The Nature and Timing of Distress among Haematological Cancer Survivors

Abstract

Many people with haematological cancers will not meet the diagnostic criteria for a psychological disorder, but will still suffer distress during treatment and beyond. The current study aimed to explore the nature and timing of psychosocial distress experienced by haematological cancer survivors. Twenty-three post-treatment haematological cancer survivors participated in a semi-structured interview. Data were analysed using thematic analysis which involved identifying, analysing and reporting themes. Four themes were identified: Apprehension about leaving the safety of the health care system comprises the struggles survivors face when transitioning from patient to survivor, Uncertainty and life transitions in the post treatment period encompasses the changes survivors face when attempting to re-enter their 'normal' lives and routines, Distress associated with ongoing physical problems or impairment describes issues associated with the ongoing physical segulae faced by survivors, and Fear of recurrence encapsulates the ways in which the continuing threat of their cancer returning had affected survivors. This study has found that distress is ongoing for many haematological cancer survivors in the post-treatment period. It is imperative that distress is identified and support offered to those in need to prevent further psychosocial issues. It is especially important to consider the psychosocial needs of survivors in the post-treatment stage who are discharged from the health system may be unsure where to seek help.

Keywords

Haematological cancer; psychosocial distress; cancer survivorship; qualitative research

Introduction

Globally haematological cancers contribute significantly to the overall cancer burden (Ferlay et al., 2015). In economically developed countries, haematological cancers are the fourth most common group of cancers (A. Smith, Howell, Patmore, Jack, & Roman, 2011). In New Zealand, the setting for the current study, combined, haematological cancers are the fifth most diagnosed cancer, with approximately 1500 new diagnoses each year (Ministry of Health, 2014). The incidence of most haematological cancers is rising in most resource rich countries (Ministry of Health, 2010; Rodriguez-Abreu, Bordoni, & Zucca, 2007), however, so is the survival rate due to factors such as improved treatment and early detection (Jefford et al., 2008).

Although these 'survivors' have successfully finished treatment, they are still frequently left with residual physical, psychological and social problems (Beckjord et al., 2014; Wallwork & Richardson, 1994). Treatment for haematological cancers is complex and often more intense than treatment for other cancers (Carey et al., 2012; Lobb et al., 2009). Aggressive therapies can cause both late and long term physical and psychosocial effects that can appear years after treatment ends (Klemm, 2008). However, there is limited research identified that focuses on psychological and social issues facing haematological cancer survivors (Leukaemia and Blood Foundation, 2011; Parry, Morningstar, Kendall, & Coleman, 2010; S. K. Smith, Zimmerman, Williams, & Zebrack, 2009). Furthermore, although research on survivorship issues is increasing, little has focused specifically upon haematological cancer (Lobb et al., 2009).

Many people with cancer will not meet a diagnostic criteria for a psychological disorder, but will still suffer from distressing emotional problems (National Cancer Institute, 2017). The concept of 'distress' is useful to capture the experience of this group experiencing emotional upheaval. Distress has been defined as "an unpleasant experience of an emotional, psychological, social, or spiritual nature that

interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis"(National Comprehensive Cancer Network, 2007). Psychosocial distress has also been associated with reduced quality of life (Shim et al., 2006), reduced satisfaction with medical care (Von Essen, Larsson, Oberg, & Sjoden, 2002), poor treatment adherence, additional visits to health professionals (National Comprehensive Cancer Network, 2013), and higher mortality (Hamer, Chida, & Molloy, 2009). These negative effects have led to distress being characterized as the 6th Vital Sign in cancer care (Bultz & Carlson, 2005) and demonstrate why it is essential to detect distress as early as possible.

The time where treatment is coming to an end, and a patient is transitioning into survivorship, brings its own set of challenges (Stanton et al., 2005). However, a recent integrative review conducted by the authors (Raphael, Frey, & Gott, 2017) concluded that there is very little literature that focuses on distress amongst haematological cancer survivors in the early post-treatment phase. Only seven papers were identified that contained data on post-treatment haematological survivors; however these studies did show that the majority of survivors suffered at least mild to moderate distress. Findings from the review also suggest that younger age may play a part in increased levels of distress for haematological cancer survivors (Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015). However, the key finding was the gap in the literature regarding this particular survivor group.

Further research is therefore essential to understand the issues that affect haematological cancer survivors post-treatment. It is necessary to explore the timing and extent of distress, as well as what support is needed to cope with this distress. Evidence of this nature could help inform the provision of appropriate post treatment support and services for this under-researched group of survivors.

It was within this context that the current study was designed to explore the nature and timing of psychosocial distress experienced by post-treatment haematological cancer survivors. An exploratory qualitative methodology was chosen given the death of existing research in this area.

Methods

Ethical approval for this research was granted by the Southern Health and Disability Ethics

Committee. (Ref: 15/STH/82). Participants were recruited through the New Zealand Cancer Registry
(NZCR). The NZCR provided a database containing information about all cancer survivors who had
been diagnosed with a haematological cancer between July 2007 and July 2015. Alongside other
selected information (including date of birth, gender, diagnosis date and ICD10 code), a postal address
was provided for those on the database. The goal was to recruit those who had finished primary
treatment within the 0-5 year period. The 0-5 year time period was chosen because it is in this period
that cancer survivors of most types are more likely to be affected by psychological and social
problems (Kattlove & Winn, 2003; Mullan, 1985; Stanton, 2012). This is also known to be the period
where the fear of cancer reoccurrence may dominate a survivor's thoughts (Hewitt, 2006). In the case
of haematological cancer, research shows that most relapses in Hodgkin's disease, non-Hodgkin's
disease and acute leukaemia patients occur within the first five years (Specht, Gray, Clarke, & Peto,
1998).

Potential participants were contacted by mail with a letter inviting them to participate in an interview exploring the psychosocial issues they may had faced during from the point of diagnosis to the post-treatment phase of their haematological cancer. Those who were interested in participating sent back a reply form which included their phone number. They were then contacted by DR who confirmed their eligibility by checking they were currently in remission (as indicated by their physician) and had also finished their primary treatment. If they met these criteria an interview was then scheduled for a day and time suitable for the participant. The number of interviews was guided by the method of saturation; interviews were conducted until no new codes or themes were occurring in the data (Hennink, Kaiser, & Marconi, 2016). This process involved DR assessing the data gathered from each new interview and comparing to previous interview data to ascertain whether any new issues were identified, or whether data was beginning to repeat, and not add anything unique (Kerr, Nixon, &

Wild, 2010). Data obtained from the interviews was also discussed with RF and MG to gain a consensus on whether anything new was occurring in the data.

Data Collection

A semi-structured interview schedule was developed to address the aims and objectives of the research. The interview questions were informed by our previous integrative review (Raphael et al., 2017) and an extensive review of cancer survivorship literature reporting on psychosocial issues in survivors of other types of cancer. The interview guide was also pilot tested on a convenience sample of three people (one cancer survivor, one family member of a cancer survivor, and an oncology nurse) to ascertain whether the questions were easily understood, and to assess the length of the interview. Interview topics are described in figure 1. Participants were invited to take part in a face-to-face semistructured (for resource reasons these could only be offered for those in, or close to, the Auckland region) or telephone interview (depending on their preference). Participants were also asked demographic information including age, ethnicity, marital status, employment status, treatment end date, and current health conditions. No age limit was applied (except that all participants be adults ie over 18) because it was considered important to explore the experiences of a diverse range of survivors. Whilst phone interviews are typically seen as inferior to face-to-face interviewing (Block & Erskine, 2012), a recent study found that participants spoke positively about their experience of participating in telephone interviewing, and found it had benefits over face- to- face interviewing, such as feeling less inhibited and not feeling judged by the interviewer (Ward, Gott, & Hoare, 2015).

Analysis

Interviews were audio recorded with consent and transcribed verbatim by the researcher. Interview transcripts were read three times and then entered into the NVivo text analysis programme to help organise the data. Data were analysed using thematic analysis (Braun & Clarke, 2006, 2013) which involves identifying, analysing and reporting themes from qualitative data. The six phases of thematic analysis are: familiarisation with the data; coding; searching for themes; reviewing themes; defining and naming themes; and writing up (Braun & Clarke, 2006). A coding framework was created by DR and then discussed with RF and MG. The coding framework was generated by carefully reading each

transcript and identifying features in the data (words or short phrases) that were relevant to the research questions (Braun & Clarke, 2013). These codes were then organised into areas of commonality and recoded where needed. Once the coding framework was discussed by all researchers and subsequently refined, the initial themes and sub themes were generated. Creating the themes involved looking at the ways in which codes grouped together to form a coherent pattern in the data (Braun & Clarke, 2013). As the analysis progressed themes were often reorganised and either grouped with another theme or separated out to form a new theme. The process of reviewing and revising themes was a lengthy process which continued through to the writing up period.

Participant Information

The sample consisted of 23 participants from various geographical areas of New Zealand (Table 1.). Participants ranged in age from 33 to 77 years. The majority were NZ European (52%), and had Non-Hodgkin's Lymphoma (61%). The self-reported time since end of treatment ranged between two and eight years with a mean of 4.1 years. Although most participants fell within the previously discussed 0-5 year post-treatment, there were five participants who had completed treatment six to eight years previously. A decision was made to include these participants to ascertain whether there were any issues found in this period that might not be found in the group who had finished treatment earlier. All but one of these participants was interviewed over the telephone, with only one person (from six in Auckland) choosing a face-to-face interview.

When comparing the five participants who had completed treatment 6-8 years previously to the rest of the sample there was nothing apparent in the data that differentiated the groups, however the number was small for the 6-8 year group compared to the 0-5 year group so this was limiting. Therefore the data was analysed as a whole rather than separating these two groups.

Findings

The analytical process led to the construction of four themes that describe the nature of distress experienced by participants in the post-treatment period. *Apprehension about leaving the safety of the*

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health care system, Uncertainty and life transitions in the post treatment period, Distress associated with ongoing physical problems or impairment, and Fear of recurrence.

Apprehension about leaving the safety of the health care system

Several participants felt distress around the time that they were finishing their primary treatment and leaving the constant support of the health system and the health professionals they were used to seeing regularly during chemotherapy and radiation. For many it was a period that made them feel like they were now 'on their own'.

...you're pretty much, you know, jump into the cold water kind of thing. You're pretty much on your own...(P09)

I think I felt a little bit strange to be discharged completely, but they can't keep seeing everybody, it was sort of just reality that you know that they can't just keep monitoring everybody who's had it. (P01)

Because I felt safe when the doctor checked me every 6 months. So now I can't because the doctor said...the doctor already discharged me from the check-ups. I'm a bit nervous now. (P21)

The last day of treatment was really quite emotional, far more emotional than I expected. You go in and do your last treatment and radiation and they give you that last thing with the green mask that goes over your face and you just shake their hands and walk out and go oh, it's done, yes! And hang fire I feel a little bit weird about this, I wasn't expecting to feel this way and sort of choked back some tears. (P22)

Most survivors had formed relationships with hospital staff and for some they were considered 'like family'. This was particularly true for people without other significant sources of support.

I found it quite hard because I felt like the people at the hospital were my second family and it felt hard letting that go. And it took me a long time to get used to that, not going back there. Because it was so much a part of my life, pretty much all for that 6 months. (P19)

I suppose there was a little bit of - not mourning – but the end of a story with the doctors and stuff. But it was fine, it wasn't you know...it's just the way it is. **(P01)**

Uncertainty and life transitions in the post treatment period

For most participants the post-treatment period was one of uncertainty in many aspects, including lack of information, their disease status, not knowing whether they would get back their normal selves, employment issues, and issues around children.

Most participants reported receiving limited information about what to expect in the post-treatment period. One participant spoke of a frightening experience he had because of this lack of knowledge regarding the physical limitations he now experienced as a result of his cancer.

So I had a lung infection and it reduced my lung capacity by about 20 per cent, and that's what they told me, and it was going to reduce some things. A while later I was out diving, and I nearly drowned...I went back and I was talking to the specialist, he said, oh you know, sometimes that can happen. (P17)

Furthermore, although some participants spoke about seeking alternate sources of information online, this could be troublesome as they would read conflicting information or things that were just frightening.

I had my daughter over in Perth and she was starting to have a look, and reading stuff on there...there's a lot of information which is too much, and it's scares the hell out of people. (P17)

For many waiting for the confirmation that they were actually in remission took months. This waiting period invoked considerable distress:

It was a progressive thing. Each time I went he said, no you're looking good, it's good no you've had no response, you've had good side effects, you've had a good response from the chemo, and there are no problems with the nodes. So as we went through each visit, I got a clearance. (P13)

But the thing is when you've finished you have to do a scan, a CT scan to see if you still have you know...even though you are finished, before that, it's not guaranteed that you're cured. It's only until that moment when you've done your scan, everything is clear then you think oh yay. (P18)

That was one of the scary things too because as Luke said after 3 cycles we will give you another scan half way through to see and then if nothing's changed then there's nothing really you can do. And I was like (gulp) ok then. But I remember the scan and it's crazy because you have the scan and then you're booked in to see him a week later. So you've got that week of just writhing with like 'what's happening', it's not instant. (P23)

The downside of finishing treatment was described in terms of exhaustion and depression. For example, one participant described being diagnosed with depression because of her inability to do physical things, particularly her normal activities. This was indicative of some participants' experiences that once they were feeling physically better, emotional stress surfaced.

It was funny because I was healing, everything was going well but I got depressed by the end...you get cancer and something happening in your life and instead of getting better you get worse with the diagnosis and with the treatment, everything gets really much much worse. (P05)

... You just feel different and when you try and explain when they say, well how do you feel? I don't know, it's different and it's not as good as you used to feel and it's not as pleasant as you used to feel, but at the end of the day it's better than what could have been. (P17)

Participants sometimes worried about their reduced capability and the long lasting effect this had on their ability to carry on with their previous employment. Many struggled when attempting to go back to full time work because they became tired easily. Indeed, some could not manage to go back full-time because of this fatigue.

And then though what you can't prepare for is the mental fatigue when you go back to work. I wasn't particularly mentally fatigued at home during or after the training, but the work demands is completely different. I think I had headaches each day after work for probably three years. (P09)

Those who had to make major employment changes were left financially far worse off than before cancer. For example, one participant had to sell his business and his house near retirement age and begin again in a whole new place.

I mean we put everything into it and had to start again. So it's a bit late in life to start again. (P12)

Unique to younger female participants was the theme of children. Most of the younger female participants spoke about the stress associated with potentially being infertile after treatment. Not all had the opportunity to harvest eggs before they started treatment so had no idea whether they would be able to have children.

My main thing was that I probably wouldn't be able to have kids. I thought oh shit, we waited and waited and now we probably won't be able to (P01)

There were additional factors to consider when contemplating reproductive issues or what the future held for the children they already had. One participant was concerned that her cancer could be potentially passed down to her children and wondered if she should even have children. Another talked about making her children a top priority now as she felt there was a good chance her cancer would return.

I did get a job offer but I had to turn it down, I was like nah my kids...especially I don't know what's going to happen in the future now with this you know. So I have to think that I have to spend more time with the kids than thinking about having a dream job. (P04)

Distress associated with ongoing physical problems or impairment

Most participants mentioned ongoing physical sequelae associated with their cancer and treatment. For some these physical complaints were significant and changed the way they now lived their lives. Some had permanent damage to hearing, vision, or speech which caused ongoing distress.

I had to teach myself to talk again; my tongue swelled up that much that I couldn't speak properly. I still don't speak like I used to. (P12)

Adaptation.

Other participants felt an overall difference in how they felt physically, and though they could not always describe why, they just felt they were not physically the same as they were before. This physical change caused distress for participants and a sense of loss because they did not feel they were 'the person they once were'. However, some participants acknowledged that these physical deficits were better than the alternative:

I will never, ever be where I was. I've most probably lost, hard to put a quantity on it, but I've lost quite a bit of my strength, and there's things that I just can't do...but I'm also aware that it's a trade-off; if I didn't have the stuff then, I would be dead. (P17)

Fear of recurrence

Fear of recurrence is something that caused distress for almost all participants. Some described it something that is always in the back of their mind. Participants noted that they were still uncertain about whether the cancer was gone for good.

You know, I've just been positive about my future and just moved on, yeah. But it's always in the back of my mind. Because for me, I've seen a lot of my own whanau people just get treated and some months or years down the line they're gone, you know. (P11)

So I know that cancer has to be treated quickly in most cases and the end of treatment is quite scary because you never know to this day when it's going to rear its ugly head again. It probably will, but just umm...even living day to day is quite scary. (P03)

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For some participants every little physical symptom caused concern. Part of this related to the vague symptoms many experienced when first diagnosed with their haematological cancer, which often mimicked common illnesses such as the common cold or influenza. Also, many participants spoke of the time and multiple visits it took to obtain their diagnosis because the symptoms were sometimes so innocuous. Participants were more aware of subtle changes in their body, for example weight loss or fatigue. They were more likely to check their body for lumps, and go to GP where they would not in the past. There was also more concern if colds or flu's did not go quickly enough.

You know, every time, even four years down the track now, every time something goes on with your body which is a little bit out of the ordinary, you straightaway think, oh, is this the first sign of things coming back, you know. (P09)

Well I'm sure if I started to have night sweats or something I would...but to tell you the truth I have longish hair sort of just below my shoulders but it's constantly up in a ponytail and I never brush it. But when I wash it quite a lot of hair comes out and that makes...sort of just...I suppose pretty much every time I was it I just think 'I wonder'. (P01)

Probably if I wasn't going for those (blood tests) I might be a bit more apprehensive, you know sort of thinking 'oh I wonder'. You're crook one day and you think 'oh, it's not coming back is it?' (P02)

Some participants seem to obtain some sort of peace of mind through continuing monitoring from their health professional team. However while having blood tests and check-ups alleviated the worry somewhat for many survivors, these tests also brought a lot of anxiety as well.

... you do get a bit worked up before you go and see him because he pokes around and things and it's like is he going to find...has it grown back. Because I couldn't feel it, he could feel it (P23)

For some the fear was related to the belief that they could not cope emotionally or physically with recurrence. One participant talked about methods he used to distract himself from the fear that his cancer may return.

I talk to my kids about what if it comes back, I may not be able to handle the next one, you know what I mean? But I just keep that out of my mind and just carry on. I'll go fishing and whatever, keep on top of things. (P11)

Yeah. But I don't know if I can I can go through that...because that time is your first time, you don't know what you're getting yourself into. (P18)

Overall, participants seemed to be seeking reassurance regarding their fear of recurrence, and did not always have the option to speak to someone who could assist with these fears.

Discussion

This study addresses a significant gap in current international evidence by exploring distress experienced by post-treatment haematological cancer survivors. Most participants reported some manner of distress in the post-treatment period. Each phase in the post-treatment period brought its own challenges and individuals had different needs depending on their stage in the trajectory, as well as their own personal circumstances. This information has important practical implications for the types of supports required by this growing cancer survivor group.

Participants reported distress in many different aspects of the post-treatment phase. The first challenge was the transition from cancer patient to survivor which was very stressful for some participants as they felt they were now on their own or away from the built in support system of the hospital environment. This is a similar finding to a study on leukaemia and lymphoma survivors focusing on the re-entry period which found survivors found one of the factors related to distress in this group was discontinuity of care at end of treatment (Parry et al., 2010). Other research that included post treatment cancer survivors of mixed cancers found, as in the current study, that the immediate post treatment period was a time of anxiety (Firmin, Pathammavong, Johnson, & Trudel, 2013). A study which interviewed nurses around barriers to care for haematological cancer survivors found that there was a difficulty in pinpointing the actual point where treatment ended for these patients, as because of the types of cancer it meant the end point was not always black and white. Therefore the nurse felt they hesitated in having survivorship discussions with these patients because they did not want patients to misunderstand the status of their disease (think they are cured) or that patients would not see themselves as survivors if they were still receiving additional treatment or monitoring (Langbecker, Ekberg, Yates, Chan, & Chan, 2016).

Another issues was the lack of information experienced by some participants regarding cancer survivorship after treatment. Other research examining unmet information needs for other types of cancers has found those with unmet information needs are more likely to be distressed (Uchida et al., 2011) and have higher rates of anxiety and depression (Faller et al., 2016). Another struggle many participants encountered was the challenge they faced trying to get back to their normal lives. Some of this was because of physical impairment caused by their cancer and treatment, or for others because of psychological sequelae including issues such as depression, anxiety, fear, or a sense of vulnerability. Research from Australia that reports similar results to the current study explored the needs of a group of mixed cancer survivors. They found the most common needs reported at treatment completion by both survivors and health professionals were dealing with fatigue, anxiety about cancer recurrence, others expecting you to be back to normal, having to create new expectations about physical ability, and anxiety about leaving the hospital system. They also found that one of the most common needs at the one year post-treatment was anxiety about medical check-ups and results (Jefford et al., 2008).

The most common concern for survivors in this study was the fear of recurrence, especially because the symptoms they experienced of their haematological cancer were very similar to other common illnesses, and therefore difficult to separate from minor illnesses. Heightening the fear of recurrence is an added concern that is particularly relevant to haematological cancer survivors, namely the difficulty in diagnosing their cancers. A study from the UK has shown that is not uncommon for the diagnosis period for haematological cancers to be long and protracted (Howell et al., 2013) and diagnostic delay has been shown to cause increased distress in other cancer patients (Miles et al., 2017; Risberg, Sørbye, Norum, & Wist, 1995). The concern regarding their prolonged diagnostic period was carried through to participants in the post-treatment period and contributed to their increased self-monitoring. The limited literature on post-treatment haematological cancer survivors shows one of the most frequently endorsed unmet needs was help managing the fear of recurrence (Lobb et al., 2009). Fear of cancer recurrence has been found to be one of the most common psychosocial concerns reported by cancer survivors (Simard et al., 2013), and has been associated with increased psychological distress

(Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Jones, Parry, Devine, Main, Okuyama, et al., 2015).

Recommendations

The information from the current study has important practical implications for the types of supports required by haematological cancer survivors. There may be distressing aspects of the cancer trajectory that cannot be avoided such as side effects of treatment, and the physical symptoms of the cancer itself. However, this research has shown that from diagnosis to the post-treatment period more could be done to ameliorate the psychosocial consequences of cancer and its treatment. This study has found that the appropriate information and relevant support could be improved for post-treatment survivors. Furthermore survivors especially need more information about psychosocial issues, it seems to rarely be discussed by health professionals, and if those in the health system make it a low priority patients may not see it as an important issue either. A good way to identify those who may be suffering distress is to implement distress screening for survivors at different points in the trajectory, including post-treatment. Without an effort to actively identify distress, it is unlikely survivors will feel comfortable enough to raise this issue on their own. However more research is needed to explore both current, and preferred, sources of support amongst haematological cancer survivors.

Limitations

This study enabled unique in-depth knowledge to be generated regarding the experiences of an underresearched survivor group. However, limitations must also be noted. Self-selection bias may have
influenced who took part. Also, participants had to rely on their memory to look back to the time when
they were diagnosed with cancer, and for some this was up to eight years before so there may have
been recall issues. Also as this was a qualitative study which included a small sample, findings are not
intended to be representative and generalizable to other populations. Finally, this was a cross-sectional
study therefore data was only collected at one time point.

Conclusion

Distress for haematological cancer survivors starts at diagnosis for many people, and can continue throughout the cancer trajectory. It is important that psychosocial distress is identified and support offered to those who need it to prevent escalation of psychosocial issues, and other negative consequences related to untreated distress. It is also important to consider the psychosocial needs of survivors the post-treatment stage who are discharged from the health system and not always sure where to turn for help. The post-treatment stage has its own particular set of challenges, especially the transition from patient to survivor. Our study has identified the need to measure the prevalence of distress in haematological cancer survivors in the post-treatment period to ascertain whether there are particular transitions and time periods that cause the most distress. There also needs to be more research ascertaining the support survivors receive currently and what support they need going forward.

Disclosure Statement

All authors declare that that they have no conflict of interest.

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Appendix

Table 1. Participant demographics

| | | n |
|-----------|-------------------------|----|
| Age | 30-40 | 5 |
| | 41-50 | 3 |
| | 51-60 | 6 |
| | 61-70 | 6 |
| Gender | Male | 10 |
| | Female | 13 |
| Ethnicity | NZ European | 12 |
| | Māori | 4 |
| | Asian | 3 |
| | Other European | 4 |
| Cancer | Non-Hodgkin Lymphoma | 14 |
| Type | Hodgkin's Disease | 3 |
| | Acute Myeloid Leukaemia | 3 |
| | Multiple Myeloma | 3 |
| Time | 2-3 years | 6 |
| post | 3-4 years | 5 |
| treatment | 4-5 years | 7 |
| | 5-8 years | 5 |

Figure

The semi-structured interview schedule topics included:

- The period when they were diagnosed
- Their treatment experience
- Their thoughts and feelings when treatment was ending
- Their adjustment back into normal life after cancer treatment
- Any information received about what they might expect post-treatment
- Information or advice received post-treatment
- Psychological or emotional strain during and post-treatment
- If they had a support person/people in their life
- Support needs post- treatment
- Fear of recurrence
- Any changes in their personal relationships as a result of their cancer diagnosis.

Figure 1. Interview topics