

2017

A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma

Leanne Monterosso

The University of Notre Dame Australia, leanne.monterosso@nd.edu.au

Karen Taylor

Violet Platt

Elizabeth Lobb

The University of Notre Dame Australia, Elizabeth.Lobb@nd.edu.au

Meinir Krishnasamy

See next page for additional authors

Follow this and additional works at: https://researchonline.nd.edu.au/nursing_article



This article was originally published as:

Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., & Joske, D. (2017). A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European Journal of Oncology Nursing*, 28, 62-68.

Original article available here:

<http://dx.doi.org/10.1016/j.ejon.2017.03.002>

This article is posted on ResearchOnline@ND at https://researchonline.nd.edu.au/nursing_article/137. For more information, please contact researchonline@nd.edu.au.



Authors

Leanne Monterosso, Karen Taylor, Violet Platt, Elizabeth Lobb, Meinir Krishnasamy, Toni Musiello, Caroline Bulsara, and David Joske



©2017. This manuscript version is made available under the CC-BY-NC-ND 4.0 International license <http://creativecommons.org/licenses/by-nc-nd/4.0/>

This is the author's post-print copy of the article published as:

Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., and Joske, D. (2017) A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European Journal of Oncology Nursing*, 28, 62-68. doi: 10.1016/j.ejon.2017.03.002

This article has been published in final form at <http://dx.doi.org/10.1016/j.ejon.2017.03.002>

Title

A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma

Leanne Monterosso PhD, BNurs(Hons), GCert Tert Teach, RN, RM, NNT, FACN^{a,b,c*}, Karen Taylor PhD(c), MNurs, GDipOnc, BN, RN^{a,d}, Violet Platt MNurs, BSc(Hons), EMBA, GAICD, RN^{a,d}, Elizabeth Lobb PhD, MAppSci, B.Ad.Ed. PGCert Bereave Counsel^{e,f,g}, Meinir Krishnasamy PhD, MSc, BA(Hons) DipN, RGN^{h,i}, Toni Musiello DPhil Health Psych, MSc Health psych, BSc(Hons)^j, Caroline Bulsara PhD, GDip Ed Studies, BA(Hons)^a, Kendall Stratton BN, RN^{k,a}, David Joske MBBS FRACP FCRPA^{j,k}

^a School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia

^b St John of God Murdoch Hospital, Western Australia

^c School of Nursing, Edith Cowan University Joondalup, Western Australia

^d Western Australia Cancer and Palliative Care Network, Perth, Australia

^e Calvary Health Care, Kogarah, New South Wales, Australia

^f Cunningham Centre for Palliative Care, Darlinghurst, New South Wales, Australia

^g The University of Notre Dame, Darlinghurst, New South Wales, Australia

^h Department of Nursing, University of Melbourne, Victoria, Australia

^l Research and Education Lead-Nursing, The Victorian Comprehensive Cancer Centre, Victoria, Australia

^j University of Western Australia, Crawley, Western Australia

^k Sir Charles Gairdner Hospital, Nedlands, Western Australia

* Corresponding author: University of Notre Dame Australia, 19 Mouat Street, Fremantle
WA 6959. Australia. Tel.: 08 94330103. leanne.monterosso@nd.edu.au

ABSTRACT

Purpose: To explore the post-treatment experiences and preferences for follow-up support of lymphoma survivors.

Methods: Two focus groups were conducted with 17 participants to explore informational, psychological, emotional, social, practical and physical needs, 6-30 months post-treatment for lymphoma. Perceptions regarding a potential model of survivorship care were also elicited.

Results: Thematic content analysis revealed five key themes: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care. Participants described a sense of loss as they transitioned away from regular interaction with the hospital at the end of treatment, but also talked about the need to find a “new normal”. Establishing post-treatment support structures that can provide individualised information, support, reassurance and referrals to community and peer support were identified as a helpful way to navigate the transition from patient to post-treatment survivor.

Conclusions: Participants in our study articulated a need for a flexible approach to survivorship care, providing opportunities for individuals to access different types of support at different times post-treatment. Specialist post-treatment nurse care coordinators working across acute and community settings may offer one effective model of post-treatment support for survivors of haematological malignancies.

KEYWORDS

Lymphoma; focus groups, survivorship; unmet needs

INTRODUCTION

Lymphomas are complex, potentially life limiting haematological (blood) malignancies that have a marked impact on quality of life and long-term health as a consequence of the aggressive or chronic nature of the treatments required to manage them (Carey et al., 2012). Lymphomas are immune-related cancers, broadly categorised as non-Hodgkin or Hodgkin lymphoma, and can be indolent or aggressive in nature (National Cancer Institute, 2016). Advances in treatment efficacy, including haematopoietic stem cell transplants, bone marrow support with blood component transfusions and white cell stimulation, along with advances in decreasing severity of infection risk, remission rates have improved (Lichtman, 2008).

In Australia, the context for this study, the 2012 estimated age-standardised rates (ASRs) of Hodgkin lymphoma incidence and mortality were 2.7 and 0.3 respectively (Cancer Australia, 2017a). These figures compare favourably with the European Union (EU-27) estimated ASRs of Hodgkin lymphoma incidence (2.3) and mortality (0.4) for the same period (Ferlay et al., 2013). The estimated Australian ASRs of incidence and mortality for Non-Hodgkin lymphoma were 19.1 and 5.4 respectively compared with EU-27 estimated ASRs of 11.6 and 3.8 respectively (Cancer Australia, 2017b; Ferlay et al., 2013)

Late and long-term side effects of treatment for lymphoma are common and can include fatigue; nutritional and physical activity deficits; fertility, sexuality and relationship concerns; and financial, employment and insurance issues (Allart et al., 2013; Arden-Close et al., 2011; Hall et al., 2013b). As advances in remission and cure rates improve, survivors are living longer with the consequences of their disease and

treatment (Sant et al., 2014), and many experience unmet needs that impact long-term health and wellbeing (Arden-Close et al., 2011). In a study of 53 long-term survivors of leukaemia and lymphoma (Zebrack, 2000), issues such as fatigue (n=23, 42%), remained an ongoing problem. The authors indicated fear of recurrence and financial concerns were also predominant factors in long-term survivors (no figures given). In a study of 437 haematology survivors in Australia and Canada, fatigue was identified as the greatest unmet concern (n=76, 16%), with the Australian cohort only (n=268, 61%) reporting a higher level of unmet financial concerns (n=39, 15%) (Hall et al., 2013a). Survivors of haematological malignancies have been shown to experience ongoing issues up to a decade or more post-treatment completion (Ferrer et al., 2011). Severe fatigue impacting functional capacity, emotional well-being and ability to return to work (Ferrer et al., 2011; Kangas et al., 2008; Oerlemans et al., 2013), and persistent cognitive impairment have been reported as debilitating long-term effects of treatment (van der Poel et al., 2014).

There is limited evidence available to inform the development of patient-focused haematology survivorship services in Australia. However, some evidence exists to indicate patients' preferences for post-treatment follow-up care. In a study of 66 cancer survivors representing the major haematological diagnostic groups (non-Hodgkin lymphoma 48%, Hodgkin lymphoma 12%, multiple myeloma 26%, leukaemia 14%), help with managing the fear of recurrence (42%) and ongoing case management (33%) were identified as unmet needs in the post-treatment period (Lobb et al., 2009). The opportunity to discuss experiences with a health care professional at treatment completion was identified as potentially helpful by 59% of participants. McGrath (2014)

reported findings from a qualitative study of 50 haematology survivors that explored use of routine telephone follow-up as a supportive care strategy. The sample represented the haematologic diagnostic groups of multiple myeloma (n=15), lymphoma (n=14) and leukaemia (n=17). Although telephone follow-up support was perceived by the majority of participants as potentially beneficial, many individuals did not support the idea as they wanted to 'move on' from cancer and would not have welcomed any contact.

Unlike more common malignancies such as breast and prostate cancer, evidence to inform the development of optimal follow-up guidelines for haematological survivorship care is lacking. This study set out to explore the experiences of and preferences for post-treatment support in Australian survivors of lymphoma 6-30 months post-treatment completion. For the purpose of the study, participants were deemed 'lymphoma survivors' if their haematologist had documented ongoing remission at least six months from treatment completion as our intent was to better understand post-treatment support needs.

METHODS

Methodological Framework

We undertook a qualitative, descriptive study (Neergaard et al., 2009; Sandelowski, 2000) utilising focus groups to explore and better understand the post-treatment experiences and support needs of lymphoma survivors. Focus groups allow for collection of a broad range of information and insight when little is known or understood about a topic (Neergaard et al., 2009; Sandelowski, 2000), while providing peer support and normalisation of experiences that group participants may share.

Excellent facilitation is important to ensure all participants have an opportunity to contribute as they wish, avoiding dominance of one or two experiences (Tausch and Menold, 2016). For the purpose of our study, a PhD prepared haematology clinical psychologist experienced in conducting focus groups with vulnerable populations, facilitated the digitally recorded focus groups and was supported by a specialist cancer nurse who acted as scribe to support detail and accuracy of interpretation of the digitally recorded focus group data.

The study was approved and undertaken in accordance with the ethical standards guiding the Human Research Ethics Committees of the relevant study site and university. Informed written consent was obtained from all participants prior to study participation.

Sample and setting

The study was undertaken at a large tertiary hospital with a comprehensive cancer centre in Western Australia. Between 1 July 2009 and 1 December 2013, 479 patients were referred to the hospital for treatment of lymphoma. Potentially eligible study participants were identified through a manual search of the hospital cancer registry patient records. Eligibility criteria included: i) aged over 25 years (in Australia Youth Cancer Services provide specialist, age-appropriate treatment and support for young cancer patients aged 15 – 25; ii) currently residing in Western Australia; iii) fluent in English; iv) completed treatment at least 6 months prior to study; and v) no cognitive impairment (as indicated in the medical record or during recruitment process where participants' ability to understand the study details and provide consent was assessed).

Exclusion criteria were patients who: i) had relapsed after first-line therapy; ii) were receiving care or follow-up or had undertaken an allogeneic transplant at another hospital; and iii) were undergoing work-up for autologous transplant. These exclusion criteria ensured experiences from other hospital sites and continuing treatment experiences did not influence the data collected.

Focus Groups

Two digitally recorded focus groups were carried out and data from each group transcribed verbatim. The transcriptions were checked for accuracy by the facilitator and support nurse, drawing on the notes taken during the groups and by listening to the recordings. Digital recordings of interviews and transcribed interviews were saved in password-protected files on a secure server.

A semi-structured interview guide was developed by the research team based on previously reported study data and clinical experience. Interview questions allowed for exploration of informational, psychological, emotional, social, practical, physical and spiritual aspects of post-treatment support need. Participants were also asked to talk about what they thought would have been or could be of help to them in the post-treatment period.

Data Analysis

The focus group transcript data were imported into NVivo to enable the management of data, and the process of data analysis. Thematic content analysis methodology was applied to explore and organise data into codes and themes (Braun

and Clarke, 2006). Transcripts were initially coded by CB. Subsequently each transcript was read independently by two other members of the study team (TM, KT). Thematic content analysis is a widely used analytical approach to qualitative data where themes, identified through coding, reflect key patterns within the textual data. This inductive approach was regarded as the most appropriate for our data, allowing themes to emerge from the content of the focus groups rather than considering data in response to questions pre-constructed by the researchers (Sarantakos, 2013). Data saturation point was reached following analysis of the two focus groups.

Rigour

Researchers (KT, CB and TM) met to discuss outcomes from the independent coding process and agreed on emerging themes. Discrepancies were discussed until consensus was reached. This allowed for development of a coding system that ensured a strategy of reliability throughout the process (Morse, 2015). Rigour of data analysis was ensured by applying the criteria of credibility, auditability and fittingness (Beck, 1993). Credibility was obtained through use of researchers to complete independent coding thereby ensuring categories accurately captured issues being discussed. Decisions related to allocation of discrete data elements to codes and fittingness of the codes, were demonstrated through extensive use of quotes or extracts from the data. Fittingness was further achieved by reflecting on the core concepts of unmet survivorship needs as confirmed by the research team (van Manen, 1997). Documentation of all steps in the analysis process, including opportunities for reflection

on the codes and debriefing about the content of the transcription ensured a coherent audit trail and therefore maintained auditability.

RESULTS

Participants

Of the 79 eligible lymphoma participants, 11 returned opt-out forms without providing a reason for this decision. The remaining 68 participants were contacted to further explain the study and provide focus group details. Of these 22 (32%) agreed to participate in a focus group, however five people did not attend on the day. Reasons for non-participation included: migrating overseas / interstate (n=2); recently relapsed or other cancer (n=5); family bereavement (n=1); working fulltime (n=1); declined to provide a reason when contacted by telephone (n=20); did not respond to voicemail message (n=13); severe symptom burden (n=1); unable to arrange transport (n=1); family objection (n=1); deceased (n=1).

The disease and demographic characteristics of the participants who did not take part in a focus group were comparable with those who participated. The age range of participants was 27 to 85 years with a mean age of 63.8 years (SD 14.5). The average time since last treatment was 14.6 months (SD 8.2) with a range of 6-30 months (Table 1).

Table 1 Participant demographic information (N=17)

Demographic variable	Focus Group 1 N=8	Focus Group 2 N=9
Gender		
Male	5	4
Female	3	5

Age		
25-35	0	1
36-50	2	0
51-64	1	2
65-79	5	5
80+	0	1
Married Status		
Married	5	5
De Facto	2	1
Divorced	0	2
Single	1	1
Diagnosis		
NHL	7	9
HL	1	0
Time since treatment completion		
6-11 months	4	
12-16 months	4	
17-24 months		7
25-29 months		2

Themes

Five themes emerged from analysis and coding of data: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care.

Information

Participants described difficulty in obtaining information from some members of the health care team after treatment had finished, feeling that professionals sometimes didn't understand or pre-empt the type of information and support they required post-treatment:

"My GP doesn't even really know that much about cancer, I think I've been teaching him ... but you could phone the Cancer Council and get quite a bit of information if you wanted to..." F_46yo_NHL

Participants indicated that a generic list of services and written information describing what to expect post-treatment would be helpful:

"An instruction sheet, so basically you've just had your last chemotherapy session one month ago, you've done your test, you're in remission, here's what you need to do for the next 12 months" M_48yo_HL

Compounding the issue of information support was recognition that retention of information given in preparation for end of treatment was challenging and that being given important information at different times or repeatedly may be helpful:

"I don't think anyone explains it all to us, is there a rule book? 'After 3 months, you should..." M_48yo_HL

"I think about things in between visits ... I have questions, so every three months I come back" F_73yo_NHL

Loss and uncertainty

Post-treatment side effects were spoken about in terms of loss; a loss of strength and physical function, a loss of control around nutrition and sustenance, a loss of energy and interest, and a loss of concentration. Comments around what to expect indicated most would have found it helpful to know how long side effects continue for, and what was normal:

"I just think, for me the chemo's given me this neuropathy and I mean I'm learning to walk again, and stuff like that, I can't feel my legs so it's like I'm on air cushions..." F_46yo_NHL

For some, the changes post-treatment were noticed when trying to get back to exercise and movement. They felt their physical abilities had declined:

"Yeah, I mean I walk the streets but I don't like doing that, I can go one block and then I'm exhausted. But I do feel better when I do something, but I can't do it long enough for it to benefit me." F_75yo_NHL

Many participants spoke about coping with the emotional experience and impact of their cancer treatment through avoidance:

"I can personally say that I did have my down moments ... but it's so hard and I thought it's worse being in this state, just get out- just get going, just don't think about it – it's easier to just get on with it rather than get depressed – I know that's easier said than done." F_28yo_NHL

Living with the fear of cancer recurrence was described as a common experience and although one or two participants talked about seeking help and reassurance to address their fear, most described getting on with living alongside the uncertainty and fear:

"I don't think you ever quite get rid of the shadow ... I don't think you ever get free of that slightly depressed feeling that's in the back of your head that it could come back." F_46yo_NHL

"I just want to be living well. ...if I'm going to live for only 5 more years, I just want to live well for those 5 years and extract as much as I can..." M_48yo_HL

The most commonly mentioned strategies used post-treatment to try and cope with the impact of their diagnosis, its treatment and on-going uncertainty included exercise, having children around, and hope for the future:

"[Weight lifting exercise class] I went twice a week and after 3 months I was really feeling much better and almost back to my energy level and I'm not even back to it now after a year, and that was a twice a week thing which was really good. So then I thought if I can go to weight lifting I can go to badminton, and I did that twice a week and that kept my mind occupied, something to do and being active and I think it is something that's very useful."
F_46yo_NHL

"I think having kids around brings you up a bit and makes you realise that life isn't so tough..." F_28yo_NHL

"...but also you need to be busy mentally and do things for the future and I really amazed myself in two months after chemo when I planted my vegetables and I thought 'will I be alive to eat it'." F_46yo_NHL

Family and significant others, support and post-treatment experience

Family members and significant others were largely seen as helpful but at times participants described experiences where they could be unintentionally dismissive and appeared to lack understanding:

"... people say to me, think positive. What does that mean? You know what I mean? I understand the concept of it..." M_48yo_HL

"... you're back doing the dishes, doing the washing, where as everyone kind of rallied before, yep you're alright now – off you go." F_52yo_NHL

"I've got young children, you know, - so you still are carrying on with your parental duties and all of that sort of stuff, but as soon as you've got your remission ... certain people in my life went – oh he's fixed, and suddenly you're not cancer boy any more so people suddenly switch off ..." M_48yo_HL

Some participants commented that as they physically and outwardly began to look better, others' expectations of them changed:

“But when your hair grows again and your skin colour comes back and you’re not passed out in the chair most of the time, ... people tend to quickly move on from that where as you haven’t you know what I mean, you haven’t’. ... whilst you’re not having chemo any more it’s not finished for you yet...” M_48yo_HL

Some participants had found value in attending peer support groups where others understood what they had gone through and experienced:

“It’s just like everybody’s been saying, it’s nice to come where people understand you – I mean that my family and friends have all been amazing but they don’t understand. They just all say yes we know you’re going through it and we feel for you, but they just don’t understand.” F_46yo_NHL

One participant found the support received from belonging to a group of other young people made a big difference to their experience:

“... I couldn’t kind of get along with the people I was having treatment with just because our lives were so different. It was so helpful ... I just went to those little meetings and there were people my age talking about the same sort of stuff.” F_28yo_NHL

But for others a group situation was difficult, at times overwhelming, leaving them feeling uncomfortable:

“You’re always identified as the cancer person or with the cancer group ... but sometimes it weighs a bit heavy, like the people there you don’t necessarily want to broadcast it to the whole world.” F_75yo_NHL

Transition, connectivity and normalcy

The relationships established during treatment and the security that came through knowing they were being treated and monitored closely by an expert or team who genuinely cared for them was greatly valued:

“I just had this feeling of ‘wow’ I am so privileged to have the treatment and the knowledge of the professional care here, the medical staff, all of them ...” F_73yo_NHL

"I was under Dr X and they always said that you know, if you ever have any problems, ring me personally and you can come straight in, don't bat an eyelid. So I was very confident in the team and I knew there was support if I needed it." F_52yo_NHL

But with completion of treatment and the transition to a different relationship with the hospital and treating team, some participants felt that although their medical needs were met, they did not feel connected or understood holistically:

"... my specialist is great, ... excellent doctor, but I walk in there and you get nothing other than your um, medical moment for want of a better term- there's no, you know, like [the doctor's] just happy that you've got a remission so [the doctor's] done the job, you know, and it was literally, ok 'so what happens now?' 'I'll see you in 3 months.'" M_48yo_HL

Leaving the support of the hospital was experienced as a loss. Some felt their safety net and reassurance had gone along with the camaraderie of other patients who were undergoing a similar experience. Many were left wondering what their purpose was moving forward:

"I used to be this guy that had a sense of purpose and a reason for going— all of a sudden all of that is taken away and no-one's telling you what to do next, it's just come and see me in 3 months' time... for me, a massive sense of loss. It's a loss of purpose and identity, actually. ... You know I used to call them my chemo buddies and yeah you'd sit with the same people every time and the nurses, everybody that you just had a connection with and it's just severed." M_48yo_HL

Participants spoke about being so focused on getting through treatment they had not had time to process what would happen when treatment finished. There was a sense of adjusting to this change post-treatment without adequate preparation. One participant talked about having to take responsibility for herself again:

"... but I felt um hang on, they've spewed me out the door and I thought; now I'm going to have to do something for myself." F_46yo_NHL

Overwhelmingly, participants wanted things to return to normal or a new normal post-treatment. They wanted to get on to with their lives, get back to work and move forward; to put cancer to one side or leave it behind:

“... and I got to a point after treatment where I just told my friends to stop talking about it and stop asking I felt like it was taking over my life and I wanted other things to focus on.”
F_28yo_NHL

But moving from the structure of treatment and hospital support back into “normal life” was difficult. Some expected to return to their life as it was pre-diagnosis and found it challenging when this did not happen:

“... when your chemo’s finished they kept telling me it would take a year to get back to normal and I’m like ‘you don’t know me, that’s not going to happen, I’m going to walk out of here and flip a switch and I’m going to be back to normal’ well it’s not the case.”
M_51yo_NHL

The need to find a new meaning or purpose post-treatment and a realisation that one had changed and that what matters in life had changed were strong elements in the data gathered:

“You lose kind of like your purpose in life, you’re not the same like you used to be before your cancer.” F_46yo_NHL

“You’re not so cocky now, ... I really have sympathy for others, whereas before – now I really listen to them.” M_66yo_NHL

“I never want to be a CEO again, I never want to be in that place, I want to be there for me and my family... it certainly makes you more empathetic- makes you have more empathy for others, it certainly gives you that gene, because I certainly didn’t have much at all [before].” M_48yo_HL

Moving away from the “cancer label” and not wanting to be stigmatised was important for many participants as they transitioned into the post-treatment phase:

“When I went to the gym with the cancer group ... I would have really benefitted from having an individual membership and being by myself ... you get a card and ‘oh, are you with the cancer group?!’ I don’t want to be labelled all the time ... even though you’re looking for support.” F_52yo_NHL

Person centred post-treatment care

Participants recognised that support needs varied from diagnosis through treatment and on into follow-up, the post-treatment stage. But when discussion was guided during the focus groups to services or support that would have been useful post-treatment, participants talked about the need for this to be individualised, stating it would be difficult to get a “one size fits all” approach to their support needs:

“A group is great. But if you were ringing up asking for help you’d probably want one-on-one.” M_70yo_NHL

However, most participants felt that some sort of “check-up” (follow-up) appointment at the hospital around one month post-treatment would be helpful where the focus was on the experience of the individual rather than the disease:

“I think a follow-up would be a good idea because there aren’t any follow-ups as such. A formal follow-up, either with a clinical psychologist or nurse when you come for your cancer follow-ups.” F_70_NHL

Some participants suggested this appointment should be mandatory, a logical transition from hospital care to a “new normal”:

“I also don’t think that if you make someone available it will do any good. You got to send me there. You’ve got to have an appointment for me to go there otherwise I’ll use tomorrow [as an excuse not to go].” M_70yo_NHL

Wanting a personal connection with a qualified professional was a strong theme, a person to seek reassurance from and check worrying symptomology:

“When you can phone somebody who is there for you right then and there specifically for that reason, to say well if you’re worried, yes go and see - because you doubt yourself, you think am I being neurotic about every little ache or pain ... am I being silly or should I see the doctor, maybe I’m just being silly. It would just be nice to have that support that you know that there’s the cancer nurse there for you, somebody in the know that can say ‘don’t worry about it’ or ‘yes come in and see your specialist.” F_46yo_NHL

Peer support was also described as valuable when the peer had undergone a similar experience and for some people it was important to get away from “the medics”:

“...probably the best thing that could happen to those other people is not go and see the specialist, but sit in a room with us.” M_48yo_HL

“...I would have appreciated a formal session like this, talking to people who’ve already been where I was and where I’m going.” M_51yo_NHL

DISCUSSION

This research contributes to a small but growing body of literature reporting on post-treatment experiences and support needs of survivors of lymphoma. Data from our study identified five key themes of relevance to the post-treatment experience of lymphoma survivors: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care.

Information needs varied across participants in our study, reflecting findings from other qualitative studies of haematological cancer survivors (Gansler et al., 2010) and emphasising the importance of flexibility in services developed if they are to successfully address the information needs of post-treatment survivors. Participants in this study described difficulty in accessing the kind of information they needed from tertiary and community health professionals once the acute treatment period was over, a finding commonly reported in studies of non-haematology cancer survivors (Taylor

and Monterosso, 2016). Participants described a sense of loss in terms of support, connectivity and reassurance when they transitioned away from active care to the post-treatment phase, indicating that there is opportunity to develop and implement tailored post-treatment preparation interventions to enhance the experience and wellbeing of haematology survivors. Living with fear of cancer recurrence was a common experience for participants in our study, and is widely recognised as one of the most distressing or prevalent concerns of cancer survivors (Butow et al., 2015; Park et al., 2013). Helping people find strategies to live with fear of recurrence is a key issue in the advancement of post-treatment survivorship care.

Dealing with the side effects of treatment was described as one of the most difficult aspects of the post-treatment phase. Participants in our study felt they weren't adequately prepared to manage the issues they faced, and suggested that information on the duration of side effects, what to expect and how to cope with them would have been helpful. This finding offers an important and achievable target for improvement in post-treatment care of survivors of lymphoma.

Some participants described difficulty in adjusting to a "new normal" post-treatment and actively sought a new sense of purpose and identity. A clear sense of moving away from cancer and putting it to one side so that a new norm could be established was evident for some. This finding suggests that working with patients ahead of treatment completion to prepare a "new narrative" for themselves may better support people to transition from their identity as a cancer patient.

Although there was a general recognition of the value of support provided through existing family and friend networks, some participants felt that once they started

to look and feel better, family or significant others' expectations of what they were capable of doing exceeded what they felt ready or able to do. The need to develop survivorship services that directly support families or important others so they can be effective partners in the transition to life post-treatment, as well as keep themselves well, is evident.

In response to questions about helpful components of post-treatment care, many participants described the ability to contact a health professional to seek reassurance, check in about concerning symptoms and get advice and information as an important element in enabling confident transition to survivorship. Specialist post-treatment nurse care coordinators working across tertiary and community settings may offer an effective model to address this need for survivors of haematological malignancies.

A follow-up appointment post-treatment focusing on reflection of the diagnosis and treatment experience as a way of being able to "move on" to the next phase of life was also recommended as a potentially useful intervention and is worthy of consideration as one component of person-centred post-treatment care.

Limitations

The limitations in this study include the small sample size and the single site recruitment. However, the findings do offer valuable insight into the post-treatment experiences and support needs of participants in our study, and offer tangible opportunity for the development of post-treatment services and interventions targeted to the needs of survivors of lymphoma, although more work needs to be done to establish the credibility of our findings to other haematological cancer patients' post-treatment.

Participants chose to opt-in and therefore it is not possible to assess whether those with greater needs or worse experiences of post-treatment care excluded themselves.

However, experiences of those people who gave their time to take part have provided a valuable addition to a small but growing body of research in this area. The use of a clinical psychologist as the facilitator for the focus groups (disclosed to participants at the beginning of the focus group) may have influenced the issues participants chose to share or withhold dependent on previous access to or attitudes toward a psychologist.

CONCLUSION

Survivors of lymphoma experience many and complex post-treatment issues that require tailored intervention as part of a comprehensive package of person-centred post-treatment care. Data from our study suggest that integration of professional, peer and family/important other support strategies may prove to be most effective. Specialist haematology nurse care coordinators working across tertiary and community settings could offer a feasible and efficient way of coordinating tailored programs of support around survivors of haematological malignancies.

Acknowledgements: We thank all participants for their willingness to participate in this important study.

Funding: The authors disclose the study was supported by funding from the Cancer and Palliative Care Research and Evaluation Unit, Western Australian Cancer and Palliative Care Network.

REFERENCES

- Allart, P., Soubeyran, P., Cousson-Gélie, F., 2013. Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. *Psycho-Oncology* 22, 241-249.
- Arden-Close, E., Absolom, K., Greenfield, D., Hancock, B., Coleman, R., Eiser, C., 2011. Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. *Psycho-Oncology* 20, 1202-1210.
- Beck, C.T., 1993. Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research* 15, 263-266.
- Butow, P., Fardell, J.E., Smith, A., 2015. Fear of cancer recurrence: An overview and Australian perspective. *Cancer Forum* 39, 95-100.
- Cancer Australia, 2017a. Hodgkin Lymphoma in Australia. Australian Government. <https://lymphoma.canceraustralia.gov.au/statistics>. Accessed 6 February 2017.
- Cancer Australia, 2017b. Lymphoma in Australia. Australian Government. <https://canceraustralia.gov.au/affected-cancer/cancer-types/lymphoma/hodgkin-lymphoma-statistics>. Accessed 6 February 2017.
- Carey, M., Anderson, A., Sanson-Fisher, R., Lynagh, M., Paul, C., Tzelepis, F., 2012. How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Education and Counseling* 88, 87-92.

- Ferlay, J., Steliarova-Foucher, E., Lortet-Tieulent, J., Rosso, S., Coebergh, J.W.W., Comber, H., Forman, D., Bray, F., 2013. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. *European Journal of Cancer* 49, 1374-1403.
- Ferrer, R.A., Huedo-Medina, T.B., Johnson, B.T., Ryan, S., Pescatello, L.S., 2011. Exercise interventions for cancer survivors: A meta-analysis of quality of life outcomes. *Annals of Behavioral Medicine* 41, 32-47.
- Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T., Esparza, A., 2010. Evolving information priorities of hematologic cancer survivors, caregivers, and other relatives. *Journal of Cancer Education* 25, 302-311.
- Hall, A., Campbell, H.S., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R., Carey, M., 2013a. Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology* 22, 2032-2038.
- Hall, A., Lynagh, M., Bryant, J., Sanson-Fisher, R., 2013b. Supportive care needs of hematological cancer survivors: A critical review of the literature. *Critical Reviews in Oncology/Hematology* 88, 102-116.
- Kangas, M., Bovbjerg, D.H., Montgomery, G.H., 2008. Cancer-related fatigue: A systematic and meta-analytic review of non-pharmacological therapies for cancer patients. *Psychological Bulletin* 134, 700-741.
- Lobb, E.A., Joske, D., Butow, P., Kristjanson, L.J., Cannell, P., Cull, G., Augustson, B., 2009. When the safety net of treatment has been removed: Patients' unmet

- needs at the completion of treatment for haematological malignancies. *Patient Education and Counseling* 77, 103-108.
- McGrath, P., 2014. Patient perspectives on the usefulness of routine telephone follow-up as psychosocial support for hematologic malignancies: Australian findings. *Oncology Nursing Forum* 41, 40-44.
- Morse, J.M., 2015. Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research* 25, 1212.
- National Cancer Institute, 2016. NCI dictionary of cancer terms. <http://www.cancer.gov/dictionary>. Accessed 3 April 2016.
- Neergaard, M.A., Olesen, F., Andersen, R.S., Sondergaard, J., 2009. Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology* 9, 52-52.
- Oerlemans, S., Mols, F., Issa, D.E., Pruijt, J.H., Peters, W.G., Lybeert, M., Zijlstra, W., Coebergh, J.W., van de Poll-Franse, L.V., 2013. A high level of fatigue among long-term survivors of non-Hodgkin's lymphoma: Results from the longitudinal population-based PROFILES registry in the south of the Netherlands. *Haematologica* 98, 479-486.
- Park, C.L., Cho, D., Blank, T.O., Wortmann, J.H., 2013. Cognitive and emotional aspects of fear of recurrence: Predictors and relations with adjustment in young to middle-aged cancer survivors. *Psycho-Oncology* 22, 1630-1638.
- Sandelowski, M., 2000. Whatever happened to qualitative description? *Research in Nursing & Health* 23, 334-340.

- Sant, M., Minicozzi, P., Mounier, M., Anderson, L.A., Brenner, H., Holleccek, B., Marcos-Gragera, R., Maynadié, M., Monnereau, A., Osca-Gelis, G., Visser, O., De Angelis, R., 2014. Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EURO CARE-5, a population-based study. *Lancet Oncology* 15, 931-942.
- Tausch, A.P., Menold, N., 2016. Methodological aspects of focus groups in health research: Results of qualitative interviews with focus group moderators. *Global Qualitative Nursing Research* 3.
- Taylor, K., Monterosso, L., 2016. Systematic Review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *The Australian Journal of Cancer Nursing* 17, 6-12.
- van der Poel, M.W., Oerlemans, S., Schouten, H., Mols, F., Pruijt, J.H., Maas, H., Van De Poll-Franse, L., 2014. Quality of life more impaired in younger than in older diffuse large B cell lymphoma survivors compared to a normative population: a study from the population-based PROFILES registry. *Annals of Hematology* 93, 811-819.
- van Manen, M., 1997. *Researching lived experience: Human science for an action sensitive pedagogy*, 2nd ed. Althouse, London Ontario.
- Zebrack, B., 2000. Quality of life of long-term survivors of leukemia and lymphoma. *Journal of Psychosocial Oncology* 18, 39-59.