Title: What are the barriers of quality survivorship care for haematology cancer patients?

Qualitative insights from cancer nurses

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Abstract (150-250 words using specified sections)

Purpose: Many haematological cancer survivors report long-term physiological and psychosocial effects beyond treatment completion. These survivors continue to experience impaired quality of life (QoL) as a result of their disease and aggressive treatment. As key members of the multidisciplinary team, the purpose of this study is to examine the insights of cancer nurses to inform future developments in survivorship care provision.

Methods: Open text qualitative responses from two prospective Australian cross-sectional surveys of nurses (n=136) caring for patients with haematological cancer. Data were analysed thematically, using an inductive approach to identify themes.

Results: This study has identified a number of issues that nurses perceive as barriers to quality survivorship care provision. Two main themes were identified; the first relating to the challenges nurses face in providing care ('care challenges'), and the second relating to the challenges of providing survivorship care within contemporary health care systems ('system challenges').

Conclusions: Cancer nurses perceive the nature of haematological cancer and its treatment, and of the health care system itself, as barriers to the provision of quality survivorship care. Care challenges such as the lack of a standard treatment path and the relapsing or remitting nature of haematological cancers may be somewhat intractable, but system challenges relating to clearly defining and delineating professional responsibilities and exchanging information with other clinicians are not.

Implications for Cancer Survivors: Addressing the issues identified will facilitate cancer nurses' provision of survivorship care, and help address haematological survivors' needs with regard to the physical and psychosocial consequences of their cancer and treatment.

Keywords (4-6): haematological cancer, survivorship, survivorship care models, post treatment, nurse, delivery of health care

Introduction

Haematological cancers are a group of neoplasms that originate in cells of the bone marrow (the leukaemias) and the immune system (the lymphomas and myeloma) [1]. These malignancies encompass a wide spectrum of diseases ranging from the chronic slow-growing, to the acute and aggressive. They are the fourth most commonly diagnosed cancers in developed countries [2, 3], and are the fifth most common cancer amongst adult Australians with an estimated 4,928 new cases of lymphoma, 2,691 new cases of leukaemia and 1,525 new cases of myeloma annually [4]. Treatment is often complex and debilitating, with increased risk of immune suppression and infection [1], and need for bone marrow support with red cell and platelet transfusions. Some will receive allogeneic stem cell transplantation that often requires in-patient stay of several weeks and life-long medical follow up. The recent increased use of targeted therapies in haematological cancers (e.g. rituximab for non-Hodgkin lymphoma (NHL), bortezomib in multiple myeloma (MM) and ibrutinib in Chronic Lymphocytic leukaemia (CLL) has resulted in improved overall survival [5]. In recent years, advances in treatment regimens, and an aging population saw an increasing number of patients living with a haematological cancer or surviving curative therapy [6].

Despite these advances, survival of a haematological cancer does not guarantee a full restoration of health, with many survivors continuing to experience debilitating complications and impaired quality of life (QoL) as a result of their disease and aggressive treatment [7]. The National Cancer Institute has drawn attention to *survivorship*, defined as the health and life of a person following cancer treatment until the end of life [8], encompassing the importance of attention to the physical, psychosocial, and economic impact of cancer, beyond diagnosis and treatment [8]. With regard to haematological cancers, this should also

incorporate issues related to late effects (both physical and psychosocial) of treatment, and secondary cancers [8].

Emerging evidence about short-term and long-term physical, emotional and social impact of a haematological malignancy highlights importance for cancer care health professionals to reduce distress and improve QoL [9, 10]. Specific unmet needs which may be the focus of intervention include fatigue, altered weight, reduced level of physical activity, loss of fertility and sexual function, altered body image, difficulty adjusting to normal life, depression, anxiety, fear of cancer recurrence and unaddressed informational needs [7, 11, 10, 12]. A study of 66 Australian adults who had completed treatment for haematological cancer found that patient needs at end of treatment were related to care co-ordination (33%), management of the fear of recurrence (73%), and the need for good communication between treating physicians (32%). Almost two thirds of patients (59%) reported they would have found it helpful to talk with a health care professional about their experience of diagnosis and treatment at the completion of treatment.

In Australia, although survivorship care is recognised as an important phase of the cancer trajectory, with the provision of follow-up care and the establishment of survivorship clinics; the delivery of care is fragmented and uncoordinated [13]. A report by the *National Services Improvement Framework for Cancer* states that some patients receive excellent follow-up care, whilst others are left to manage and seek resources as they are able. Not only are there gaps in service delivery, patient reports suggest follow-up care needs to be more tailored to psychological and physical needs, including education regarding fatigue and anxiety management [14]. Given nursing training and education emphasises holistic patient assessment, symptom management and care planning, cancer nurses (as the largest cancer

care workforce) are ideally suited to deliver survivorship care [15]. With the increase in the number of cancer survivors, there is a pressing need to develop strategies for enabling nurses to make the most of these opportunities to support patients along their survivorship journey. This qualitative analysis was designed to expand the understanding of the barriers to nurse provision of survivorship care and changes needed to ensure optimal survivorship care provision for haematological cancer patients.

Methods

Study design and participants

Open text responses from two prospective cross-sectional surveys of nurses caring for patients with haematological cancer [16] formed the basis of the data for analysis. As the methods have been reported elsewhere, they are reported here in brief. The first survey was conducted in a single Australian tertiary cancer care centre. Nurses employed full- or part-time at the centre were invited to participate by email by the investigators or by nursing unit managers or research assistants during their clinical handover time. The second survey was conducted across Australia, with invitations sent to members of two professional groups. The Cancer Nurses Society of Australia (CNSA) and Haematology Society of Australia and New Zealand (HSANZ) Nurses' Group sent email invitations and two-week reminders with links to an online survey to all members.

For both studies, inclusion criteria required participants to be aged at least 18 years and be an enrolled or registered nurse (assistants in nursing or other non-regulated nursing staff were excluded). Participants' responses were anonymous and survey completion was accepted as implied consent. The research ethics committees of the Royal Brisbane and Women's

Hospital and the Queensland University of Technology provided ethical approval for the single site and national studies respectively.

One hundred and nineteen nurses participated in the single-site study, and 310 in the national study. A response to the open-text item was provided by 35 and 101 nurses for the single-study and national surveys respectively. The characteristics of participants providing qualitative data are shown in Table 1. The majority of participants were female (>88%), clinicians providing direct care with majority of their work time (>60%), with a Bachelor degree (>91.4%), and experienced nurses with over six years of experience in caring for patients with cancer (>82%).

Measurement

The questionnaires administered in each study were essentially identical, with minor amendment to collect additional information in the national survey to describe participants' work settings. Closed-item questions assessed nurses' confidence in delivering survivorship care, frequency of providing survivorship care and barriers to optimal survivorship care. Twelve potential barriers (individual, organisation and professional) were listed (Box 1), with participants asked to indicate the extent to which each factor impeded their provision of survivorship care for patients with haematological malignancies, and for caregivers or family members. The participants also could list any other barriers that are not yet included in the 12. Further, one additional open-response item allowed participants to provide any other comments regarding their survivorship care provision.

Data analysis

Open-ended responses were analysed thematically, using an inductive approach to identify themes [17]. NVivo version 10 was used for data management. Two researchers (DL & SE) initially independently coded the data, and then discussed these analyses to establish a consensus on recurrent themes in the data. Each researcher then independently recoded the data a second time using this coding scheme. After further discussion between the researchers and further exploration of emergent themes which led to some changes in the coding schedule, a third round of independent coding was conducted. The major themes reported in this article were identified through the first round of coding, with sub-themes refined through the subsequent two coding rounds.

Comparison of the coding decisions made by the researchers in the third round of coding was conducted using percent agreement and Kappa coefficient statistics within NVivo. This has been recommended to demonstrate transparency in coding procedures when multiple coders are used, and quantifies the consistency in coding [18]. Percent agreement is the percentage of content where the two users agree on whether the content may be coded at the node. The Kappa coefficient assesses the extent to which this agreement is beyond that which can be expected to occur by chance alone [19]. Across all codes, average percentage agreement was 95.5% (range 88.1% to 98.9%), and an average Kappa coefficient of 0.65 (range 0.40-0.94) was obtained, which may be interpreted as substantial agreement [20].

The analysis presented in this paper provides sample quotes to illustrate the broader themes identified. Quotes are presented verbatim, with the exception of the correction of typographical and grammatical errors. The source of the quotes (single-site or national

survey) and participant identifier are provided to demonstrate how quotations were distributed across the whole study group.

Results

Two predominant themes were identified through the analytic process reported above (see table 2). One theme related to the challenges in providing care at the level of individual for haematological cancer patients; the second to the systems in which survivorship care was or could be delivered.

Care challenges

Specific to haematological cancer

A number of participants reported that the nature of haematological cancer and its treatment, specifically the uncertainty around the timing of the completion of treatment, acted or could act as a barrier to their provision of survivorship care.

“The difficulty with haematological malignancies is that the treatment trajectory is determined by lots of ‘what ifs’ therefore it is difficult to define when treatment ends and survivorship starts.” (National survey, N232)

Nurses reported difficulties in recognising that the end of treatment was approaching or indeed there not being an “end of treatment” for patients where the disease is chronic or treatment protocols were ongoing. Difficulties recognising the intent of treatment (i.e. cure, remission or palliation) also acted as survivorship care barriers. These particularly acted as

obstacles to the nurses' provision of care in terms of knowing when to commence or have survivorship care discussions, and what issues would be relevant to the patient and family. Some nurses also worried that having survivorship care discussions may lead families to think that the patient was cured without chance of relapse, or not be accepted by patients who do not identify as survivors due to ongoing treatment or monitoring.

Focus on active treatment rather than survivorship

A number of nurses highlighted the competing priorities of active treatment and survivorship care. The priority they could give to survivorship care discussions in a busy ward was limited when there was a need to administer chemotherapy or address symptoms. Nurses' feelings of being inadequately trained or prepared to have discussions about survivorship, and a lack of formal systems for the provision of survivorship care acted to prioritise the provision of active treatment over survivorship care. Nurses also reported that this prioritisation occurred among other clinicians.

"I know our provision of survivorship care is wanting....This is challenged due to many things, priorities of service (especially by individual nurses who don't prioritise this due to limited experience, knowledge and skills), time in the day chemotherapy administration becomes our main focus." (National survey, N281)

Recognition that patients and families were focused on active treatment and the difficulty in determining the best time to discussing survivorship issues when they had this focus also acted as a barrier.

“prior to treatment survivorship discussions can seem trite and unimportant when compared to their urgency to have treatment, during treatment their treatment related symptoms can make considering anything other than getting through this day, this hour, inconceivable. at the end of treatment they may still be unwell OR they consider this info a 'downer' on a celebration” (National survey, N169)

System challenges

Professional responsibility for providing survivorship care

Many participants reported that the particular aspects of survivorship care described in the fixed-response survey questions should be provided by particular professionals, including physicians, allied health professionals, and specialist nurses. Having a single person or role providing survivorship care was recommended to ensure correct and consistent information was provided and avoid information being missed. A single role was also advocated as the relevant person would have more time to take on survivorship care responsibilities, and have the knowledge to provide the information to patients.

“Most of this care is currently provided for the patients by the cancer care co-ordinators and the transplant co-ordinators. They are in a better position time wise to advise the patient as well as to know where the patient stands on his/her treatment plan” (Single-site survey, N24)

Other participants highlighted that survivorship care was provided by a range of disciplines such as social work, rehabilitation, psychology, occupational therapy, by not-for-profit organisations such as the Leukaemia Foundation, as well as by nurses. Participants

recognized that a multidisciplinary approach provided specialist skills and knowledge, although some reported having limited access or availability of these disciplines within their work setting. Some participants also saw physicians or allied health professionals as having “responsibility” for the provision of certain aspects of survivorship care, particularly for sensitive topics such as fertility, future intimacy or financial issues.

“do not feel skilled in the area of financial/ employment. also it is much better to use the multidisciplinary team such as dietician and physiotherapist and use their expertise. Nurses should not be expected to provide care/ education in all areas- too many time constraints and lack of knowledge” (National survey, N210)

A potential negative consequence of this multidisciplinary approach, however, was that the provision of particular aspects of survivorship care by different health professionals could result in fragmentation of care. This meant that care was not coordinated, that it was unclear who was providing particular aspects of care, or how nurses could complement this.

Team approach

Given the expertise of specific clinical roles, a multidisciplinary team approach to the provision of survivorship care was suggested by many participants.

“I feel that there should be a multidisciplinary team approach to survivorship. Not only is it the nurses and doctors responsibility but OT, physio and social work can give more insight into different areas” (National survey, N113)

Participants acknowledged the role of the nurse within this team, for example, starting conversations and making referrals, and coordinating the survivorship approach across clinicians to ensure that issues are followed up. As nurses spend a significant amount of time with patients, many saw that they have an integral role within the team in coordinating survivorship care and reinforcing the messages from other team members. A few nurses highlighted that a team-based approach to care may lead to increased administrative burden and the possibility of divergent opinions, requiring a system in place to ensure clear decisions could be made about the various components of survivorship care and the professionals responsible for delivering each of these components.

Information exchange

Difficulties with the exchange of information between health professionals were identified as significant issues impeding survivorship care provision. This frequently related to the lack of a method to communicate what survivorship care had been provided by different clinicians within the care team. Many nurses felt that this limited their ability to assess what survivorship care was yet to be provided or a way to ensure that consistent information was provided.

“So many of these conversations would be had with patients however the nurses on the floor/ward etc are not privy to these therefore is it our place to instigate some of these discussions when we don't know what is in place” (National survey, N145)

Nurses also highlighted the absence of a method to communicate with primary care to enable a shared care model of follow-up or survivorship care to be used. The lack of links with General Practitioners (GPs), formal processes for nurses and GPs to communicate or for this communication to be documented, or a tendency for GPs tended to communicate with consultants rather than nursing staff hampered nurses' abilities to coordinate survivorship care across practitioners. A minority of nurses also reported that oncologists or haematologists, particularly when providing care within the private health system, also provided limited information about patients' plan of care to nurses and/or other clinicians, which further limited care provision.

The interface between inpatient and outpatient units was particularly highlighted by participants as an area where information exchange could be improved. As patients may commence their treatment within the inpatient setting but complete treatment in the outpatient setting, good communication between these settings about patients' care and support needs, and the ability to follow-up patients to ensure their survivorship care needs were met after treatment ended, was suggested.

“Having a direct nursing link between inpatients and outpatients would be beneficial. Inpatient nurses could highlight to the outpatient areas any issues or problems that may arise and vice versa.” (Single-site survey, N44)

Models suggested for survivorship care provision

A number of participants suggested models which could be used to provide survivorship care. A dedicated end-of-treatment consultation was recommended by participants as a way of

ensuring that survivorship care was provided to patients, and time was allocated for nursing staff to provide this care.

“A formalised approach plus education for nursing staff would be beneficial in providing this care to the patients. An end-of-treatment consultation scheduled time would ensure that this happened.” (Single-site survey, N39)

In contrast, some participants suggested survivorship care may need to be provided from the beginning of a patient’s treatment, recognising the difficulties in recognising when a patient’s treatment would end.

“The timing of this information should span their entire disease and treatment trajectory.” (National survey, N213)

A clinical pathway or guide to direct nurses as to what information or support should be provided and different stages of patients’ treatment, and to direct referral to other clinicians, was also recommended. As well as providing a plan for nurses to follow, some participants commented that this would help ensure consistency across health professionals, who may have different ways of providing care.

“There is nothing that I know of that is available for guiding survivorship care, in terms of informing me where the patient is on their treatment trajectory, what support,

if any they're receiving etc. A guide or care plan/clinical pathway would be very helpful for helping me to deliver survivorship care.” (Single-site survey, N86)

The final model suggested by participants was a dedicated survivorship clinic, with many suggesting this clinic could be nurse-led. Similarly to the suggestion of a single person coordinating survivorship care, a survivorship clinic was seen as a way of ensuring survivorship care was provided, and that the person who provided it was sufficiently skilled to do so.

Discussion

This study has identified a number of issues that nurses perceive as barriers to their provision of survivorship care to adults with haematological cancers and their carers. Two main themes were identified; the first relating to the challenges nurses face in providing care (‘care challenges’), and the second relating to the challenges of providing survivorship care within contemporary health care systems (‘system challenges’). Within the first theme, the nature of haematological cancer and its treatment was highlighted as posing specific care challenges. As study participants emphasised, unlike many other cancer trajectories, there is no typical trajectory for patients with haematological cancers [21]. This means that, at least for the haematological malignancies with less standardised trajectories, it can be difficult to plan when to start survivorship care. The appropriate timing for survivorship care provision is further complicated by the ongoing or chronic nature of many types of haematological cancer. Patients experiencing periods of treatment and remission followed by relapse, those with chronic disease, and those with an incurable malignancy may experience needs relating to both survivorship care and active treatment. Although cancer survivorship is usually

defined as starting at the time of diagnosis [22], in practice it usually is given priority after (or towards the end of) treatment [23]. For patients with haematological malignancies, the overlapping of treatment and survivorship phases means that survivorship care needs may go unmet. This problem is probably not uncommon to many other cancers today, highlighting an increasingly common challenge for quality survivorship provision for all cancer patients receiving modern treatments.

The care challenges described above can be compounded when active treatment is prioritised over survivorship care. This prioritisation likely reflects a number of historical and organisational factors: the traditional focus of health care on “cure” and the minimal extent to which survivorship is addressed in health workforce education [24]; the absence or inadequacy of staff training in survivorship issues to ensure confidence in providing such care [25]; the low priority given to survivorship issues at an organisational level, evidenced by the lack of comprehensive integrated survivorship care services which comply with all IOM recommendations in most hospitals [23]; and the lack of appropriate funding models to support the delivery of survivorship care [26-31].

In addition to the care challenges outlined, system level challenges can create further barriers to survivorship care. One significant issue is who should provide survivorship care, and how information about this care should be exchanged within the health care team or setting. As the nurses participating in this study articulated, some professions may have specialist knowledge and hence be most suited to providing important elements of survivorship care (for example, information with regard to fertility or financial issues). Haematological cancer survivors in particular may face long-term and late effects of treatments impacting on issues such as

employment and risk of recurrence or further primary cancers, and thus specific survivorship care components in addition to those for more common cancers [32] may be required. However, the sustainability of a specialist-led survivorship care model and the capacity of this workforce to meet survivorship care needs are uncertain. One way forward may be for specialist care about specific survivorship issues to be complemented and enhanced by nurse-led “universal” care to improve quality of life and address survivorship care needs. Given nurses’ existing roles in the assessment of patients’ unmet needs, provision of information and support, and the coordination of care during treatment [33], they may be ideally suited to undertake this role within a multidisciplinary survivorship care team. As illuminated by Gates and Krishnasamy [34], there is a small but growing body of literature showing positive impacts from nurse-led services for haematological cancer survivors. Future research efforts should also be given to enable effective transition to community care and investigate the value of self-management support in improving outcomes.

There is currently scant evidence underpinning effective strategies for communicating information about survivorship care provision within health care teams, across inpatient and outpatient departments, between public and private hospital settings, and with primary care services. The inefficient transfer of information between professionals and across boundaries in cancer care and health settings more generally has been well described [35, 36], but its specific impact on survivorship care is unclear. The need for coordination and communication between specialists and general practitioners is essential to continuity of care [37], and tools such as treatment summaries and care plans have been promoted to provide a “roadmap” of survivorship care and delineate role boundaries [23]. This study adds to this literature by highlighting the need for clear communication between physician and other members of the health care team about when patients’ treatment may end – to the extent to

which this information is available – so that nurses may better judge when to offer survivorship care. Nurses should also be informed about the relatively more standardised treatment trajectories within haematology (e.g. patients with Hodgkin’s disease and myeloma). For these patients, survivorship care should be planned as early as they are diagnosed and commenced with treatment. Although, for a large population of patients with haematological malignancies, it may be a challenge to identifying when to initiate survivorship care, prompt communication to all health professionals of test results and their implications for treatment completion should enhance this process.

This study shows nurses’ interest in the development of new survivorship care models for haematological cancer patients and identifies challenges that must be overcome to achieve this. Reviews of the evidence supporting models of survivorship care for cancer survivors and for haematology cancer survivors more specifically – whether physician-led, nurse-led, or shared care models – have been unable to conclusively determine the best or most appropriate model [38, 39, 32]. In the absence of empirical evidence, insights from clinicians such as those involved in this study may assist with implementation [40]. Both the quantitative [16] and these qualitative results of the study found the inability to predict when treatment would end and the associated scope for an end-of-treatment survivorship consultation was a significant barrier to survivorship care provision for haematological cancer patients. Although survivorship care may be provided many years after treatment completion, [34] this study suggests nurses believe the provision of information earlier in the treatment trajectory is desirable. Further work is necessary to determine how best to overcome these challenges, and engagement with the nursing community is essential to develop models which will work in practice. Lastly, the patient voice should not be neglected in the development of care models.

Limitations

As this analysis was of open text responses within a largely quantitative study, sampling was not theoretical or purposive, and the impact of this on findings is unclear. Analysis of open text comments meant it was not possible to ask participants to expand on issues raised; further information may have enabled additional exploration and understanding of participants' views [41]. Participants' expressed views in qualitative responses may also have been influenced by the quantitative items in the study. Despite these limitations, this study provides further depth on topics covered in the quantitative analysis of the questionnaire data,[16] enabling identification of additional challenges for exploration in future research.

Conclusion

Overall, cancer nurses perceive the nature of haematological cancer and its treatment, and of the health care system itself, as barriers to the provision of haematological cancer survivorship care. Care challenges such as the lack of a standard treatment path and the relapsing or remitting nature of haematological cancers may be somewhat intractable, but system challenges relating to clearly defining and delineating professional responsibilities and exchanging information with other clinicians are not. Addressing these issues will facilitate nurses' provision of survivorship care, and help address haematological survivors' needs with regard to the physical and psychosocial consequences of their cancer and treatment.

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Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

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Box 1 Potential barriers to nurses' provision of survivorship care assessed via closed-item questions, with regard to patients with haematological malignancies and caregivers or family members

You lack time
You lack knowledge/skills
You lack dedicated educational resources for the patient (booklets etc.)
You lack an appropriate physical location (e.g. a quiet room)
You lack interest in providing survivorship care
You do not know when patients are completing treatment
You do not know where the patient is at in their disease trajectory*
Patients' lack of interest
Communication barriers between you and the patient (i.e. language, hearing/sight deficit etc.)
You don't think that survivorship care will have a positive impact on the patient
There is no end-of-treatment consultation to dedicate to survivorship care
Survivorship care is not a priority for the organisation

* Item assessed with regard to patients only, not caregivers/family members

Table 1 Characteristics of participants providing qualitative responses in each study

	Single-site (n=35) %	National (n=101) %
Age		
18-29 years	18.2	10.9
30-39 years	27.3	17.8
40-49 years	39.4	23.8
50-59 years	15.2	37.6
60+ years	0	9.9
Sex		
Female	88.6	94.1
Years of experience in oncology nursing		
<5 years	17.1	15.8
6-10 years	22.9	19.8
11-20 years	40.0	34.7
>20 years	20.0	29.7
Highest qualification		
Hospital certificate/diploma	8.6	6.9
Bachelor	57.1	16.8
Graduate certificate/diploma	22.9	49.5
Masters/doctorate	11.4	26.7
% of work time spent caring for haematological patients		
100%	14.7	22.8
>75%	20.6	10.9
50-75%	32.4	26.7
<50%	32.4	39.6
Main role		
Direct clinical	71.4	52.5
Managerial/administrative	14.3	10.9
Education	2.9	9.9
Research/clinical trials	8.6	10.9
Other	2.9	15.8

Table 2 Themes and subthemes identified through the analytic process

Themes	Subthemes
1. Care challenges	1. Specific to haematological cancer
	2. Focus on active treatment rather than survivorship
2. System challenges	1. Professional responsibility for providing survivorship care
	2. Team approach
	3. Information exchange
	4. Models suggested for survivorship care provision