [12] have been found between patients who did or did not receive an SCP. Second, at this point, no definitive statements can be made about the potential negative consequences of SCPs. In the ROGY Care trial, receiving an SCP increased the degree to which the illness was perceived as threatening and the amount of cancer-related contact with the PCP. It is unclear whether these consequences are beneficial, facilitating patients' self-monitoring, or harmful, leading to unnecessary distress and overconsumption of health care. Third, it is unclear whether the effects of SCPs are different for different patients groups. As we observed that outcomes of SCPs are different for patients who do or do not search the internet for disease-related information [14], it is likely that there are more patient characteristics that influence the impact of SCPs. Fourth, cost-effectiveness of the SCP has only been established in one trial, showing that it is costly to introduce on a large scale and not cost-effective [26]. Finally, even if larger scale implementation of SCPs would be warranted, practical barriers, such as time constraints, need to be addressed before SCPs can be more widely adopted. Although SCPs could be automatically generated in the ROGY Care trial, oncology providers still had difficulties finding the time to discuss the SCP with all of their patients.

However, at present, there is also not enough empirical evidence to warrant abandoning SCPs altogether. Essential gaps in the knowledge about SCPs need to be thoroughly examined in future research before conclusive statements can be made. These studies need to evaluate new ways to further decrease barriers and optimize the use of SCPs in clinical practice. Finally, it is possible that so far, no benefits of SCPs have been found, because the influences of the content, length, format and delivery of SCPs on the outcomes of SCPs have received limited attention [7,9].

Survivorship care plan content and length

Previous research indicates that cancer survivors and PCPs have different preferences regarding the content and length of SCPs [7]. In general, cancer survivors prefer more detail rather than less [27], and want more information on health promotion, psychosocial support and other resources [7]. PCPs preferred a more concise SCP that is focused on their specific needs (i.e. focusing on diagnosis, treatment, and possible consequences) [24]. Consequently, it would be problematic to create one SCP that is tailored to both the needs of patients and PCPs [27]. For that reason, it may be better to make different SCPs for patients and PCPs that are tailored to their specific needs.

There is a lack of consensus regarding the optimal content and length of SCPs for patients [27]. If an SCP consists of all components recommended by the IOM, thus containing both a treatment summary and a follow-up care plan it could be up to 20 pages long, depending on a patient's specific situation. However, providing this amount of information, particularly on possible side effects and recurrence of the cancer, may also cause distress in some patients [8]. A study that assessed the effectiveness of a one-page SCP among Hodgkin lymphoma survivors, found that 91% of the patients were positive about the SCP, and that the SCP did not increase patients' tension and anxiety [28]. It is possible that providing a shorter SCP that includes only the most important information may have similar results regarding patients' perceived information provision as a longer SCP, while having less emotional impact on patients. In addition, a shorter SCP may minimize the required resources and may increase the use of the SCP. As the difficulty of implementing SCPs in practice has become more of a concern for clinicians, given that the CoC now requires this for accreditation [25], ASCO has developed a clinical expert statement that defines the minimum elements needed to complete an SCP. This should serve the needs of patients and their families and PCPs caring for those survivors after cancer treatment [29].

Moreover, it may be useful for health care providers to tailor (part of) the content and length of the SCP to patients' individual needs, by asking their patients whether they would like to receive certain information or not. The internet may provide a useful setting for tailoring the content and length of the information provision.

Survivorship care plan format: paper versus online

Although SCPs were originally designed to be printed on paper and delivered by the oncology provider [2], it is also possible to provide patients with access to an online SCP. Online dissemination of SCPs may have several advantages over paper SCPs, such as possibly taking less time for health care providers and making it easier to exchange the SCP between health care providers. In addition, it may be easier to adapt an online SCP to patients' specific information needs, by providing patients with the option to click on more information if they want to, but not to click on information if they do not want to receive the information. To be of added value, the online SCP should entail more than merely providing the content of the paper SCP online. A suggestion would be to provide patients with access to a tailored online portal, where information from different sources is brought together to help these patients find reliable information and resources online. For instance, in addition to access to their own medical file and contact details of the hospital and specialists, the portal could provide access to different online sources of information that are tailored to their specific situation, and direct access to different online services that provide supportive care and psychosocial support.

However, not all patients may benefit from online dissemination of SCPs. For instance, patients who are older, lower educated or do not have a partner or a job are less likely to use the internet [30,31]. Paper SCPs appear to be beneficial for patients who do not search for disease-related information on the internet [14]. Providing an SCP that can only be accessed on the internet may therefore alienate patient groups that actually need the support the most. A recent review [7] showed that both paper and online SCPs are

considered useful by cancer survivors and that some patients prefer to receive both. Based on the current evidence, we would propose that, ideally, health care providers tailor the SCP format to patients' preferences, by asking patients how they would like to receive the SCP: printed on paper, an account that gives access to an online SCP, or both. Future research needs to investigate whether this approach is effective and feasible in routine clinical practice.

Survivorship care plan timing and frequency of delivery

In previous studies, the moment of the delivery of the SCP ranged from newly diagnosed patients to patients who were up to six years post-treatment [8–12]. Although the IOM recommended delivering the SCP at the end of treatment [2], it may be preferable to provide the SCP directly after initial diagnosis, allowing patients to discuss the planned treatment with their oncology providers and family [27]. The POSTCARE trial targeted cancer survivors within one year after the completion of active treatment [9], based on input from survivors which indicated that the acute survivorship transition was the most stressful. The authors suggest that the optimized timing of the support in their trial may have contributed to the positive impact of their intervention.

The impact of the timing of the delivery of an SCP should be further investigated, by comparing whether providing the SCP directly after initial diagnosis leads to different outcomes than providing the SCP at the end of treatment.

Moreover, as patients' need for information may be different at different time points in the follow-up trajectory, a single SCP may not be sufficient. It has therefore been suggested to provide updates of the SCP in follow-up consultations, rather than a single, static SCP [32]. However, it is unclear whether constraints in clinical practice would limit oncology providers' ability to provide these updates. In the ROGY Care trial, a third of the patients in the SCP care arm actually received more than one SCP, suggesting that automatically generating SCP updates from a registration system may ease some of the potential barriers in clinical practice [8]. Nevertheless, it is important to consider that, although updates of the SCP could be provided in the ROGY Care trial, patients still received nearly all of the information in the first SCP. Consequently, patients already received information about possible long-term and late effects directly after initial diagnosis. It may be better to provide the information in the SCP in different parts at different time points, so that patients only receive information that is directly relevant for them at that specific time.

Who should deliver the survivorship care plan?

There is no clear consensus regarding who should develop and provide the SCP [9,27]. In the ROGY Care trial the majority of the oncology providers indicated that the oncology nurse should provide the SCP [22]. As we did not ask the oncology providers about their motivation, their motives for this preference remain unclear. It is possible that oncology providers consider providing the information and follow-up plan in SCPs primarily as a task for oncology nurses. However, it is also possible that this finding partly reflects the perceived time barriers. The recent POSTCARE trial [9] took a radical different approach by emphasizing the care plan delivery as a behavioral intervention, rather than a focus on delivery of information. The survivorship coaching intervention was delivered by master-level mental health care professionals who completed motivational interviewing training. As the POSTCARE trial was the first to show positive patient outcomes, the framing of the SCP within a chronic illness management model that stimulates self-management deserves further research. Cost-effectiveness of the mental health care professional as survivorship transition coach should be further investigated.

Concluding remarks

Using SCPs to help cancer survivors deal with the long-term or late effects of their cancer was proposed by the IOM in 2006. Ten years later, there is not enough evidence to warrant large-scale implementation of SCPs, or to abandon SCPs altogether. Although the first four trials failed to show a positive effect on patient-reported outcomes, SCPs improved the amount of information provided and communication of PCPs with medical specialists and patients. Interestingly, a recent study that changed the focus from SCP as primarily an information delivery intervention to a behavioral intervention revealed the first positive effects on patient outcomes. The emphasis on the SCP process and survivor engagement, supporting self-management may be an important way forward in SCP delivery. Whether this is beneficial and cost-effective on the long term and among different groups of cancer survivors needs further investigation. It is important to bear in mind that SCPs are not a purpose in itself, but merely a possible tool to improve the quality of information provision and follow-up care for cancer survivors.

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References

[1] Ganz PA. Why and how to study the fate of cancer survivors: observations from the clinic and the research laboratory. Eur J Cancer. 2003;39:2136–2141.

[2] Hewitt M, Greenfield S, Stovall E, editors. From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academies Press; 2006.

[3] Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. Ann Oncol. 2011;22:761–772.
[4] Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. Patient Educ Couns. 2005;57:342–349.
[5] Mesters I, van den Borne B, de Boer M, et al. Measuring information needs among cancer patients. Patient Educ Couns. 2001;43:253–262.
[6] Rutten LJ, Arora NK, Bakos AD, et al. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). Patient Educ Couns. 2005;57:250–261.
[7] Mayer DK, Birken SA, K CD, et al. Summing it up: an integrative review of studies of cancer survivorship care plans (2006-2013). Cancer. 2015;121:978–996.
[8] Nicolaije KA, Ezendam NP, Vos MC, et al. Impact of an automatically generated cancer survivorship care plan on patient-reported outcomes in routine clinical practice: longitudinal outcomes of a pragmatic, cluster randomized trial. J Clin Oncol. 2015;33:3550–3559.
[9] Kvale EA, Huang CS, Meneses KM, Demark-Wahnefried W, Bae S, Azuero CB, et al. Patient-centered support in the survivorship care transition: outcomes from the patient-owned survivorship care plan intervention. Cancer. 2016;122:3232–3242.
[10] Brothers BM, Easley A, Salani R, et al. Do survivorship care plans impact patients' evaluations of care? A randomized evaluation with gynecologic oncology patients. Gynecol Oncol. 2013;129:554–558.
[11] Hershman DL, Greenlee H, Awad D, et al. Randomized controlled trial of a clinic-based survivorship intervention following adjuvant therapy in breast cancer survivors. Breast Cancer Res Treat. 2013;138:795–806.
[12] Grunfeld E, Julian JA, Pond G, et al. Evaluating survivorship care plans: results of a randomized, clinical trial of patients with breast cancer. J Clin Oncol. 2011;29:4755–4762.
[13] Smith TJ, Snyder C. Is it time for (survivorship care) plan B? J Clin Oncol. 2011;29:4740–4742.
[14] Nicolaije KA, Ezendam NP, Pijnenborg JM, et al. Paper-based survivorship care plans may be less helpful for cancer patients who search for disease-related information on the internet: results of the Registrationsystem Oncological Gynecology (ROGY) care randomized trial. J Med Internet Res. 2016;18:e162.
[15] Hewitt ME, Bamundo A, Day R, et al. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. J Clin Oncol. 2007;25:2270–2273.
[16] Watson EK, Sugden EM, Rose PW. Views of primary care physicians and oncologists on cancer follow-up initiatives in primary care: an online survey. J Cancer Surviv. 2010;4:159–166.
[17] Forsythe LP, Parry C, Alfano CM, et al. Use of survivorship care plans in the United States: associations with survivorship care. J Natl Cancer Inst. 2013;105:1579–1587.
[18] Birken SA, Mayer DK, Weiner BJ. Survivorship care plans: prevalence and barriers to use. J Cancer Educ. 2013;28:290–296.
[19] Campbell MK, Tessaro I, Gellin M, et al. Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. J Cancer Surviv. 2011;5:271–282.
[20] Stricker CT, Jacobs LA, Risendal B, et al. Survivorship care planning after the institute of medicine recommendations: how are we faring? J Cancer Surviv. 2011;5:358–370.
[21] Earle CC. Long term care planning for cancer survivors: a health services research agenda. J Cancer Surviv. 2007;1:64–74.
[22] Nicolaije KA, Ezendam NP, Vos MC, et al. Oncology providers' evaluation of the use of an automatically generated cancer survivorship care plan: longitudinal results from the ROGY Care trial. J Cancer Surviv. 2014;8:248–259.
[23] Grunfeld E, Levine MN, Julian JA, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. J Clin Oncol. 2006;24:848–855.
[24] Ezendam NP, Nicolaije KA, Kruitwagen RF, et al. Survivorship care plans to inform the primary care physician: results from the ROGY care pragmatic cluster randomized controlled trial. J Cancer Surviv. 2014;8:595–602.
[25] Commission on Cancer ACoS. CANCER PROGRAM STANDARDS: ensuring patient-centered care. Chicago, IL; 2016 Edition.
[26] Coyle D, Grunfeld E, Coyle K, et al. Cost effectiveness of a survivorship care plan for breast cancer survivors. J Oncol Prac/ Am Soc Clin Oncol. 2014;10:e86–e92.
[27] Keesing S, McNamara B, Rosenwax L. Cancer survivors' experiences of using survivorship care plans: a systematic review of qualitative studies. J Cancer Surviv. 2015;9:260–268.
[28] Oeffinger KC, Hudson MM, Mertens AC, et al. Increasing rates of breast cancer and cardiac surveillance among high-risk survivors of childhood Hodgkin lymphoma following a mailed, one-page survivorship care plan. Pediatr Blood Cancer. 2011;56:818–824.
[29] Mayer DK, Nekhlyudov L, Snyder CF, et al. American Society of Clinical Oncology clinical expert statement on cancer survivorship care planning. J Oncol Prac /Am Soc Clin Oncol. 2014;10:345–351.
[30] van de Poll-Franse LV, van Eenbergen MCHJ. Internet use by cancer survivors: current use and future wishes. Support Care Cancer. 2008;16:1189–1195.
[31] Kowalski C, Kahana E, Kuhr K, et al. Changes over time in the utilization of disease-related internet information in newly diagnosed breast cancer patients 2007 to 2013. J Med Internet Res. 2014;16:e195.
[32] Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. J Clin Oncol. 2006;24:5112–5116.