

The Need for Focus on Outcomes and the Role of Informatics

By Ellen Beckjord, PhD, MPH

The articles on survivorship care plans (SCPs) by Coyle et al¹ and Rosales et al² reach different conclusions regarding the value of SCPs. In the Coyle et al study, which examined societal costs and quality-adjusted life-years (QALYs) among 408 survivors of breast cancer who had been part of a randomized trial³ in which SCPs were or were not added to an end-of-treatment discharge visit, SCPs added about \$67 (Canadian) to the cost of the end-of-treatment visit and had no demonstrated impact on QALYs. Rosales et al² describe an observational study of SCP implementation, in which SCP provision occurred as part of a 1-hour interdisciplinary health care visit. Their results for 118 survivors of breast cancer showed that satisfaction with the SCP was extremely high; maintenance of progress toward survivorship wellness goals was good; and the average cost of SCP provision (\$141.73 US) was reimbursable at an average profit margin of 6%.

The Coyle et al and Rosales et al studies are not directly comparable, and there are two factors on which the studies differ that represent critical issues of focus for future research on SCPs. The first factor is the primary outcome measured in relationship to the provision of the SCP; specifically, whether the primary outcome is one that can or should be reasonably expected to change for the cancer survivor as a result of receipt of an SCP. Coyle et al anchor their analysis on QALYs derived from the Short Form-36 general health status questionnaire.⁴ This is a limitation. Although the field should strive to develop models of SCP implementation that ultimately positively affect survivors' health status, we must keep in mind a statement by Parry et al⁵: "care plans are vehicles for communication and coordination of care, nothing more. We cannot expect a document to do the work of a process."^{5(p2651)} Parry et al present a conceptual framework for SCP research that identifies several interim outcomes thought to be potentially affected by the provision of SCPs, including improved patient-provider communication, appropriate use of health care resources, and survivor adherence to surveillance guidelines.⁵ We do not know whether these interim outcomes were positively affected by the SCP intervention in the Coyle et al study, which makes their conclusion that the SCP intervention was not cost-effective premature (for additional discussion about the outcomes of focus in the SCP randomized trial used in the Coyle et al study, please see the article by Stricker et al⁶).

Whereas Coyle et al¹ may have overreached in their choice of primary outcome, Rosales et al² do not reach far enough. Their finding that survivors were highly satisfied with the SCP intervention is consistent with several other articles showing that survivors, as well as their primary care providers, respond favorably to SCPs (eg,⁷⁻¹⁰). The analysis by Rosales et al contributes to the literature by outlining a successful reimbursement pro-

cess for the provision of care plans, but it does not really demonstrate their value over and above the important—but insufficient—outcome that survivors felt satisfied with and supported by the SCP. The Coyle et al article,¹ its parent study,³ and others⁶ have championed the meaningful argument to not invest limited health care resources into SCPs unless they can be demonstrated to have significant impact. To move the field forward, we need more studies that investigate SCP impact and cost-effectiveness that take the rigorous methodological approach used by Coyle et al; that detail reimbursement models in the way done by Rosales et al; and that consider a variety of interim and more distant outcomes as described in the conceptual framework described by Parry et al.⁵

The second factor that differs between the articles by Coyle et al¹ and by Rosales et al² that is critical to the future of SCP research is the role of informatics in the creation of SCPs and their structure. In Coyle et al, the creation of the SCP was based on chart extractions from paper medical records, whereas in Rosales et al, the SCP was derived from an electronic health record (EHR). Rosales et al reported that use of the EHR enabled a registered health information technician to create the SCP in less than 1 hour per patient. Penetration of EHRs in medical systems is quickly growing,¹¹ and it is reasonable to assume that, over time, SCPs will more often be derived from EHRs, thus lowering the resources and costs required to create them. This stands to significantly improve the value proposition of SCPs.

However, perhaps most exciting—and critical to creating SCPs that have a meaningful, positive impact on the lives of cancer survivors—is the role of informatics in the format and structure of the SCP. Both Coyle et al and Rosales et al report on survivor responses to paper-based SCPs. The impact of a document, as noted by Parry et al⁵ is limited. But what if the SCP was more than a document? What if the SCP lived within a consumer health informatics system that enabled the SCP to be dynamic, to respond to the changing needs of the survivor over time and push recommendations and actionable feedback to the survivor to optimize their health and wellness? Hesse et al^{12,13} have articulated an innovative vision for informatics-enabled interventions in survivorship¹² and have described several use-cases for ways that informatics can be a foundation for enabling highly personalized and responsive cancer care.¹³ Realizing this potential will admittedly require improvements in data liquidity,¹⁴ both with respect to the nimble movement of data between an EHR and an SCP, and between the SCP and the survivor's response to it, whether measured actively (eg, self-reports of symptoms via surveys or ecological momentary assessment¹⁵ or passively [eg, weight monitoring via a wireless scale that communicates with the EHR and SCP]). Some data

exist on survivor responses to informatics-enabled SCPs,^{7,16} although this is a growing area of inquiry. Additionally, it should be noted that even an informatics-based SCP should not be divorced from a care planning context that includes clinical encounters such as those described by Coyle et al¹ and by Rosales et al.² Data suggest that survivors prefer to receive an SCP in the context of survivorship care delivery,¹⁰ and informatics is more often positioned to enhance, rather than eclipse, existing processes of care. Survivors who prefer a paper-based SCP should have their preferences respected; however, it is possible that, over time, with the growing adoption of mobile devices,¹⁷ survivors will prefer—and expect—an informatics-enabled SCP that responds to their needs over time and provides actionable feedback toward achieving and maintaining health and wellness.

With this future in mind, one in which the ways that SCPs are created and delivered will be different from what is described in the articles either by Coyle et al¹ or by Rosales et al,² we should commit to continue to study how to optimize the impact and cost-effectiveness of SCPs and be cautious about drawing conclusions using data on the basis of processes that are sure to change. Although SCPs have been deemed an essential element of survivorship care,¹⁸ adoption will be slow until their benefits are clearly demonstrated and their implementation positively, rather than negatively, affects efficiency in the health

care system.¹⁹ As with many facets of health and health care, there is reason to be hopeful about the potential of health informatics to improve the benefits of SCPs and the efficiency of their use. That potential will be demonstrated through continued research by those who care deeply about the growing population of cancer survivors.

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Corresponding author: Ellen Beckjord, PhD, MPH, University of Pittsburgh, Biobehavioral Medicine in Oncology Program, University of Pittsburgh Cancer Institute, 5115 Centre Avenue, Suite 140, Pittsburgh, PA; e-mail: beckjorde@upmc.edu.

Ellen Beckjord, PhD, MPH, is Assistant Professor, Department of Psychiatry and Biobehavioral Medicine, University of Pittsburgh, Biobehavioral Medicine in Oncology Program, University of Pittsburgh Cancer Institute.

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