

Recommendations for implementing and delivering shared survivorship care

Full Version

1. Background and Purpose

Survivorship care that is shared between primary care and oncology providers may be a suitable model to care for the growing population of cancer survivors, however recommendations supporting implementation of shared care are lacking. The Australian Cancer Survivorship Centre (ACSC) undertook a rigorous exploration of facilitators and barriers to the implementation, delivery and sustainability of shared survivorship care via systematic review and qualitative enquiry. Outcomes were translated into practice and policy recommendations to support broader implementation of the shared care model.

2. Approach

Systematic Review

The systematic review included both qualitative and quantitative studies addressing shared cancer care. MEDLINE, Embase and Emcare databases were searched in June 2019, with 13 papers (10 qualitative, 3 quantitative) ultimately included. Data were extracted and synthesised using a mixed methods approach. Key themes included the perceived lack of knowledge and need for further training for general practitioners (GPs), the importance of clearly defined roles for each health care professional (HCP) in the shared care team, the requirement for rapid, reliable and accurate channels of communication between providers, and the role of survivorship care plans (SCPs) and electronic medical records as communications tools.

Qualitative Study

ACSC researchers conducted semi-structured focus groups with a total of 22 HCPs, representing both oncology and primary care-based providers. Data were analysed by inductive thematic analysis, with 22 themes developed under the broader categories of 1) considerations for HCPs; 2) considerations regarding patients; 3) considerations for planning process; and 4) policy implications. There was substantial agreement between the findings of the review and the qualitative study. Unique themes from the qualitative study included stratification of patients suitable for shared care, strategies to engage HCPs with shared care models, and ongoing collection of outcome data to allow for evaluation and improvement. Policy implications included sustainable funding mechanisms and development of policy to support a consistent shared care model.

Expert Consultation

Based on the systematic review and qualitative study, a draft list of 33 recommendations regarding implementation of shared survivorship care were developed. The combined results of the project as well as the recommendations were presented to a multidisciplinary group of 40 HCPs active in cancer survivorship participating in a Victorian Survivorship Community of Practice event in December 2019. Participants were asked to rate each recommendation on a five point scale from 1 – not at all important to 5 – essential. Results were collated and recommendations that were endorsed (rated as very important or essential) by 75% or more of participants were included in the final guidance document.

3. Recommendations for Implementation of Shared Care

Eighteen final recommendations for implementation of shared survivorship care between oncology and primary care providers are listed below. The recommendations are listed under four headings regarding relevance for planning, design and process, HCPs, patients, and policy. Providers seeking to implement shared survivorship care may wish to apply these recommendations to their setting.

PLANNING, DESIGN AND PROCESS

- 1. Undertake engagement activities with both oncology providers and GPs prior to implementation.** A lack of engagement from HCPs across both oncology and primary care settings may pose a challenge to implementation of shared care, therefore undertaking engagement activities with HCPs prior to implementations is recommended. Engagement activities may vary and be targeted to specific settings or stakeholder groups. For example, engagement activities for hospital-based HCPs may include presentations at multidisciplinary meetings (MDMs), marketing the benefits of shared care such as improved efficiency and easing the pressure on busy clinics. For primary care providers, including GPs and practice nurses, running information sessions, involving primary care providers in hospital placements or engaging HCPs through one-to-one relationship building may be considered.
- 2. Identify one or more senior clinical leads to act as champion for shared care.** Shared care champions may support implementation by taking ownership and responsibility for implementation and adoption of a shared care model, and providing leadership and setting an example for others in a clinical setting. HCPs may have different preferences for how they care for patients; having one or more senior clinical leads acting as a shared care champion may be a suitable approach to manage individual provider preferences, advocate for shared care and lead by example. Shared care champions may advocate for shared care in other settings, for example advocating for policy or funding changes.

3. **Establish rapid referral pathways to oncology providers if recurrence or other serious events are suspected.** It is essential that rapid re-access pathways for patients back to oncology providers are available should a recurrence or other serious event be suspected. Rapid referral pathways may increase confidence of both GPs and patients in shared care, as they may feel reassured that if a recurrence or serious event occurs they will not experience delays in accessing required care. Rapid re-access procedures should be clearly documented in a SCP and communicated with patients.
4. **Establish effective administration systems and processes to support shared care.** Implementation of shared care requires sound administrative support systems to facilitate appointments, keep track of follow-up schedules and any surveillance tests that may be required, scan and store documentation, and to prepare and share required documentation to all providers and patients. Without established administrative support or dedicated and protected time of appropriate staff to carry out administrative tasks, these tasks may over-burden existing staff or take time away from clinical roles. Effective administration systems and processes may also protect against patients being lost to follow-up.
5. **Consider a dedicated care coordinator role to enable shared care.** Designating a dedicated care coordinator role to facilitate shared care may be useful. A care coordinator may carry out critical tasks to support shared care, including scheduling appointments, generating SCPs, advising and educating patients, and facilitating communication between different providers.

HEALTH CARE PROFESSIONALS

6. **GPs should be involved as part of the shared care team from the point of diagnosis onwards.** Having a patient's GP included in the care team from the beginning of a patient's cancer journey may increase patient trust and confidence that their GP is able to provide their follow-up cancer care, and also reassure them that their oncology providers and GPs talk to each other. Involving GPs in a shared care team may include GPs attending or dialling in to MDMs if this is practical.
7. **Provide a direct line of communication between primary care and oncology providers.** Shared care relies on rapid and reliable communication between members of a shared care team. Sending letters via post or information by fax may not be suitable if quick or urgent advice or information is needed. HCPs may value direct phone numbers or email addresses to other members of a shared care team, and these should be provided where possible. It is important to avoid placing responsibility for communication between providers in a shared care team on to the patient.

8. **GPs should be provided with information about patients' diagnoses, treatment history, and expected side effects.** It is important that GPs know the details of a patient's cancer diagnosis and treatment history in order to provide appropriate care. Ideally, this information should be provided by the cancer team in a written format directly to the GP, and may be in a treatment summary, letter or as part of a SCP that is also shared with the patient.
9. **GPs should be provided with clear and concise guidance regarding cancer follow-up care, including timelines, actions required and re-entry procedures if recurrence is suspected.** GPs having access to current guidance regarding cancer follow-up schedules and referral pathways back to cancer services is essential. Having clear and consistent guidance regarding cancer follow-up care ensures that all members of a shared care team are aware of what follow-up care should be provided and when. Guidance may be communicated in a letter or SCP, or may be accessible online. Where complex or lengthy information is provided, it may be useful to include a more concise summary of key points to make it easier and quicker for GPs to readily access the most important information.

PATIENTS

10. **Consider which patients might be suitable for shared care based on factors such as risk of recurrence or new cancers, persistent, complex side effects, personal circumstances and capacity for self-management.** Not all patients will be appropriate for shared care, and it is important to assess patients based on their risk factors and personal circumstances to determine if shared care is a suitable model. Recognising that patient's circumstances and risk profiles may change, it is important to re-assess patients over time (as deemed appropriate depending on the context) and change the model of care if suitable.
11. **Engage patients in shared care by promoting and communicating the benefits of shared follow-up, such as greater continuity of care with their GP, reduced travel and waiting times.** Some patients may be reluctant to reduce contacts with their oncology team once treatment finishes. Others may perceive shared care or follow-up for their cancer in a primary care setting as inferior to receiving follow-up by their oncology providers. Communicating the benefits of shared care may increase patients' acceptance of the model. Educating patients on the role of their GP in their follow-up care and setting realistic expectations for follow-up may also be increase patients' acceptance of shared care.

12. **Discuss shared care with patients early so they know to expect shared care and consider this standard.** Some patients may feel 'abandoned' by their oncology providers at the end of treatment; introducing shared care and increased involvement of their GP at the end of treatment may contribute to feelings of abandonment. Preparing patients for shared care earlier (prior to the end of treatment) may mitigate this issue. It is however not recommended to have this discussion at diagnosis when a patient may already be overwhelmed with information. When this discussion occurs, it is important for oncology providers to ask patients about their GP; if patients do not have a known or trusted GP, it may be helpful to work with the patient to find a suitable GP for shared care.
13. **Educate patients on which HCP to see for different issues they may experience.** It may not be clear to patients if they should see their oncology provider or primary care provider for various issues or concerns. Educating patients on the roles of their respective providers in their follow-up and providing information regarding which provider to see for different issues or concerns they may experience, whether these are related to their cancer or not, may reduce any uncertainty. Role delineation might be defined within the SCP.
14. **Provide information resources to patients, but avoid overwhelming patients with too much information.** Patients will have different levels of need or desire for information, different levels of literacy and health literacy, and preferences for how they want to receive information about their survivorship care. It is helpful to tailor the information given to patients in response to individual needs rather than providing all patients with the same information. It is also important to consider the needs of different patient groups (for example based on language spoken, cultural background, sexual orientation etc.) and availability of suitable resources when planning shared care. Critical information that must be provided to all patients includes contact details for each of their providers.

POLICY

- 15. Define outcome measures to evaluate effectiveness and cost-effectiveness of shared care, and determine processes for regular and accurate data collection.** To support a sustainable shared care model, data regarding shared care (for example the number of patients managed through shared care), the effectiveness of shared care (where effectiveness may be measured by adherence to follow-up and other clinical care processes, patient-reported outcomes such as quality of life and unmet needs, patient experiences of care etc.), costs of shared care, and any other outcome deemed relevant or appropriate given the context, should be collected. It is important that outcomes to be measured are discussed and agreed upon by relevant stakeholders, and that processes are in place for collection of accurate and reliable data over time. Longitudinal data may be used for quality improvement activities, benchmarking, and may be leveraged to embed shared care as a standard model. Regular stakeholder feedback or evaluation may also be considered to facilitate continual improvement and refinement of the shared care model.
- 16. Establish consistent policy and guidelines regarding shared care and SCPs to reduce variation across settings.** Policy that mandates shared care (either at a health service or health system level) as the standard model of follow-up care may reduce fragmentation and inconsistency in care across different settings. Standard processes across different health services, cancer types and institutions will facilitate shared care. This may include consistency in structure and content of SCPs.
- 17. Advocate for a policy environment that supports shared care as standard care.** Shared care for cancer survivors is not the standard of care in Australia. Until there is policy to support shared care as standard care, shared care will continue to be implemented inconsistently and will not be available to most patients.
- 18. Advocate for sustainable funding mechanisms to support shared care.** A major challenge for implementation and sustainability of shared care is access to funding. Sustained or long-term funding is required to fund secure and protected roles that are needed to provide shared care, rather than shorter-term funding for finite 'projects' implementing shared care. This may also include advocating for compensation mechanisms for GPs providing shared care.

**This is a full version of recommendations for implementing shared survivorship care.
A two-page summary version of these recommendations is available at
petermac.org/acsc/hp/models-care.**

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