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TITLE

Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care.

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Keywords

Lymphoma cancer, Survivorship, Qualitative interviews, Nurse-led clinic intervention, Survivorship care plans and treatment summaries

Abstract

Purpose: To explore and describe lymphoma survivors' thoughts and perceptions of the components of a nurse-led lymphoma survivorship clinic intervention.

Methods: An exploratory, qualitative descriptive study using interviews from 10 participants who had transitioned post-treatment into the survivorship phase via a nurse-led lymphoma survivorship clinic intervention.

Results: Thematic analysis revealed three major themes: Reassurance and individualised care; Information and support; and Empowerment. Participants described the reassurance they gained from having contact with a health professional post-treatment who individualised information and support. A survivorship care plan and treatment summary was developed for this study and was believed to be very patient-centred and helpful. This enabled participants to take back control of their health and well-being and to rebuild confidence.

Conclusions: In this study, participants expressed a need for patient-centred follow-up care that addressed their concerns and supported them in the survivorship phase to get their life back on track. Nurse-led follow-up may offer a viable model of post-treatment survivorship care to lymphoma cancer survivors.

Introduction

Lymphomas are haematological cancers that originate from the lymphatic system, and are mainly categorised as either Hodgkin (HL) or non-Hodgkin lymphoma (NHL) (American Cancer Society, 2014). Worldwide, lymphomas represent the sixth most commonly diagnosed cancer (Surveillance Epidemiology and End Results (SEER), 2014). Australian incidence is increasing with an estimated 6,323 cases expected in 2017, which will equate to 4.6% of all cancer cases (Cancer Australia, 2017). However, developments in treatment and supportive care options such as chemotherapy, haematopoietic stem cell transplantation, radiotherapy and targeted therapies have improved five year survival to 76% (Cancer Australia, 2017). With increased remission and survival rates, many survivors experience issues and concerns, called unmet needs, which can impact quality of life and well-being (Carey et al., 2012; Sant et al., 2014). These can relate to issues such as: fatigue; poor nutrition; exercise capacity; cognition impairment; fear of recurrence; fertility, relationships; finances; employment; and insurance (Taylor et al., 2015; van der Poel et al., 2014). Health can be further compromised by late effects of treatment such as cardiovascular disease and second cancers (Grinyer, 2010; Ng et al., 2011; Travis et al., 2012), often experienced earlier than the general population (Panek-Hudson, 2013).

Haematological survivorship studies mainly report on mixed haematological samples regardless of variations in clinical features, treatment, curability and relative survival (Hall, Campbell, et al., 2013; Lobb et al., 2009; McGrath, 2014). A study of lymphoma (n=236) and myeloma (n=178) survivors on anxiety, depression and unmet needs in the early survivorship period (under two years) reported decreasing anxiety and depression rates in the myeloma cohort and increasing rates in the lymphoma

cohort (Oberoi et al., 2017). The authors indicated a need for cohort specific studies, especially in the early survivorship period (Oberoi et al., 2017) to ensure targeted support. Lymphoma only studies often reflect a survivorship period beyond two years at assessment (Ferrer, Huedo-Medina, Johnson, Ryan, & Pescatello, 2011; Friedman et al., 2010; Oerlemans et al., 2014), which may not reflect the unique needs of those who have recently completed treatment, limiting generalisability. A recent study by the authors (Monterosso et al., 2017) reported on focus groups with lymphoma survivors (n=17), the majority (n=13, 76%) who were 12-30 months post-treatment completion. Participants recounted unmet needs related to information, coping strategies and support, especially when transitioning into survivorship. Findings suggested cancer nurse coordinators could be a feasible approach to delivering structured, individualised support early post-treatment (Monterosso et al., 2017).

Nurse-led models of survivorship care have been proposed to transition patients post-treatment and have demonstrated acceptable outcomes in haematology cohorts (Gates et al., 2015; Howell et al., 2012; John & Armes, 2013). As a minimum, nurse-led models should include: administration of survivor-specific needs assessments to identify patient concerns (McDowell et al., 2010; Stricker et al., 2011); development and delivery of a survivorship care plan and treatment summary (SCPTS), to guide holistic follow-up (Clinical Oncology Society of Australia, 2016; MacMillan Cancer Support & NHS Improvement, 2010; McCabe, Bhatia, et al., 2013); and support to assist survivors to take ownership of their health and well-being (Bodenheimer et al., 2002; Kuijpers et al., 2013). To date, studies that have tested nurse-led models of care have focused on survivors of common cancers (breast, prostate, colon) (Jefford et al., 2016; Maly et al., 2017; Taylor et al., 2015), been based in acute care settings, used long consultations, and involved more frequent patient

contact (Cooper et al., 2010; De Leeuw & Larsson, 2013), which may preclude generalisability to other cancers or limit economic viability.

In order to provide lymphoma survivors with specific and responsive supportive care, the unique issues and unmet concerns of this cohort need to be assessed in the early survivorship period (under one year). The aim of this sub-study was to provide qualitative semi-structured interview data from a sample of participants who had been randomised to the intervention group of the Care After Lymphoma (CALy) phase II randomised controlled trial study (RCT) (Taylor et al., 2016). The RCT aimed to develop and test a nurse-led lymphoma survivorship clinic (NLSC) intervention to assist participants transitioning from treatment completion into the early survivorship phase. This study will add to the limited literature that exists in lymphoma specific early survivorship.

Methods

Methodological framework

A qualitative descriptive methodology was utilised to provide a comprehensive summary of a specific experience by the participants (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000), using a semi-structured interview design. The interview schedule consisted of the same open-ended questions and was developed by the researchers. To ensure participants felt able to express themselves and their perceptions freely, interviews were conducted by an experienced independent researcher.

Sample and setting

A purposive sample of lymphoma patients from a large tertiary hospital cancer centre in Perth, Western Australia were recruited from the intervention group of the RCT. A non-probability purposive sampling provides rich information from participants who have the greatest amount of in-depth knowledge and experience of a particular circumstance or event (Patton, 2014). Only participants who had completed all aspects of the NLSC intervention were approached by the survivorship cancer nurse conducting the clinic intervention. These participants had completed four measures: Short Form Survivor Unmet Needs Survey (SF-SUNS); Depression Anxiety Stress Scale (DASS21); Mini Mental Adjustment to Cancer Scale (Mini-MAC); and Patient Empowerment Scale at three time points; baseline (prior to randomisation), 3 months and 6 months. At the first NLSC appointment (approximately one week after baseline), participants completed and received an individualised lymphoma SCPTS, developed for this study (Taylor et al., 2016). Participants' GP were sent a copy. A motivational interview technique was used to provide evidenced-based information, advice and support at the first intervention appointment and reinforced with additional resources and support as required over the next two appointments.

All participants approached agreed to be interviewed. Each participant was nine months' post-treatment completion and the sample reflected an equal gender distribution and range of ages. Data saturation was achieved after ten interviews.

Interviews

The study was approved by the relevant hospital and university human research ethics committees. Informed written consent was obtained by all participants prior to interview scheduling. Interviews were conducted from February 2016 to May

2017 and occurred after the last NLSC appointment. Telephone interviews were conducted at a time convenient for the participant and were digitally recorded. The following are examples of the interview questions: 'Did you have any concerns or needs not addressed by any of the questions?'; 'What aspects of the clinic would you want to stay the same for future patients?'; 'Would you recommend the clinic to other patients finishing treatment?'; 'How do you feel about having the health concerns, goals and actions individualised to yourself?'; and 'Overall how useful was the SCPTS to you?' Interviews were transcribed verbatim, de-identified and an identifier code applied. Digital recordings and transcribed interviews were saved in a password-protected file on a secure server. After the first three interviews, the question order was slightly altered to enhance the flow of the interview.

Data Analysis

Interview transcripts were imported into NVivo 11 (NVivo 11, 2016) to facilitate management of data and completion of the analysis. Thematic analysis was used to establish patterns and themes within the text (Grbich, 1998; Patton, 2014; Smith, 2007). Thematic analysis allows for participant diversity of ideas and perceptions (Smith, 2007), thus providing a depth of information regarding the personal impact of the NLSC on the participant. Subthemes were developed from the data, and allowed for a logical organisation of the themes that emerged. The criteria of credibility, auditability and fittingness were applied to the data analysis process to ensure rigor (Beck, 1993). Credibility was maintained by triangulation with another member of the research team (Beck, 1993) to ensure independent reading and analysis of the transcripts by KT and CB who allocated codes and themes to the generated data (Braun & Clarke, 2006). The researchers met to discuss the codes and any

discrepancies before consensus on emerging themes was reached. The ample use of extracts or quotes from the data demonstrated fittingness to the agreed codes. A comprehensible audit trail maintained auditability, demonstrated by documentation of research planning through to analysis, and through a reflective discourse and debrief process with colleagues.

Results

Participants

Ten semi-structured interviews were conducted with all participants willing to share an opinion for each of the interview guideline areas. Demographic and disease information is shown in Table 6.3.1. There were equal numbers of males and females, with similar age range (24 – 74 years) and lymphoma type. The majority of participants resided within the metropolitan area (n=8, 80%), were working (n=6, 60%), were married or defacto (n=6, 60%) and had a university degree or trade qualification (n=8, 80%).

Time elapsed from end of study to interview ranged from 1 to 26 days (mean 6.5 days, SD 7.8 days). The majority of interviews (n=8) were done within 5 days. No time limit was set and interviews ranged from 17 minutes through to 48 minutes (mean 30.5 minutes).

Table 1 Demographic Characteristics for Interview Participants (n=10)

Characteristics	Males n=5	Females n=5 (50%)
	(50%)	
Age group at baseline		
24-25	2	2
48	1	1
65-74	2	2
Lymphoma diagnosis		
Non-Hodgkin	2	2

Hodgkin	3	3
Highest level of education		
Secondary school or less	1	1
Trade / vocational college	2	2
University	2	2
Employment status		
Working	4	2
Retired	1	2
No return to work date	-	1
Marital status		
Single	1	2
Married / defacto	4	2
Divorced	-	1
Residence		
Metropolitan	4	4
Regional	1	1

Themes

Three major themes emerged from analysis and coding of data: Reassurance and individualised care; Information and support; and Empowerment. Subthemes have been included to add clarity.

Reassurance and individualised care

Overall, the NLSC was well received and deemed a positive experience for participants, although it would have been reassuring to know about the clinic intervention during treatment. The assessment questionnaires and the SCPTS were perceived to facilitate individualised care.

Timing of support

Most participants indicated they would have liked knowledge of the clinic intervention during treatment so they could feel reassured that someone was still

interested in supporting them and they were 'not going to be abandoned'. This would take the form of a contact person they could trust.

"Just knowing that I was still going to get some support" F_25yo_HL

"But to know that look, don't worry, after treatment you are going to see a nurse, that would have been very calming for me" F_64yo_HL

The use of questionnaires to elicit unmet needs and concerns

Questionnaires were used to elicit unmet needs and areas of concern that could be discussed with participants at the NLSC appointment. Participant responses served as a focus for the follow up appointment. Feedback about the questionnaires indicated some questions were hard to answer.

"Sometimes I found that I couldn't say yes or no to the questions, because they didn't apply I suppose, and I had to answer" F_64yo_HL

Nonetheless, the questionnaires were able to cover aspects thought to be important to participants' overall wellbeing, as one said,

"They covered a multitude of the different things like your emotional well-being, mental well-being and physical well-being, all the things that you know you can struggle with" F_24yo_HL

The supportiveness of the intervention

All participants wanted the intervention structure to remain the same, describing the one-to-one, personalised nature of the intervention a valuable opportunity to talk to someone who was not family, friends or a doctor. They described being listened to and 'feeling safe' to ask questions on a range of topics, especially questions they felt they could not ask their haematologist. Participants indicated support was individualised and felt reassured they could get their life back on track.

"The one-on-one was really helpful because then you felt like you could pretty much ask anything, or talk about anything, and you didn't feel like there would be other people around to listen to your private conversations. A safe space, ask questions and get reassurance and the right answers. That was good" F_24yo_HL

"Someone that you can speak to and address the problems that you don't get the time with the doctors to talk about" F_64yo_HL

Another participant also commented on how he could discuss other aspects of the cancer experience. He said,

"What I particularly liked was the opportunity to have a conversation around things other than treatment. Dealing with some of the fears that you may have that you didn't feel like you could ask your specialist about. Or where do I go for complementary therapies. The kind of questions that specialists I don't think are necessarily geared for. Or don't have time really to cover. The ability to have a chat to a nurse that can help you through the next part of the journey" M_48yo_NHL

A couple of participants indicated that the intervention should have been conducted according to patient preferences. This included a preference for the NLSC to be away from the hospital and closer to their home.

"We should be providing services close to home where possible and I think there are some really great opportunities for the survivorship study to get out into the community even though they are still run by the hospital" M_48yo_NHL

Although two participants found returning to the hospital traumatic, they felt the NLSC experience helped them to overcome their aversion as it was felt to be a safe place they could communicate their fears and receive reassurance.

"The torture as a result of the treatment – going back to the hospital made me feel all that. It actually helped me deal with the fact that I can go to the hospital and not feel sick – so there was a positive to" M_48yo_NHL

Nurse contact and rapport

It was also felt contact should have been more frequent with telephone support between face to face visits, to provide extra support and to 'check-in' with the participant.

"I think you need to make them a bit closer together – a bit more frequent. And also make it where patients can choose. Make it more patient-driven - where the patient tells you how often they want to see or talk to someone" F_48yo_NHL

There was also an indication that many wanted the contact to go beyond the study timeframe. As one participant said,

"I don't feel like I am on my own steam yet. I am thinking 2 years before I have got my confidence and hopefully my health back" F 64yo HL

All participants described the relationship with the nurse who ran the intervention as comfortable and flexible, and felt they could call or speak to her with any issues if they wanted to. Participants provided comment and perceptions of the nurse as follows:

"And she did explain things so that I understood them more. She was really good at making you feel relaxed" F_48yo_NHL

"You felt like you had enough time to talk about and ask questions you didn't feel rushed and I think that was really good" F_24yo_HL

Survivorship care plan and treatment summary

The written patient-centred SCPTS was described as reassuring when it guided follow-up and for keeping on track with healthy lifestyle behaviours.

"Yes, it was good because it is reassuring, it is a guideline of what to do which I needed and knowing what to look out for and should be doing" F_64yo_HL

Feedback from participants regarding the SCPTS being sent to the GP indicated only two GPs discussed the SCPTS with them. Other participants indicated they either had not seen the GP or the GP acknowledged receipt but did not discuss.

Information and support

Participants appreciated the opportunity to discuss, record and receive written individualised information, support and resources. Although some information such as late effects was confronting at the time, it was nevertheless appreciated. All felt the information received at the NLSC was relevant and appropriate because it was tailored to their unique needs. Most felt they had not received this information or support from the treating team, however, it was acknowledged that possibly verbal information had been given but not retained.

Individualisation of the SCPTS

Participants liked the individualisation of the health concerns, goals and actions, and the accompanying written information and/or contacts.

"When I did have a concern, I was given printed notes about those issues and I think that is really good. Because I do have trouble with my memory now, and I can go back over those notes and sometimes it is like reading it anew, you know" F_64yo_HL

The treatment summary was well-received with most participants describing it as 'good to have', especially as a tool for communication with other health professionals.

"I think it was useful to sit down and have that initial meeting. I think it was really good that it was sent to my GP" F_25yo_HL

However, one participant was unsure of the value to himself,

"But I think this kind of treatment summary is the sort of thing I would give to my GP, or if I am seeing a new Dr, or if I was travelling and I got sick. I almost feel like it's less useful for me, but more useful for other people" M_24yo_HL

One participant felt the terminology related to the disease location could have been put in simpler language and this helpful recommendation was utilised for subsequent treatment summaries.

"Sometimes you don't always understand the medical terms so I think putting it into more simpler language would be a bit more helpful" F_48yo_NHL

Late effect information

The potential late effect information given on the SCPTS was individualised to each participant. It came as a shock to many that heart disease and other cancers, for example, were possible consequences of the treatment received.

"Well that was a bit of a shock to me because they hadn't been mentioned prior to the treatment. ... but at the same time, it was probably easier on me not knowing anyway" F_64yo_HL

Participants appreciated having the information and felt it could help with GP consultations, specifically around planning of health management into the future.

"That gave me something to go to my GP with and go okay I think I need to monitor this and this. And it helped me set out a care plan with my Dr as well" F_48yo_NHL

"It is always a bit overwhelming, but I think it is a good way to highlight the possible things that could happen. I think it reduces you're stress because you are not just in the dark about it. I think it is really important for yourself and the GP. If anything does change you know at least you are going to get it early" F_24yo_HL

One participant indicated they had heard the potential late effect information at diagnosis and another described being told there were some possible late effects after she had completed treatment,

"Oh, he just briefly spoke about 'you just need to be careful, you need to look after your skin, you need to do annual breast checks, you need to look after your heart. You know there is a possible risk you could get these problems in the future'. That is sort of how he mentioned it" F_24yo_HL

Neither participant had received written information and did not feel they knew how to follow-up these risk factors. This was an important consideration when developing the SCPTS to ensure follow-up suggestions for the GP and participant were given.

"[GP] just asked me to come in and discussed it with me and then he kind of just saved it and then he linked me in with support services to make sure I was monitoring all of my side-effects, so I think he thought it was good" F_25yo_HL

Empowerment

Most participants perceived the intent of the NLSC was to assist with transitioning away from a reliance on the treating team, to taking responsibility for monitoring and seeking support.

Nurturing empowerment

All participants described the SCPTS as useful and perceived it as a means to remind them to 'stay on track' with healthy lifestyle behaviours or for encouragement with achieving their goals.

"It just kind of helped remind me of my goals, and every time I had the meeting with [KT], it was like a kind of thing to remember my goals and I thought was a really beneficial thing" M_24yo_HL

Although one participant described the initial discussion and plan as helpful, she felt she should not have had to seek out services and arrange appointments.

"Maybe actually getting linked into the services they talk about. Rather than just getting the information and being left with it, it was kind of like I had to go and seek it out myself. I think it would have been really helpful to have someone contact me" F_25yo_HL

It appeared she did not want to take responsibility for her follow-up care. The remaining participants described understanding and appreciating the need to take back control of their health and well-being. They described the opportunity to discuss and write down their own health concerns, health goals and the actions they planned to take with a health professional as confidence building and assisted in increasing their positivity post-treatment completion.

"There are definitely days where you go thru and you start to question yourself, but being able to talk to someone about it made me feel more confident about being finished" M_25yo_HL

"I started thinking a bit more positive" M_71yo_HL

Participants noted that having the opportunity to record and discuss participantspecific issues had personalised both the appointment and the SCPTS.

"It identified what you personally were worried about and it wasn't just a general thing that everyone can be worried about, but it was specific to you. And then having the specific needs addressed with a certain plan or the actions column that you could put in place. I think that was really helpful because you see how you could be proactive about things" F_24yo_HL

Monitoring progress

Participants felt the follow-up over the next six months in the NLSC allowed them to monitor their progress and see how they were going.

"That was good. It was something to monitor my progress and it feels more personal" M_25yo_HL

"It sort of crystallises your thinking for the future. If you don't do something like that you tend to drift along day to day" F_74yo_NHL

Receiving written and contact information for support allowed participants to engage and take ownership for how and when they dealt with their goals and concerns. Even when issues remained unmet, having the issue normalised was equally important.

"Well the fatigue and the memory [problems] I have still got. It was useful to find that other people suffer the same things, that I am not alone on that!" F_64yo_HL

Usefulness of general health information

Participants received general health and screening information and felt it was helpful. Most read it again at home, then put it aside. They felt the value was in having it to refer to if needed.

"I think that it is really good to get the information and just have it there. I thought that was very handy" F_24yo_HL

This document was not sent to the GP, as GPs involved in evaluating the SCPTS for content clarity, internal consistency and content validity, indicated they knew this information and did not want it. It was noteworthy that two participants had given it to the GP and it had guided follow-up care.

"I basically took all the information into my GP and let him read thru it and he used it to help guide my care plan in the right direction" F_48yo_NHL

Discussion

This study contributes to the growing body of cancer-specific survivorship literature. The current model of specialist follow-up care for cancer survivors is inadequate, with many survivors experiencing unmet needs that can remain poorly addressed throughout the survivorship continuum (De Leeuw & Larsson, 2013). It is

essential survivorship care incorporates an awareness of treatment and disease, long-term and late effect risks, as well as healthy lifestyle behaviours (Taylor et al., 2015), and facilitates communication amongst all health professionals and the patient and family. Expertise in the provision of health promotion, support and information has always been the purview of cancer nurses (Jackson et al., 2013), therefore nurse-led models should be considered within any proposed model of survivorship care.

This study involved a cohort of lymphoma participants and specifically targeted those in the early survivorship phase (first nine months' post-treatment). Studies that involve a single subtype of haematological cancer are important in ascertaining the psychosocial and supportive care interventions that are specific and most appropriate (Oberoi et al., 2017). Assessing and providing an intervention in the early survivorship period has been shown to lead to a reduction in the unmet needs as survivors continue beyond five years (McDowell et al., 2010).

Participants described having time within the NLSC appointment to ask questions and seek individualised support as fundamentally helpful. An important point of difference with medical follow-up where participants perceived the specialist as too busy, or perhaps not interested when they were seeking reassurance and support. Interestingly, some participants would have preferred a follow-up appointment away from the hospital, an important consideration with future planning of nurse-led clinics. Participants had not previously met the nurse who provided the intervention, she is however, a cancer nurse coordinator with extensive haematology/oncology nursing and counselling experience and qualifications. A health professional who can quickly build a strong and positive rapport allows participants a greater opportunity to explore their own unmet needs (Ross, 2013). This may be why participants responded

favourably to the intervention and is important when considering nurse-led models of survivorship care.

Empowering participants with an individualised SCPTS that provided disease and treatment knowledge, and allowed them to assume responsibility for their future health and well-being (Taylor & Monterosso, 2015), was described as helpful from all participants. The expectation of younger survivors living longer with potential issues is important (Jabson & Bowen, 2013), nevertheless all participants in this study, regardless of age, appreciated the follow-up guidance they could discuss and implement with their GP. Information on general health and screening allowed participants a sense of independence of when and how they would seek follow-up. Of particular importance to participants was the opportunity to personalise the SCPTS and concentrate on what was important to them as they moved forward after treatment had completed. Conversely, our study revealed a small subset of participants who were not ready to take back control of their future health and well-being. It is important to acknowledge those patients and provide individualised support that meets their needs at the time, without building further dependency in the survivorship phase.

Survivorship literature highlights the concept of 'teachable moments' (Alfano et al., 2012; Grant & Economou, 2008; Hewitt et al., 2005; Panek-Hudson, 2013) at the end of active treatment to support and promote patient participation in healthy lifestyle behaviours. It was thought that participants in this study would need to be encouraged to engage in healthy lifestyle behaviours. However, it was evident that participants did feel a need to improve their health, and for some, change their lifestyle to adopt healthier lifestyle behaviours they had not been able to do during the stress of treatment. These participants particularly described the opportunity to revisit the

SCPTS over the preceding months allowed them to monitor and reflect on their achievements and help them to keep focused on their goals.

Limitations

This study reflects the views of a subset of lymphoma participants who underwent a nurse-led clinic survivorship intervention and therefore could not be generalisable to the wider survivorship population who have experienced a nurse-led clinic. Nonetheless, the use of qualitative interview research allowed an opportunity to gain a deeper understanding of the experiences of this select group. The findings are presented to help build research that is based on patient experience and feedback. The small number of participants is not a methodological limitation in qualitative research when data saturation is reached.

Conclusion

The interviews were conducted to ascertain the participant's perception of the efficacy and value of the components of the nurse-led intervention and to highlight any issues or challenges for this cohort that could be better addressed in the future. Survivorship care offered by nurses may address the patient-perceived unmet needs at the conclusion of active treatment. Participants indicated the need for security in knowing there would be support when treatment completed and would likewise value the opportunity to have their concerns heard. An individualised SCPTS that empowers survivors to address healthy lifestyle issues and provide a follow-up guide for late effects of the disease and treatment assists in refocusing responsibility back to the patient. Nurse-led survivorship care may offer an acceptable model to deliver patient-

centred post-treatment follow-up. This model allows the time required to individualise and tailor supportive survivorship care.

Competing Interests

There are no competing interests. No conflict of interest has been declared by the authors in relation to this study.

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