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Author(s)	Hackett, Fidelma; Dowling, Maura
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ABSTRACT

Aims and Objectives: The aim of this study was to explore lymphoma survivors' experiences on their end of treatment and follow-up care at a large urban haematology centre in Ireland.

Methods: This was a qualitative study using semi-structured interviews with lymphoma patients post treatment (n=14). Thematic analysis guided the analysis of interview data. The study adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines.

Findings: Five main themes were identified following analysis of the interview data: dealing with uncertainty, changed relationships, returning to work, extended recovery time and concerns for the future. Findings of note were that some participants were unaware that their treatment had ended, many experienced recurrent infections which prolonged recovery time, and many had no recall of discussions on healthy lifestyle behaviours or recommended screening programmes at their follow-up visits.

Conclusions: The findings suggest that the period of transition from active treatment to survivorship can be challenging for lymphoma survivors and they experience ongoing needs. While the challenges of survivorship in lymphoma mirror those of other cancers, this cohort of patients require focused preparation for the end of active treatment and the transition to follow-up care. Moreover, this patient group require repeated specific education on late effects and second cancers, education with regards to identifying the signs of cancer recurrence and promotion of healthy lifestyle practices.

Relevance to clinical practice: This study highlights the importance of a dedicated end of treatment visit with the clinical nurse specialist to confirm the completion of active treatment with lymphoma patients and focus on health promotion.

Key Words: Cancer, Haematology, Lymphoma, Survivorship, Qualitative.

What this paper contributes to the greater clinical community?

- An understanding of the challenges faced by lymphoma survivors when their treatment ends.
- Highlights that some lymphoma patients may not be aware that their treatment has ended.
- Highlights the need a dedicated end of treatment visit with a clinical nurse specialist to prepare lymphoma patients for transition to follow-up care.

- Highlights that many lymphoma patients can experience recurrent infections following treatment and need to be provided with specific health promotion advice for survivorship.

Introduction

Lymphomas are cancers of the immune system mainly categorised as either Non-Hodgkin lymphoma (NHL) or Hodgkin lymphoma (HL). HL is the 20th most common cancer in the UK with 2,110 new diagnoses in 2015 (Cancer Research UK) and the 17th most common cancer in Ireland, with an average number of 140 cases diagnosed each year (National Cancer Registry Ireland (NCRI)). NHL is the sixth most common cancer in the UK with 13,682 new diagnoses in 2015 (Cancer Research UK) and the fifth most common cancer in Ireland, with an average number of 771 new cases diagnosed each year (NCRI). Treatment pathways are complex and unique to each subtype and include 'watchful waiting', chemotherapy, antibody treatment, radiation and stem cell transplantation (Irish Cancer Society). Lymphoma survival of 10 years or more is high at 63% for NHL and 80% for HL (Cancer Research UK).

Increasing incidence and survival rates means that survivorship issues for people with lymphoma are increasingly relevant. Managing the transition phase from initial treatment to long term survivorship is vital to long term cancer survivorship outcomes (Hewitt *et al.* 2006). A coordinated approach to cancer survivorship care is recommended. Survivorship care should be comprehensive and include holistic assessment and surveillance for recurrence. Moreover, it should address prevention and screening for new cancers, early detection and interventions for the physical,

psychosocial and economic late effects of cancer treatment, promotion of healthy lifestyles practices and co-ordination of care between health care providers (Denlinger *et al.* 2014, National Comprehensive Cancer Network).

While studies reporting on the experience of cancer survivorship care predominately focus on solid tumours such as breast, prostate and lung cancer, more recent reports on haematology cancer patients' survivorship experiences highlight their many complex problems (Monterosso *et al.* 2017). Specific needs include the importance of informational, emotional and support needs in the first twelve months following completion of treatment (Lobb *et al.* 2009), and in particular information on fertility and sexual function (Hammon *et al.* 2008, Matheson *et al.* 2016). Assistance with sexual relationships, body image are also major concerns for this group (Matheson *et al.* 2016; Parry *et al.* 2011), as well as dealing with medical and living expenses, emotional difficulties and problems with employment, life insurance, childcare and family (Parry *et al.* 2011). In addition, other reported needs for haematology cancer survivors include managing fatigue and the need to talk to someone who has been through a similar experience (Hall *et al.* 2013).

Methodology

A descriptive qualitative approach was used, with a view to understanding the experiences of lymphoma survivors following completion of active treatment. Descriptive qualitative research does not aim to generate theory or interpret findings within a theoretical framework. Rather, it is an approach to providing an accurate description of events and people's response to a specific experience (Sandelowski, 2000). The study adhered to the

consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong *et al.* 2007).

Ethical Considerations

Ethical approval was granted by the hospital's research ethics committee. Access to medical records without consent was granted for the early stage of the research study in order to identify participants who fulfilled the inclusion/exclusion criteria. Written consent was obtained from each participant prior to their interview. A pseudonym was assigned to each participant. A distress protocol was developed as there was potential participant distress when discussing and reflecting on their end of treatment experiences and the effects of cancer and treatment on their lives.

Inclusion Criteria

Eligibility criteria for inclusion in the study included having a diagnosis of lymphoma which required intensive treatment, having completed treatment between 3 to 60 months prior to the study commencement, aged over 18 years, able to give consent and having fluent spoken English not requiring an interpreter.

Recruitment and Participants

The study was undertaken in a large urban university hospital specialist cancer. Potentially eligible participants were identified from the hospital's database which yielded a potential sample population of 83 adult lymphoma patients attending the cancer centre over a five-year period from 2011-2015. Nineteen eligible participants were excluded for the following reasons: cognitive impairment and unable to give consent (n=3), underage (n=1), non-fluent in English and requiring an interpreter

(n=1), moved away and no longer attending the centre (n=2), surveillance only, not required treatment (n=5), oral treatment (n=5), and extended treatment (n=2).

Purposive sampling was utilised in order to ensure that a range of age groups were represented, specifically the adolescent and young adult population (18-39yrs), middle age (40-65yrs) and older age (>65 yrs.). Age is justifiable as a sampling criterion on the basis that the implications of cancer treatment and concerns in the post treatment period can vary by lifespan age (Jones, 2015). Three cases were set as the minimum number of cases required for each age category. Of those selected as suitable for the study (n=64), all were invited by letter of invitation to participate in interview and requested to contact the first author by telephone if they wished to participate in the study.

Data Collection

All one-to-one interviews were semi-structured audio-recorded and conducted by the first author. The interviews lasted between 18 minutes to 60 minutes with an average time of 44 minutes. The questions asked were related to feelings once active treatment was complete, feelings and opinions regarding challenges once treatment was complete and knowledge regarding the end of treatment visit and information received. One final question was informed by haematology survivorship literature (Taylor and Monterosso, 2015; Marbach and Griffie, 2011; Morgan, 2009) and focused on participants' views on a survivorship care plan (Table 1).

Data Analysis

All interviews were transcribed verbatim. Data analysis was guided by thematic analysis as outlined by Braun and Clarke (2006). This process allows for flexibility in searching for codes and themes as its six phases can be used interchangeably (Clarke and Braun, 2006). Both authors repeatedly read each transcript interview and generated initial codes. These initial codes numbered over 60 and were given distinct labels such as 'unprepared'; 'persistent physical effects'; 'concept of cancer'; 'contact'; 'security'. In phase four of the analysis process, the generated codes were discussed by both authors and five major themes (with subthemes) were agreed. The fifth phase of analysis involved a review of the themes. Therefore, the transcripts were read over again by the first author and themes previously identified were further refined and agreed by both authors (Figure 1). The final phase of analysis required integration of vivid interview data in support of the identified themes.

Comprehensive field notes were taken by the first author following each interview. A reflexive diary was also kept and records made before and after the interviews, and during data analysis. Questions guiding reflexivity included the following: Are there any personal characteristics of mine that may have affected the study? (age, gender, staff member); Do I hold any assumptions that I held about the participants? What do I think were possible perceptions held by participants about me? What did I expect to find during analysis that did not turn up? What did I interpret in analysis that I did not expect to find? Reflections on these questions were then discussed with the second author.

Results

The final number of participants interviewed was 14 (Table 2). While a total of 18 participants contacted the first author, 15 expressed their agreement to participate and 3 declined (busy with college, exams or travelling). One participant later declined (panic attacks) and one participant was unable to commit time to the interview process. A participant who did not fit the criteria (as he had completed treatment eight years prior to the study) was also interviewed. He contacted the first author requesting to participate (his daughter was a study participant). While he did not meet the study's specific inclusion criteria, the authors concluded that his request to be interviewed should be facilitated in order to uphold the principle of beneficence, i.e. the potential of the qualitative interview as 'therapeutic' (Birch and Miller, 2000) and the principle of non-maleficence, i.e. the potential to cause distress if not provided the opportunity to share his experience.

Following analysis and coding of the interview data five themes emerged as the most salient to participants, as follows: dealing with uncertainty, changed relationships, occupational engagement, extended recovery time and concerns for the future (Figure 1).

Dealing with Uncertainty: "What happens now?"

This major theme describes participants' experiences when their treatment ended. Some participants found it uneventful but others described it as an abrupt and traumatic transition. The latter response was expressed most strongly by those who had undergone intensive primary chemotherapy and were transferred to scheduled follow up care once remission was achieved. These participants missed monitoring by the treatment team.

"it's a bit like throwing a bird up that had a broken wing to see if it can fly and some of them soar and others are like oh oh maybe I want to go back into the

cocoon [...] you know it's a warm cozy place where you feel safe" (Emily,37, HL)

This was in contrast to their experience of feeling supported and cared for during the treatment phase and a sense of loss of security was evident.

"It is almost a comfort to come in, because you are coming in and you think [...] that you are fighting your battle on that ground, that's your little battleground, and you do it and you feel surrounded by soldiers [...] so it is a bit scary when you have to stop doing that" (Martha,56, FL)

Participants also described feeling unprepared and alone in managing the ongoing side effects from primary treatment and emerging late effects.

"not knowing what to expect [...] because you're told all the things that could happen to you when you go through chemo [...] you're told what to expect" (Lucy,28, HL)

"When you are at home you are on your own and this is only happening to me and this is the worst possible situation ever" (Michelle,44, DLBCL)

A common expression among participants was what to do now and how long it would take to return to normal.

"I remember thinking what do I do now? I really wanted somebody to tell me what I did now" (Emily,37, HL)

Participants spoke about their feelings on being told they were in remission and a sense of disappointment.

"It was very uneventful, I guess I thought it would be kind of a bit of a thing or I was expecting it to be more but it wasn't [...]" (Lucy, 28, HL)

However, some participants were positive in their descriptions of the transition from intensive care in the treatment phase to scheduled follow up. These participants had the continued support, reassurance and monitoring of a treatment team because they were on maintenance treatments (antibody therapy, P.C.P. prophylactic therapy

or immunoglobulin replacement therapy) or they had more frequent and intensive visits because of transplant follow up.

“it was nice to come every month because [...] you get that reassurance”
(Frank, 74, FL)

Changed Relationships “All the relationships that matter are stronger”

The majority of participants described themselves as lucky to have achieved remission and positively compared their diagnosis of lymphoma to other cancers. Many described how deeper relationships were forged with partners. One participant described his relationship with his fiancée as stronger for having survived cancer together and felt that the experience assured him of their relationship *“almost like a guarantee”* (Ryan, 31, HL). Another became emotional when speaking about the support his wife gave him throughout the whole experience, *“I will never forget what she did for me”* (Lorcan, 77, DLBCL). Strong supportive relationships with family was also valued by many participants.

“if I had been in any doubt about how much I was loved I figured it was thrown at me during all that time” (Emily, 37, HL).

Not all relationships were seen as supportive and some described lost relationships as friends and family were unsure of how to deal with the diagnosis of cancer.

“I'd have a large circle of friends but that kind of whittled down a small bit, people got scared and weren't sure how to talk to me” (Ryan, 31, HL)

Many described companionships with other patients during treatment which were formed by simply chatting in the treatment area. The open plan layout of the day unit was referred to by many as advantageous due to proximity to other patients for *“sharing battle scars and battle stories”* (Ryan, 31, HL). This support was not

available in the post treatment period, and only two participants shared experiences of accessing cancer support groups.

Occupational engagement “I need to go back and get everything back to normal”

The experience of employment and occupational engagement was an important issue for participants who had previously been in employment. Returning to work was discussed in terms of getting back to normal, *“treatment won’t be finished until I get back working”* (Owen, 51, TCL), or *“a new normal”* (Emily, 37, HL). Some participants spoke of their inability to decide on their capacity for return to work and found the advice from health care professionals that *“it was entirely up to you”* (Emily, 37, HL) unhelpful. Returning to work for personal reasons was identified by many participants as important.

“when I was working I was a very good worker, I really loved my job [...] There’s a big gap there” (Owen, 51, TCL)

For others, it was important for mental well-being and keeping occupied both physically and socially and was a source of emotional support.

“You need to get through it. I keep busy; I’m always busy” (Martha, 56, FL)

Employer support and flexibility were important factors facilitating return to work. Participants returned to work initially with the option of flexible hours, shorter working hours or incremental hours which allowed them sufficient time to recover from lingering fatigue.

“work was very good to me [...] if I felt tired in the evening I often went home at lunchtime and I wouldn’t come back in at all.” (Dermot, 56, DLBCL/FL)

The impact of lingering immune-deficiency on their ability to return to previous employment was an issue for some participants:

“I’m not hyperaware of germs or anything but I do know that with the illness I’ve got that I don’t need to be catching things” (Martha, FL, 56)

Extended recovery time “the little reminders”

The majority of participants described effects from their disease and treatment which lingered long after treatment, referred to by one participant as the “*the little reminders*” (Emily, 37, HL), another as “*damaged by chemo*” (Fiona, 80, MZL), and another as “I can’t have babies” (Emily, 37, HL). The most common effects experienced included fatigue, recurrent infections and weight gain.

Most participants described ongoing fatigue which affected their ability to socialise, function at work or spend time with family.

“I had no hair, I was exhausted and you are just really a shell of a person” (Michelle, 44, DLBCL)

“You find you continue even up to two years to get rid of the tiredness at times” (Dermot, 56, DLBCL/FL)

“the other I suppose obvious symptom was fatigue I was very, very tired for months afterwards, I was knackered at the end of each day” (Frank, 74, FL)

Recurrent infections were reported by most participants as persisting for a number of years post treatment. For some, this had the effect of prolonging recovery time, “*I got a bad infection [...]that knocked me out two months*” (Owen, 51, TCL). For others it was a source of anxiety and worry that it may be a symptom of recurrence:

“things last a long time and you don’t know if that is normal or not...and you don’t know if this is a sign of something else so all this is running in the back of your mind all the time” (Michelle, 44, DLBCL)

All participants expressed their desire to manage infection without hospital intervention.

“Too busy here [hospital] [...] don’t like disturbing the set-up here.” (Jack, 71, FL)

“But the local G.P. sorts that out. I can’t be coming into you here [hospital] for small things like that” (Owen, 51, TCL)

Weight gained during treatment and fluctuating weight after treatment was an issue identified by most participants:

“I do seem to have a problem with weight I watched my diet I am very good now and all that kind of thing but I do plenty of exercise and all that but the weight don’t seem to be able to go down” (Dermot, 56, DLBCL/FL)

Many used dietary changes and exercise regimens with varying degrees of success.

Concerns for the future: “Still in treatment”

Lymphoma patients continue structured follow-up with their hospital consultant after treatment. This was viewed in different ways, from one of pragmatism *“like you’d bring your car for a service I just need to go in for a check-up as well”* (Ryan, 31, HL), to one of obstruction, preventing transitioning to life after treatment: *“I need to cut the umbilical cord with here and to move on”* (Emily, 37, HL).

The fear of recurrence and concerns related to recurrence was discussed by many participants. These fears intensified in the days preceding and the day of their scheduled visit.

“The only time I’d worry about it or be nervous about a thing is when I’m due for my check-up” (Max, 72, DLBCL).

[You are] “*there to find out whether or not you have cancer again [...] it’s awful, it’s a horrible feeling*” (Emily, 28, HL).

In general, the worry regarding recurrence was greatest in the initial year or two post treatment but reduced with time. Participants worried that any physical symptom experienced between follow-up visits was a sign of recurrence. Many participants reported vigilance for signs of recurrence, in particular, checking for lymphadenopathy.

The lengthening of the time interval between visits was discussed by all participants except those with indolent lymphoma who continue three monthly visits indefinitely. In particular this was seen as a positive sign or often referred to by participants as a “promotion” or one participant asking “*will I get the marathon?*” (Max, 72, DLBCL) referring to the yearly interval.

Those with indolent lymphoma, some of whom had already experienced recurrent disease, were more accepting of the risk of recurrence “*it’s just part of life and you get on with it*” (Frank, 74, FL) and appeared to accept the limited durability of their remission and the inevitability of recurrence “*I always expected it will come back sometime*” (Andy, 52, FL). But they still valued the scheduled follow up visit and the reassurance that “*nothing has gone on in the last three months*” (Frank, 74, FL).

A high value was placed on the availability of a contact number if they experienced a worrying symptom that was potentially a sign of recurrence. This direct route of contact with the hospital team was described as “*like having an alarm in your house*” (Ciara, 72, DLBCL) and was viewed with great significance and value by the majority

of participants. Many participants described “scares” or times when they experienced night sweats or other worrying symptoms and were reviewed quickly and reassured by the hospital team.

The scheduled follow-up hospital visit was viewed as a comprehensive surveillance for cancers and health problems. However, one unexpected finding was that continued scheduled follow-up was perceived by some participants as being “in treatment”.

At follow-up, many participants did not recall any discussions on healthy lifestyle behaviours or recommended screening programmes. Moreover, participants reported little education on the signs of lymphoma recurrence. Those who were vigilant about checking for lymphadenopathy had learned to do so by copying the technique used for the medical examination during clinic visits.

Thoughts on a survivorship care plan

When questioned on a survivorship care plan, most participants were in favour of a written summary of treatment and follow up, in particular information and reassurance with regards to managing ongoing symptoms, late effects and expected recovery time frame. Some felt unprepared for managing the ongoing effects of treatment and were given no opportunity to discuss these issues. At follow-up, the majority of participants expressed the view that a review by a nurse specialist soon after they were in remission would be their choice. Most participants also indicated they wanted the care plan in written format, although some favoured it electronically,

and to be made available to their General Practitioner, other consultants involved in their care and carers.

Discussion

This study adds to the limited published qualitative literature describing the experiences of lymphoma survivors. For some, the transition phase when treatment ended was uneventful but for others it was abrupt and traumatic and they felt unprepared. This was felt most strongly by those who had undergone intensive primary chemotherapy and were transferred for scheduled follow up once remission was achieved. These participants missed monitoring by the treatment team. These findings are also reported by other lymphoma survivors who describe a sense of abandonment and feeling unsupported when interaction with the treating team is less frequent (Monterosso *et al.* 2017; Parry *et al.* 2011).

This finding suggests the need for health care providers to communicate that the time of transition from active treatment can be challenging and provide a point of contact and appropriate referral to support services. Younger lymphoma survivors in particular may be more likely to report unmet needs in dealing with emotional and family problems (Parry *et al.* 2012) and having higher levels of cancer -specific distress (Brant *et al.* 2011; Jones *et al.* 2015). In addition, young adults who received combined treatment modalities were found to have substantial symptoms at six-month time point following treatment (Muffly 2016).

Positive life changes and more meaningful relationships were also described by participants. This is consistent with previous research in the area of post traumatic growth, which relates to benefits in life perspectives, interpersonal relationships and

self-perception following an event, both generally (Calhoun and Tedeschi 2001) and specifically with NHL survivors (Bellezi *et al.* 2007). However, this fades over time as the experience integrates into daily life (Cormio 2010).

Participants also described longer-term physical effects such as recurrent infections and fatigue. These findings reflect those reported by long term cancer survivors (n=3138) in the US, and survivors' greatest need was for information on long-term treatment side effects (Playdon *et al.* 2016).

The prolonged effect on the immune system may be accounted for by immune deficiency which is inherent in haematological malignancies and compounded by the effect of combined modalities of chemotherapy, radiotherapy, immunosuppressive therapy and immunotherapy treatment on the immune system.

Additionally, the majority of participants, some post treatment up to five years, described ongoing fatigue. This is reported in other studies of haematology cancer survivors (Korzun *et al.* 2014, Hall *et al.* 2013), and non-haematology cancer survivors (Wu and Harden, 2015). Moreover, even with the return of pre-cancer muscle characteristics and function, HL survivors' self-reported fatigue remains a burden (de Lima *et al.* 2018). Physical activity has been shown to result in a moderate beneficial effect on lymphoma patients' fatigue, but engagement with the physical activity must be consistent to achieve this result (Husson *et al.* 2015).

Issues with weight management, specifically weight gain, was an unexpected finding in this study. Weight gain post diagnosis is well described in breast cancer survivors

(Vance *et al.* 2011) but little is known about this experience among lymphoma survivors. A higher than expected weight gain in adult lymphoma patients for up to eighteen months' post treatment has been found but the mechanism for weight gain is not fully understood (Lynce 2012). It has also been reported that adverse prolonged body composition changes can occur with increased weight and decreased muscle mass in male NHL survivors following treatment with chemotherapy (Xiao *et al.* 2016). Referral of lymphoma patients to the clinical nutritionist is mainly as a reaction to weight loss at diagnosis or, as a result of intensive treatments, such as allogeneic transplant. Our findings would suggest the need for increased awareness by health care professionals of the need for lifestyle interventions and weight management advice and referral for lymphoma patients.

Patient concerns, challenges, barriers and facilitating factors regarding returning to work after treatment are highlighted in this study. Employer support and flexibility was the main factor which aided return to work, reflecting findings reported elsewhere (Mc Grath *et al.* 2012). The main barriers to return to previous employment was noted to be lingering immune-deficiency and fatigue. Health care professionals should consider the impact of treatment on patients' ability to return to work and support patients accordingly by appropriate referral.

Overall, participants valued scheduled follow-up and in particular, bloods results for detecting recurrence. This is despite low numbers of patients experiencing relapse being detected at scheduled follow up with most having clinical signs and symptoms (Thompson *et al.* 2014). The purpose of structured follow-up and review includes monitoring for disease relapse, late effects of treatment and development of second

malignancies and health promotion advice. However, many participants did not recall any discussions on healthy lifestyle behaviours or relevant recommended cancer screening programmes for age and gender, and some overlooked regular screening programmes. It has been reported elsewhere that during follow-up consultations, doctors tend not to be organised and systematic in their approach to health promotion with lymphoma patients and it is patients that highlight their engagement with healthy behaviours without prompting (Franco *et al.* 2017).

Similar to findings by Marbach and Griffie (2011), the majority of participants were in favour of a written summary of treatment and survivorship care plan, either in paper or electronic form, delivered by a nurse specialist at a dedicated visit and made available to others involved in their care. Cancer nurses have been identified as potential providers of survivorship care including addressing issues of concern and providing education, support and co-ordination (Marbach and Griffie 2011) and developing survivorship care recommendations into survivorship care plans (Taylor and Monterosso 2015).

Limitations

The sample size was small and restricted to one haematology centre. Therefore, generalisability to all lymphoma survivors is limited.

Conclusions

The findings suggest that the transition period for lymphoma survivors following active treatment can be challenging and they have ongoing needs. This finding is similar to the experiences of patients with non-hematological cancers. However, this

cohort of patients clearly require more preparation for the end of active treatment because some may not even be aware that treatment has finished. Education and promotion of healthy lifestyles, monitoring for late effects and second cancers is also vital for lymphoma survivors. Moreover, the findings highlight the need for health care professionals to ensure the provision of a point of contact and appropriate referral to support services such as counselling, clinical nutrition and physiotherapy at the end of active treatment. The importance of co-ordination of information between acute and primary health care providers in monitoring for and management of late effects of treatment and promoting the uptake of recommended programmes for cancer surveillance is also highlighted.

In conclusion, this study highlights the need for a dedicated end of treatment visit with a clinical nurse specialist to confirm the completion of active treatment with lymphoma patients. This end of treatment visit should also outline the purpose of post treatment follow up and the importance of patients identifying the signs of cancer recurrence. Scheduled follow up could then offer an opportunity to continue ongoing needs assessment, appropriate referral and a focus on health promotion. Further research is required to determine the feasibility of survivorship care plans to an already under-resourced specialist nursing service in Ireland and if any education needs exist for haematology nurse specialists in the area of survivorship care.

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Table 1 Semi-structured Interview Guide

1. Tell me about your experiences when you completed treatment?

Probe: How did you feel when you completed treatment?

Prompt: How did it affect you?

2. How did you find the transition from active treatment to follow up?

Probe: What was that like? Was it managed well?

-If there were positive experiences then:

Prompt: why and what helped?

-If negative experiences then

Prompt: what was problematic and what would have helped?

3. Did you encounter any difficulties during follow up post treatment?

Probe: If so, tell me about the difficulties?

Prompt:

-Were they psychological, social, physical, financial?

-At what point after treatment did they occur?

-How do/did you cope with those difficulties?

-What do you think would have been helpful in dealing with those difficulties?

4. Did you have an end of treatment clinic visit?

Probe: If so tell me about the visit?

Prompt:

-What was discussed-disease status, test results, follow up schedule, late effects, points of contact, recurrence, risks of secondary malignancies, health promotion?

- What particular aspects of the visit did you find helpful?

-Would you have liked further information or support at that visit?

-If didn't have an end of treatment visit, would it have been helpful to you when you finished treatment?

5. What type of information did you receive at completion of treatment?

Probe: Was the follow up plan discussed?

Prompt:

-Were you told about follow up schedule, late effects, points of contact, recurrence, risks of secondary malignancies, health promotion?

-Would you have liked further information/support?

6. What are your thoughts on a survivorship care plan of care at the completion of treatment?

Probe: Do you feel a care plan is necessary following completion of treatment?

Prompt: If positive response:

-What type of information do you think is needed in a survivorship care plan?

-What would you not like included?

-When would the best time be to discuss a survivorship care plan, at what point post treatment?

-In what type of format would you like the plan?

-Who do you think should have the copy of the plan, Yourself? Your GP? Your PHN/Community nurse? Other consultants/HCPs involved in your care?

Table 2: Study participants

Characteristics	N=14
Age at Diagnosis (years)	
18-39	3
40-64	5
>65	6
Employment	
Full-Time	5
Part-Time	3
Unemployed	2
Retired	4
Gender	
Male	9
Female	5
Diagnosis	
Hodgkin Lymphoma (HL)	3
Diffuse Large B Cell Lymphoma (DLBCL)	4
Follicular Lymphoma (FL)	4
DLBCL/FL	1
T-Cell lymphoma (TCL)	1
Marginal Zone lymphoma (MZL)	1
Treatment	
Cytotoxic chemotherapy alone	9
Cytotoxic chemotherapy and radiotherapy	3
Cytotoxic chemotherapy and Allogeneic transplant	2
Time since treatment	
3mths-1 year	1
1-2years	1
2-3years	2
3-4 years	5
4-5years	4
8 years	1

Figure 1: Study findings

