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RESEARCH ARTICLES

A quality improvement pilot to initiate treatment summaries and survivorship care plans in oncology services in South Australia

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ABSTRACT

Aim: To review, test and refine standardised tools for nurses to initiate treatment summaries and care plans, and identify barriers and enablers to providing them.

Background: This paper reports on a pilot study informed by the development of a Survivorship Framework in South Australia.

Methods: Expression of interest was sought for adult medical oncology services to pilot standardised tools within existing services and resources. A quality improvement approach was used over three months with nurse practitioners and nurse practitioner candidates to obtain feedback, refine tools and resources, and identify barriers and enablers. Quantitative and qualitative data was recorded at each site using spreadsheets, at fortnightly meetings, and at a final debriefing. Content analysis was used to identify key themes in the context of barriers and enablers.

Findings: Four medical oncology clinics in South Australia participated (three metropolitan, one regional). Forty-three consultations were delivered at three sites. Barriers included time to complete documentation, perceived knowledge and skills, re-orientation of clinics and referral

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pathways, competing service priorities and lack of administrative support. Enablers included interrelationships within and between pilot teams, supporting resources, and increased familiarity with tools.

Discussion and conclusion: There is potential for nurses to initiate treatment summaries and care plans in the treatment setting with the use of standardised tools. Further refinements are needed to make the process less time burdensome, additional specialised training is needed to improve confidence of nurses to work in a wellness model, and numerous system challenges need to be overcome to improve overall feasibility of using standardised tools to provide survivorship support to patients. Lack of systems to populate information, and lack of referral processes to support survivorship discussions with patients are likely to limit the initiation of survivorship care in treatment settings in South Australia. Further nurse-led development of tools for treatment summaries and care plans should occur in parallel with translational research designed to address system challenges.

Key words: Survivorship; care plans; treatment summary; implementation; medical oncology; South Australia

What is already known about the topic?

Structured survivorship care is recommended to facilitate the individual follow-up needs, health and wellness of people treated for cancer.

Many health services are grappling with the challenge of delivering survivorship care in a sustainable way. It is clear that embedding survivorship care routinely and at scale presents a significant implementation challenge for oncology services.

What this paper adds:

Nurses are well placed to lead the initiation of treatment summaries and care plans, however, this pilot provides real-world insight into the system and practical challenges that need to be addressed to provide essential components of survivorship care in South Australia.

BACKGROUND

As more people are living longer following cancer treatment, health services must address how to best manage the consequences of cancer and its treatment in coordination with other care providers.[1] The structured delivery of information that includes a summary of the treatment received (treatment summary, TS) and a plan for follow-up care (care plan, CP) has been recommended to support care coordination and facilitate transition from regular contact with the treatment team to follow-up care that can be delivered by other health professionals within and external to the treatment setting.[1-3] The initiation of a TS and CP led by nurses within the treatment setting is the focus of the present paper.

Although our understanding of the efficacy and effectiveness of TSs and CPs is still emerging [4,5] many organisations and professional bodies in the United States, Europe and Australia recommend that TS and CPs are initiated in the treatment setting. [6-12] Despite endorsement to do so, there exists a gap between recommendations and uptake of TSs and CPs into practice [13,14] due to issues such as organisational support, funding and resources, and expertise of staff. [3,15,16] Educational sessions with a specialist nurse are amongst the models that have been evaluated in research settings but there is little understanding of the tools required to assist nurses with this task in routine care across diverse settings.[17] The development of appropriate tools and identification of barriers and enablers to delivery are therefore important in building the evidence to enable the design and scale up of survivorship care in local contexts.

To progress the delivery of survivorship care in South Australia (SA), the National Cancer Expert Reference Group commissioned the SA Cancer Service (SACS) responsible for statewide cancer service planning to develop and pilot the SA Cancer Survivorship Framework (Framework). South Australia has a population of 1.7 million, mostly concentrated around the capital city, Adelaide. Cancer care is delivered across public cancer services as well as through the private sector. Approximately 61,000 South Australians were living with cancer in 2014.[18] The SACS facilitates and supports the coordination of cancer care and alignment of service planning with the SA Cancer Control Plan across public cancer services.

The Framework was developed to identify and recommend the minimum level of care cancer survivors should receive following completion of treatment. Key components of the Framework include the provision of a cancer TS and the development of a CP (informed by a needs assessment). The Framework and standardised templates of the key components were developed following a review of the literature regarding survivorship care elements, standards, and implementation; national guidelines [2,19]; several years of survivorship care experience at an established site in SA, and refinement via stakeholder consultation.[20]

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The objective of this paper is to report on the lessons learned from a pilot project with a particular focus on the barriers and enablers to documenting TSs and CPs and to identify key issues and strategies that could be used for future implementation. An existing nurse-led model initiating survivorship care was considered the most appropriate and likely to be successful based on a successful model established at one site in SA and support by survivors for the involvement of nurse practitioners in follow-up care.[21] The aims of the pilot were:

1. To review, adapt, and refine the standardised tools for TS and CP to provide support to survivors to transition to primary care services
2. To identify barriers and enablers to implementation of the TS and CP within existing services and resources via a once-off, nurse-led survivorship consultation

METHODS

CONTEXT

This paper reports on a pilot study undertaken as part of a larger project to develop a state-wide Survivorship Framework. The project activities were based on a strategy for translating evidence into practice developed at John Hopkins University [22], which includes four stages: (1) summarising the evidence, (2) identifying local barriers to implementation, (3) selecting measures of performance, and (4) implementing the evidence. The pilot presented in this paper addresses stage 2.

A multi-disciplinary Survivorship Steering Group including cancer survivors, clinicians and researchers was established to oversee the project and review the literature to identify best practice guidelines to survivorship care, chronic disease management and relevant state-wide and national policies and reforms. The literature was presented to a diverse range of stakeholders at an initial forum in 2015 with a focus on the newly developed Model of Wellness for Survivorship Care by the Clinical Oncology Society of Australia (COSA) and to adapt the model within the SA context. The forum explored current practice in SA including the barriers, enablers and gaps to delivering best practice survivorship care. Subsequent to the forum smaller working groups were convened to closely examine the core components of survivorship care outlined within the COSA Model with consideration to the barriers and enablers identified at the forum.

This led to the development of a theoretical Framework that captured the delivery of three core components including a cancer TS, needs assessment and survivorship CP. Standards, principles and templates were developed for each component. Implementation principles were also developed with consideration to challenges expressed during stakeholder consultation. A health economic analysis of the theoretical Framework was also conducted that made recommendations for measuring the effectiveness of the proposed Framework once implemented.

Four self-selected teams consisting of a nurse practitioner (Site D)/nurse practitioner candidate (Sites A, B and C) and a medical oncologist participated in the pilot study to identify local barriers and enablers to implementation. The aim was to have multiple sites but there were no inclusion criteria regarding patient demographics or cancer type. The teams represented three metropolitan hospitals (Sites A, C, and D) and a regional hospital (Site B) (Table 1). There were two large comprehensive cancer centres (Sites A and D), one smaller centre with lower volume but full casemix (Site C), and one rural centre with more limited services (Site B). The pilot was undertaken over three-months (February–May). Each site delivered a once-off survivorship consultation for cancer survivors completing treatment or adjuvant therapy with a senior physician providing support. Pilot teams worked with

TABLE 1: CHARACTERISTICS OF PILOT SITES

	Site A	Site B	Site C	Site D
Population serviced	Adults	Adults	Adults	Adults
Service location	Metropolitan	Regional	Metropolitan	Metropolitan
Survivorship clinic already established	✓	✓	✕	✕
Experience prior to pilot				
TS, CP	✓	✓	✕	✕
NA	✓	✓	✓	✓
Change in practice with pilots	Replaced existing TS & CP with pilot templates within survivorship clinic	Replaced existing TS & CP with pilot templates within survivorship clinic	Created survivorship clinic and adopted TS & CP pilot templates	Created survivorship clinic and adopted TS & CP pilot templates
TS/CP developed by	Nurse practitioner candidate	Nurse practitioner candidate	Nurse practitioner candidate	Nurse practitioner

Note: ✓= existed prior to pilot; ✕ = did not exist prior to pilot
CP = Care Plan, NA = Needs Assessment, TS = Treatment Summary

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their local teams to establish the flow of work. The model was based on the Survivorship Framework. Two sites (Sites A and B) were already providing a once-off survivorship consultation prior to the pre-implementation pilot and replaced existing templates with study templates (ie. developed by the American Society for Clinical Oncology.[23] The remaining two sites re-oriented services by creating clinics to incorporate survivorship consultations. Participant nurses from the experienced sites were those that worked in the existing model. All nurses were experienced cancer nurses. All sites had support from the SA Cancer Service and local site management.

FRAMEWORK TOOLS

The survivorship consultation involved the development and provision of a cancer TS and CP in partnership with the cancer survivor using standardised tools. Templates for the tools were modelled on the IOM recommendations, COSA Model, established approaches to chronic disease self-management [24], and the inclusion of goals in care plans.

The TS template was designed to record information relating to cancer type, diagnosis, stage, pathology findings, treatment, and complications. The CP template was designed to record surveillance and monitoring requirements, side effect management, problems reported by the survivor, other health problems; recommended wellness and health promotion activities (eg. screening practices, dietary and lifestyle modification) and any other concerns (eg. financial, relationship concerns). The CP template was designed to be underpinned by principles of chronic disease self-management and include goals to support transferability into the primary healthcare setting and become a 'living' document.[24,25]

The National Clinical Cancer Network (NCCN) Distress Thermometer and Problem Checklist was utilised during individual consultations with the survivor to identify key needs and priorities and establish goals to address these within the CP.[26] The goals were to be developed in accordance with the chronic disease management approach based on the Flinders Program of Chronic Disease Management (https://www.flindersprogram.com.au) and were expected to be specific, measurable, achievable, realistic and time specific (SMART). This CP was designed to facilitate the delivery of ongoing care provided by other healthcare and service providers and reengagement with specialist cancer services where indicated, but this aspect was beyond the scope of the current intervention.

Completed TS/CP exemplars, instructions to utilise templates within the current electronic medical health record system (where available), a generic letter template to the survivor's general practitioner (GP), and a spreadsheet to record information related to process and outcomes measures were also provided. Each team was required to use the standard templates but could adapt to best fit the respective service. Each site was to determine its own system of identifying patients at completion of treatment or adjuvant therapy and to deliver a once-off survivorship consultation, using a toolkit provided. Example materials are available on the SA Health website.[27] There were no eligibility criteria applied to the recruitment of survivors and all cancer types were included, and no differences in the criteria applied at each site.

A copy of the TS and CP was provided to the survivor and their GP upon completion.

STUDY DESIGN

A continuous quality improvement design was used to trial, adapt, and collect feedback on the design and delivery of the TS and CP.[28] The project was coordinated by a Senior Projects Officer from SA Cancer Service. A pragmatic approach was adopted for data collection. Fortnightly debriefing meetings were held to collect data on process and outcomes and to provide support and ongoing contact with other pilot teams (nurses and specialists). Meetings enabled participants to receive informal training on using the tools and templates. A final debrief with each site also took place. The meetings were used to review processes, collate and review information recorded in spreadsheets, develop new strategies, processes and improvements as required. An actions and outcomes log was used to track common issues. De-identified TSs and CPs were collected and analysed by an independent reviewer using a pre-defined scoring process to assess the quality and level of detail in the information documented. Feedback from survivors was sought via a survey. A summary of the data collected and methods for collection and analysis are provided in Table 2. The findings related to quality and survivor feedback are presented in a separate paper.

MEASURES

The following measures were reported on:

1. Time to deliver the TS and CP including preparation, consultation, follow-up and finalisation.
2. Barriers and enablers to implementation and differences in approaches adopted across sites. This information was collected at the fortnightly debriefing meetings, final debrief, and on the data collection spreadsheets.

ANALYSIS

Qualitative data were analysed using content analysis and quantitative data were analysed using descriptive statistics. For the content analysis, text from the spreadsheets and hand-written field notes from the fortnightly meetings and a final debriefing for each site were copied into Excel. The text was then coded inductively to identify key themes. The coding was undertaken by the Senior Project Officer and the interpretation was verified by all participants. This method was considered appropriate given the project context, nature of the information, and depth of analysis required.[29]

TABLE 2: DEMOGRAPHICS OF CANCER SURVIVORS

	Site A	Site B	Site C	Site D	Total sites A-C
Consultations (N)	34	6	3	0	43
Age range (years)	39–80	32–75	53–71	0	32–80
Median age (years)	59	58.5	59	0	59
Gender (N, %)					
Male	7 (16%)	1 (17%)	0	0	7 (16%)
Female	36 (84%)	5 (83%)	3 (100%)	0	36 (84%)
Tumour type					
Breast	23 (67%)	6 (100%)	3 (100%)	0	32 (74%)
Other[a]	11 (33%)	0	0	0	7 (16%)

[a] Other included 7 colorectal cases and individual cases of ovarian, tonsil SCC, testicular, and cholangiocarcinoma.

ETHICAL CONSIDERATIONS

Submission to one of the Local Health Network (LHN) Human Research Ethics Committee was made for approval to collect data during the implementation pilots. The pilots were deemed a quality improvement initiative, and approval was granted with mutual acceptance agreed across all LHNs involved (R20160104).

RESULTS

STUDY OF THE INTERVENTION

During the early stages of the pilots, nurses requested that de-identified TS and CP be shared to check consistency, develop ideas to support completion, build confidence in content related to goal setting, and identify credible support resources. They indicated that the sharing of experiences across sites helped in the development of 'response templates' to address common clinical problems to help to improve the efficiency of preparing and developing the CP. They identified the need to have access to a list of credible resources that were available and could be recommended to survivors in supporting their understanding and ability to self-manage. Survivorship Care Plans developed during the early phase of the pilots were used to start identifying relevant resources. A Framework Companion Document – Resources was developed by the end of the pilot. The CP template was revised to list resources at the bottom with reference to relevant websites.

As a result of early discussions at the debrief sessions, a list of key phrases and examples for common issues being identified within CP were developed. These included examples of SMART goals and action-based strategies.

Terminology that catered for various health literacy levels to enhance understanding and meaning for cancer survivors was included. Feedback was sought from consumer representatives on the Survivorship Steering Group following to ensure readability and user friendliness.

As the pilot progressed, nurses reported reduction in time and improvements in efficiency as a result of improved familiarity with the tools. The sites that had replaced existing templates reported improved time efficiency due to the more simplified and less content rich detail required.

There was agreement that the survivorship consultation would be held three to six months following completion of treatment to ensure toxicities and effects of treatment had subsided.

NUMBER OF CONSULTATIONS AND SURVIVOR DEMOGRAPHICS

Forty-three survivorship consultations were held across three sites (A, B, and C) over the three months (Table 3). There were no consultations in site D. In total, 74% (n=32) of survivors had been treated for breast cancer, 84% (n= 36) were female and median age was 59 years.

TIME TO IMPLEMENT TREATMENT SUMMARIES AND CARE PLANS

The average time to prepare, develop, follow-up and finalise the TS and CP was 154 minutes (median 165 minutes) per person. The time breakdown included: preparation (compilation of medical records and commencing pre-population of the TS; 20–90 mins, median 50 mins), appointment (discussing treatment, completing the needs assessment and translating areas identified onto the CP; 45–90 mins, median 60 mins) and finalisation (completion of TS and CP, delivery to survivors, letter to GPs; 30–75 mins, median 50 mins).

BARRIERS AND ENABLERS

Compiling the information

Implementation time, particularly in the preparation phase was affected by: location of medical records and files (in some instances across multiple sites), access to original documentation (eg. pathology reports), and compiling

TABLE 3: DEMOGRAPHICS OF CANCER SURVIVORS

	Site A	Site B	Site C	Site D	Total sites A-C
Consultations (N)	34	6	3	0	43
Age range (years)	39–80	32–75	53–71	0	32–80
Median age (years)	59	58.5	59	0	59
Gender (N, %)					
Male	7 (16%)	1 (17%)	0	0	7 (16%)
Female	36 (84%)	5 (83%)	3 (100%)	0	36 (84%)
Tumour type					
Breast	23 (67%)	6 (100%)	3 (100%)	0	32 (74%)
Other[a]	11 (33%)	0	0	0	11 (16%)

[a] Other included 7 colorectal cases and individual cases of ovarian, tonsil SCC, testicular, and cholangiocarcinoma.

information of treatment, particularly if survivors received services across both the public and private sectors, and complexity of treatment, management and/or risk of complications of cancer and its treatment as well as other co-morbidities.

Although electronic templates were available, there was a preference for handwriting the TS and CP to maintain rapport and the flow of conversation during the consultation and formalising after the appointment using the computer-based patient record summary system or computer-generated word file. This resulted in duplication of processes and additional time. Nurses suggested that the progressive development of a TS commencing at the point of diagnosis, and documented by the relevant treating team, could be an enabler by improving the efficiency of collating and accurately summarise the treatment received.

Providers

Nurses reported that it was challenging to transition from a medical, acute model of care, to one of wellness, and from a directive approach to one that promoted/facilitated self-management. They felt they had limited training and experience in developing and setting suitable goals and strategies with survivors; limited awareness of other service providers available and referral processes to link survivors of cancer with support beyond the acute cancer setting. Concerns were also expressed regarding preparedness of cancer survivors to engage in a model of wellness and discussions in relation to their needs; and how to intervene when items nurses thought were important were not identified as priorities by the survivor. Switching the focus to wellness was challenging if the survivorship consultation was held too early because toxicities and effects of treatment were still evident and therefore most salient to the survivor.

Nurses identified existing and potential enablers to overcome these challenges. These included: further training and education particularly in the area of motivational interviewing and goal setting; forwarding a pre-appointment information pack to survivors to encourage thinking about health and wellness needs and goals; and having specialists discussing with and preparing survivors for post-treatment care including the survivorship consultation.

System readiness for innovation

System barriers included competing demands on nurses' time and lack of explicit process to identify survivors. It was not possible to determine the number of patients eligible for consultations as this information was not captured within any system at the sites. The sites were reliant on specialists for referrals to the survivorship consultation which was ad hoc and mostly included patients with breast cancer. Referral pathways were reported to be dependent upon specialists and their preferences for follow-up care and perceived value of survivorship care. Site A who produced the largest number of TS and CP expressed concerns of capacity if all cancer survivors were referred to the survivorship clinic. It was recognised that the competing demands and other priorities toward the end of treatment for both survivors and their specialists may have had an impact on discussing and referring to survivorship consultation. Another challenge related to administrative support for coordinating appointments and disseminating the finalised documents. When administrative support was unavailable or limited, the process of coordinating appointments and disseminating the completed documents was more time consuming, and in some instances delayed. The pilot sites had limited levels of administrative support for finalisation and timely distribution of the documents.

Contextual elements and unexpected outcomes

In the case of Site D, major service changes (upcoming move to a new hospital location) made it difficult to mobilise resources for the pilot and engage specialists outside the pilot team and these were insurmountable barriers to referral despite good will and intentions of the pilot team. A possible lesson is that innovations in survivorship practices should be tested during periods of service stability.

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DISCUSSION AND CONCLUSION

This paper reports on a quality improvement study undertaken as part of a larger project to develop a South Australian Survivorship Framework. The study was a pilot in four oncology settings designed to initiate the development of treatment summaries (TS) and survivorship care plans (SC) by nurse practitioners/nurse practitioner candidates to (1) test and refine the core components of the Survivorship Framework and (2) determine local barriers and enablers to implementation. In relation to aim 1, several improvements to the TS/CP templates were made to improve the ease and efficiency of the documentation templates. In relation to aim 2, several barriers to delivering TS and CPs were identified including challenges associated with manual data extraction required for the TS and the skills required to construct the goals and strategies in the CP. There were system constraints that made it difficult for teams to set up survivorship consultations and referral pathways, including lack of system infrastructure to identify patients coming to the completion of treatment. The opportunities for sharing learnings, development of supporting resources, and increased familiarity with the resources, were key enablers.

Our findings are consistent with other research. Organisational resources including time and having adequately trained personnel are often cited as barriers to the use and uptake of survivorship care plans [13,30-33] including at sites with established survivorship clinics [34] and even when there is buy-in from clinicians.[35] Lack of systems to populate information and for systematic referral have also been reported as barriers to use and uptake.[30] A lack of training in survivorship care and rehabilitation amongst health professionals is thought to be a barrier to referral to appropriate services.[36] In our pilot, a lack of system infrastructure to support referrals for cancer survivors proved difficult to overcome when there were competing service priorities and when engagement beyond the pilot teams and the rest of the cancer team was required. There was no unifying system across sites to identify people coming to completion of treatment, and therefore identification of cancer survivors was ad hoc and largely reliant on clinicians in the pilot teams.

The strategies that participants identified to address these barriers have also been suggested by others. For example, populating the TS from diagnosis is an approach used by Macmillan Cancer Support.[9] Training in survivorship is thought to assist health professionals to provide survivorship care activities [33] and to encourage referral to relevant survivorship services.[36] The use of electronic records or other systems to auto-populate information is thought to be a way of addressing efficiencies in production of TSs and CPs.[37] A flexible approach aligned to the preferences of survivors for brief or detailed information is also recommended.[38]

The documentation process for TS/CP improved with increased familiarity but was nevertheless time consuming and cumbersome, requiring manual and often challenging data extraction from medical records to populate. In the CP, translation of needs and problem areas into SMART goals and provider strategies were challenging to construct. Whilst additional training could be provided to assist with the development of skills required to develop goals and strategies, this may not be feasible in all settings and by staff with varied training and expertise.

Future implementation of survivorship care in South Australia will require critical examination and addressing of the barriers to care delivery including systematic approaches to identification of eligible survivors, system changes to improve efficiency, and staff training and support. In addition, strategies will be required to improve perceptions of the value of providing TSs and CPs. Future work could explore whether re-framing the activity as an example of quality clinical handover, which is identified in the national safety and quality standards,[39] would be more meaningful to wider network of clinicians. There should be engagement with community services and ongoing evaluation of any implementation efforts.

The main strength of the study was its pragmatic quality improvement design. This approach recognises that the use of small pilots is an important strategy in large system change[40] and that innovations are more easily adopted when they can be trialed, readily adapted and refined.[41] By situating the pilot in the context of usual nursing practice, system barriers and potential solutions to the feasibility of initiating treatment summaries and care plans were readily identified.

The limitations of the study need to be considered. Most consultations were undertaken at site A that had an established clinic infrastructure, referral pathways, time to establish relationships with stakeholders, and was the only site to see survivors with diverse cancer albeit amongst a breast cancer majority. Although participants were operating within limited existing resources, they were motivated and engaged in survivorship and had unique qualifications to enable them to consider expanded roles. The findings may therefore moderately over-estimate the feasibility of delivering TS/CP. The barriers and enablers identified are relevant to the public sector setting and service providers and the experiences may not be generalisable across sector boundaries including community private providers and the community sector. Finally, the pragmatic nature of the project had some inherent methodological limitations such as reliance on field notes for data collection and analysis that did not allow an in-depth or nuanced analysis of the challenges encountered.

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In conclusion, this pilot indicates that the standardised tools for treatment summaries and care plans outlined in the South Australian Survivorship Framework can assist nurses to structure a survivorship consultation with patients completing treatment. The tools appear to assist with streamlining the compilation of treatment information and developing strategies to align to patient needs and goals, although further specialised training skills may enhance confidence with the latter. By testing the templates in the context of a quality improvement project, we were able to identify that the establishment of referral processes and resourcing for survivorship specific activities are critical hurdle steps to enable TS/CP to be implemented in treatment settings.

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