Survivorship care after testicular cancer
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Easy navigating through the forest of survivorship care

Chapter 6

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Comment on:
Carla Parry, Erin E. Kent, Laura P. Forsythe, Catherine M. Alfano and Julia H. Rowland, Can’t See the Forest for the Care Plan: A Call to Revisit the Context of Care Planning, 2013, J Clin Oncol. 31: 2651-3
To the editor

With great interest we have read the article by Carla Parry and colleagues. Based on the report of the Institute of Medicine Committee on Survivorship Care and, more recently, the ASCO Survivorship Care statement, it is strongly recommended to provide cancer patients with a treatment summary and follow-up plan to guide their necessary aftercare.\(^1,2\) Parry et al. clearly state that experiences with survivorship care plans (SCPs) up to now have had limited success.\(^3,4\) Survivors of adult-onset cancers often lack a high-quality health care plan. Moreover, SCP's are not integrated well into processes of care coordination. By focusing too much on the care plan as a document summarizing the treatment we tend to forget the primary goal of a plan in general: guiding follow-up care to ensure that survivors receive the appropriate care after cancer treatment.

Parry et al. propose a very elucidating conceptual framework based on the past years of survivorship care research and organization (figure 1). They advocate the embedding of SCP's within the context of models of care, processes of care, and technology platforms. Contemporary technology platforms should be used to generate and share SCP's and support patient-centered care planning and patient-provider communication.

We absolutely embrace this idea of integrating electronically available information in the process of compiling SCPs. Many of the theoretical concepts that comprise the framework of Parry et al. are put into practice in the Survivor App, a mobile application we recently developed\(^5\) (Figure 1). The Survivor App serves as a carrier for a digital personal SCP. Patients become increasingly accustomed to handling digital data by using websites and smartphones. With this personal SCP at their fingertips, the survivors not only know what care needs to be provided, but also when, where and by whom (e.g. oncologist, nurse practitioner or primary care physician).

Currently, the generation of SCPs is the limiting step in the organization of patient-centered survivorship care. Patients receive complex cancer treatments with known late effects but resources are often simply insufficient to summarize this information in patient-friendly documents. Collecting relevant diagnosis and treatment data and reporting this in a paper document is a time-consuming process. In addition, even if these documents can be provided they often lack time-specific follow-up plans, which impairs care coordination between patients and multiple care providers.

For this Survivor App a selection of relevant data is derived by the treating oncologist from the patients' health records. The data is entered in a web-based plan generator. Algorithms based on existing guidelines are used to personalize care plans depending on the individual diagnosis, co-morbidity and treatment characteristics. The data is subsequently encoded in a QR code that can be scanned with the Survivor App by the patient, directly from the computer screen of their oncologist. This technology not only ensures convenient data transfer from physician to patient, but also limits security risks. The technology can be made available to oncology centers in the Netherlands and other countries. The SCP can be printed on paper for patients without a smartphone.

During follow-up, the Survivor App allows patients to keep track of different appointments. This enables patients to be optimally in control and co-manage their own follow-up and offers the
possibilities of individualized education and healthy lifestyle support. The information describes
the goal of follow-up assessments and redirects to online resources and communities.

Parry et al. underscore the importance of evaluation of survivorship care. This app is
being evaluated as part of a trial of a shared-care survivorship care program for testicular cancer
patients who are subjected to an intense follow-up schedule after treatment with chemotherapy
for metastatic disease (ClinicalTrials.gov ID NCT01783145). Both the patients’ primary care
physician and oncologist receive a copy of the SCP, extended with additional information on
patterns of disease recurrence, late effects, and cardiovascular risk management. Due to the long-
standing curability of testicular cancer, the research on late effects of treatment in these survivors
is extensive and well-organized. Testicular cancer patients still function as a model for a curative
treatment of advanced cancer.

The steadily growing population of cancer survivors should have the best available
survivorship care. Simple and smart instruments like the Survivor App can help survivors easy
navigate their follow-up based on a personal plan, which is executed in conjunction with other
caregivers. As such, the Survivor App fits perfectly into the Parry framework. Survivor care should
combine the expertise of several disciplines. This app will accommodate easy navigation through
the “forest of survivorship care” with the patient in control.
Easy navigating through the forest of survivorship care

Figure 1. Parry’s conceptual framework put into practice.

Frame of work by Parry et al.

- Processes of Care
- Testicular cancer
- End-of-treatment summary
- Care plan is discussed with patient at start of follow-up

- Models of Care
- Shared-care follow-up or oncologist-only
- In shared-care oncologist visits are alternated with family doctor visits

- Technology Platforms
- Web-based survivorship care plan generator
- iPhone app for patients as carrier for plan
- Plan is imported via QR-code

Application by Boer et al.

- Generation
  - Processes of Care
    - Testicular cancer
  - Models of Care
    - Shared-care follow-up or oncologist-only
  - Technology Platforms
    - Web-based survivorship care plan generator
    - iPhone app for patients as carrier for plan

- Navigation
  - What, when, where and by whom?
  - Care plan enables patient to navigate through survivor care
  - Patient is provided with overview of follow-up:
    - Oncological surveillance
    - Management of long-term and late effects

- Evaluation
  - Adherence and management
    - Adherence to surveillance and adjunct treatment guidelines
    - Management of long-term effects
    - Proportion of intervention for late effects
    - Management of comorbid conditions
  - Health care resource use
    - Appropriateness
    - Duplication of services
  - Organizational effects
    - Processes required to implement
  - Costs
    - Patient/family, provider, systems, payers
  - Evaluation of the model of care
    - Evaluation of the model of care and prevention of duplication of services
    - Psychosocial interventions based on questionnaires

Interventions
- Cardiovascular risk factor management
- Psychosocial interventions

Illustration of the end-of-treatment summary (●) and survivorship care plan (●)
Chapter 6

References
