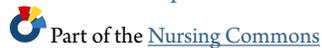

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Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial

Karen Taylor
The University of Notre Dame Australia

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Chapter Seven – Discussion



7.0 Discussion

The following discussion will present and explore the relevance of the major findings from this study in relation to theoretical and clinical issues. This will be followed by a discussion on the limitations and strengths of the study. The final chapter will present the conclusions from this study in addition to implications and recommendations for nursing practice, education and future research.

The principal research question developed and tested in this study was that it might be possible to decrease the number and level of unmet informational, practical and emotional needs that may occur when lymphoma patients finish treatment, and promote self-empowerment using a nurse-led lymphoma survivorship model of care. This research was undertaken in four phases, and development of the components of the nurse-led lymphoma survivorship model of care and their implementation are reported in detail in this thesis.

It was intended that this study would build on Australian cancer survivorship research, in particular, lymphoma-specific survivorship. The conceptual framework for this study was based on Bandura's theory of self-efficacy. This was considered the most appropriate framework to guide the development of the nurse-led lymphoma survivorship model of care since it emphasises the importance of individual empowerment to enable the patient to take responsibility for their future health and well-being. In addition, providing support and encouragement may assist with better adjustment to having cancer and resumption of normal activities of daily living. To achieve this aim, a pragmatic RCT to examine a nurse-led model of survivorship care was conceptualised, developed and delivered to a cohort of lymphoma survivors at a large tertiary cancer centre in Perth, Western Australia. The

intervention comprised a patient-centred survivorship care plan and treatment summary (SCPTS), motivational interviewing to empower survivors to make healthy lifestyle changes and individualised support and tailored resources. To date, no RCTs have been published that report a nurse-led survivorship model of care using a lymphoma survivor cohort.

This study utilised and collaborated with a multidisciplinary advisory committee that included lymphoma survivor consumers. It was particularly important that this research engaged with consumers who had undergone previous lymphoma treatment at the study site and were thereby able to have input into the design, delivery and evaluation methods of this research. This research is, therefore, able to address the Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service (NSQHS) Standard 2, Partnering with Consumers (Australian Commission on Safety and Quality in Health Care, 2017). Likewise, this research addresses the NSQHS Standard 5, Comprehensive Care, as it ensured the care given to participants was individualised and considered the impact of the disease and treatment on their health, quality of life and well-being (Australian Commission on Safety and Quality in Health Care, 2017).

A diagnosis of cancer is the beginning of a profound and life-changing experience that can have a long-lasting effect on the remainder of a person's life and the lives of their family and friends (Corner & Bailey, 2009). Research is constantly striving to improve the treatment offered and therefore overall survival rates (Hewitt et al., 2005; Wait et al., 2017); however, a valuable opportunity is missed in supporting the quality of survival once treatment is completed (McConnell, White, & Maher, 2017). A cancer-free future may often be characterised by ongoing physical and psychosocial health concerns (Aaronson et al., 2014). Post-treatment, health professionals have an

opportunity to provide support for a range of biopsychosocial issues and have a positive effect on facilitating a change or improvement in healthy lifestyle behaviours. There is increasing evidence that a healthy lifestyle reduces the risk of morbidity and mortality and many interventions, such as exercise, are safe and effective (Aaronson et al., 2014); however, promotion and referral for these interventions is low (Boyes et al., 2012).

The rationale for Phase One (the systematic and integrative reviews) was to examine: how lymphoma survivorship follow-up is occurring and the models of care currently in use; the use of survivorship care plans and/or treatment summaries with this cohort; and the assessment measures that are used to determine survivorship unmet needs. This was followed by Phase Two where components of the intervention were developed for use in Phase Three which comprised the pragmatic RCT. In Phase Four additional evaluation of the model of care and the SCPTS was conducted with GPs and a subset of intervention participants.

A full discussion related to each of the three literature reviews, qualitative interviews with intervention participants and the SF-SUNS test-retest results is in each published article. The first section of this chapter will provide a summary of the three literature reviews. This will be followed by a presentation and exploration of the relevant major findings from the pragmatic RCT and GP evaluations. Furthermore, a summary of the qualitative interviews and the SF-SUNS test-retest is provided in this chapter. This chapter concludes with a consideration of the limitations and strengths of this thesis.

Summary of the Phase One Literature Reviews

Published models of post-treatment cancer follow-up and/or survivorship care was explored in the *models of survivorship care provision in adult patients with haematological cancer: an integrative literature review* (Taylor et al., 2015). This review found a lack of guidance and consensus for follow-up care including determination of the appropriate health professional/s to deliver survivorship care. The review likewise highlighted a lack of consensus regarding the type of care model most appropriate for the early survivorship period. It was also evident that further lymphoma-specific models of survivorship care research are required. This particular cohort of cancer patients has different needs (Parry et al., 2010) than those of the more prevalent cancers such as breast, prostate and colorectal. These cancer types have similar trajectories of treatment and care and generate the most survivorship model of care research. Any model of care proposed for early lymphoma survivors needs to be offered in addition to haematologist follow-up as the risk of lymphoma recurrence in the first two years' post-treatment is very high (Lymphoma Association, 2017).

Haematology follow-up for at least five years appears the norm in the published literature (Franco et al., 2017); and concurs with follow-up provision undertaken by the haematology department in Western Australia where this research was undertaken. In this follow-up period other health professionals, including GPs, may be involved in care provision and therefore open and effective communication is essential (Dicicco-Bloom & Cunningham, 2013). Nurses have been proposed as a conduit to transition survivorship care from the treating team to the GP (Cooper et al., 2010). This will necessitate the communication of potential late effects of disease and treatment and the recommended surveillance and management. Research

has indicated many GPs may not be provided with this vital information (Hall, Lynagh, et al., 2013). Nurses may similarly have an important role in normalising post-treatment effects (Franco et al., 2017) and encouraging survivors to seek information and support on healthy lifestyle behaviours and how to return to "normal functioning" sooner (Cooper et al., 2010). These findings were the basis for conceptualising and developing a nurse-led lymphoma survivorship model of care.

A key recommendation of the Institute of Medicine for survivorship care was the dissemination of SCPTS to all cancer survivors (Hewitt et al., 2005). The *survivorship care plans and treatment summaries in adult patients with hematologic cancer: an integrative literature review* (Taylor & Monterosso, 2015), reported a lack of evidence on their use with lymphoma survivors and furthermore on the most appropriate methods of developing and delivering this document. The reviewed literature (Taylor & Monterosso, 2015) and the researcher's recent search for newly published literature on lymphoma SCPTS usage demonstrated a continued lack of routine use.

Experienced oncology nurses are able to provide holistic and individualised information provision and have therefore been recognised as a practical solution to the creation and delivery of SCPTS (Jackson et al., 2013; Marbach & Griffie, 2011). To provide timely information and resources, two authors (Curcio et al., 2012; Sabatino et al., 2013) proposed that dissemination of SCPTS should occur soon after treatment completion. This recommendation was endorsed by a recent qualitative study with lymphoma patients undertaken at the same treatment centre as this research. These participants indicated a lack of information and support when treatment ended (Monterosso et al., 2017). In the present study, delivery of the SCPTS to participants randomised to the intervention group occurred three months

after treatment completion to facilitate early identification of issues and concerns and provision of appropriate support, information and resources. The SCPTS review likewise reported a lack of detail on how standardised templates were completed and the evidence-based guidelines that were used. This was addressed in the development of a unique lymphoma-specific SCPTS for this thesis. A recent study with breast cancer participants (Mayer et al., 2016), as outlined in the literature review update in Chapter Two, reported a decrease in levels of anxiety in patients when SCPTS provision by a nurse was coupled with GP follow-up to discuss the SCPTS contents. Although this finding had not been available when this thesis was developed, participants in the present study who had received an SCPTS were encouraged to discuss the contents with their GP after the first NLSC appointment and then at each subsequent GP visit. Qualitative results from this thesis reported that participants experienced feelings of shock when potential late effects information was given. However, participants indicated an appreciation of this knowledge to empower them to follow-up in the future (Ng, 2014). This finding confirmed those of previous studies that reported tailored SCPTS could empower survivors to assume responsibility for future surveillance and disease management (Hill-Kayser et al., 2013; Jabson & Bowen, 2013; Jackson et al., 2013).

Nurses and health professionals require reliable, validated and accurate measures to assess survivors for unmet issues and concerns once treatment has completed (Muzzatti & Annunziata, 2013). Early identification is important to ensure management and support is delivered effectively and appropriately (Girgis, Delaney, & Miller, 2015). The *systematic review of the tools used to assess the informational and practical needs of the acute leukaemia and lymphoma survivors* (Taylor & Monterosso, 2016) in this thesis reported a need for survivorship-specific needs assessment measures that had been used in

lymphoma survivor cohorts. Likewise, early assessment to mitigate unmet needs in the future was reported (McDowell et al., 2010) and considered applicable for this research. Therefore, a post-treatment timeframe of three months for baseline assessment was established. As the review found limited published literature on survivorship-specific measures to assess unmet needs in lymphoma survivor cohorts, this is an area that requires further research.

In developing the SCPTS for this study, it was important to seek and act upon the feedback given by clinicians and survivors. GPs indicated a preference for a succinct treatment summary, a finding supported by a recent study delivering an SCP to primary care physicians (Ezendam et al., 2014). Therefore, a concise document was developed that was deliberately patient-centred and only reported possible late effects that were pertinent to each participant. The SCPTS literature review undertaken as part of this thesis reported on large templates which covered all potential late effects and were therefore not tailored to the individual. As reported by Klemanski et al. (2016), the American Society of Clinical Oncology (ASCO) has recently reduced their SCPTS templates to two pages, in line with Commission on Cancer standards which clarified the type of information that an SCPTS was to include (Klemanski et al., 2016). The minimum information required is similar to that included in the SCPTS developed for this study (Deline, 2016); however, the care plan element differs. The new ASCO SCPTS templates provide a list of problem areas encountered by survivors, whereas participants in this study were able to generate their own lists.

Discussion of Phase Three Pragmatic Randomised Controlled Trial

This pilot study contributes evidence-based data to the emerging body of nurse-led survivorship research, and in lymphoma-specific care. In Western Australia, the current model for all haematology cancer survivorship follow-up is haematologist-led, however many survivors experience a range of unmet needs that may be poorly identified and addressed throughout the survivorship period (De Leeuw & Larsson, 2013; Monterosso et al., 2017). Health care providers need to recognise the importance of survivorship care as a standard component of optimal holistic cancer care that involves patients and families, along with other health professionals, including primary care. The objective of the study was to assist participants, randomised to the intervention, to transition from the end of treatment into follow-up care, often referred to as the early survivorship phase, up to two years' post-diagnosis (Aziz, 2007; McDowell et al., 2010). The aim was to assess if the intervention reduced the number and level of self-reported unmet informational, practical, emotional needs, depression, anxiety and stress and increased adjustment to cancer and patient empowerment. Additionally, the study assessed the use of an individualised SCPTS as a resource for participants and their GPs to have a written record of their disease, treatment and future surveillance of potential late effects (Taylor et al., 2015). Notably, the SCPTS was also a tool for participants to record their three most important concerns and three most important health goals, along with the actions required to deal with concerns and achieve health goals. The intervention likewise utilised the 'teachable moment' (Alfano et al., 2012; Panek-Hudson, 2013) that presents at treatment completion, to support and encourage healthy lifestyle behaviours (Taylor & Monterosso, 2015). This

was particularly salient for the younger participants, as there was an expectation of a longer survivorship period (Jabson & Bowen, 2013).

The early survivorship phase was chosen to provide responsive, supportive care for the unique concerns and unmet needs of this cohort. A prospective longitudinal study found 30% (n=353) of survivors had five or more unmet needs at treatment completion that did not improve after six months (Armes et al., 2009). This concurs with research which has suggested less unmet needs were evident in the extended survivorship phase (over five years) if assessments and interventions were undertaken in the early survivorship phase (up to two years' post-diagnosis) (McDowell et al., 2010). It is possible this thesis study may have also decreased the feelings of abandonment survivors often feel at treatment completion (Matheson et al., 2016; Monterosso et al., 2017; Taylor, Monterosso, & Bulsara, 2018).

The present pilot study suggests that survivors do have issues and concerns post-treatment that can remain unresolved over time. This may impact quality of life (QoL) (Hansen et al., 2013). Although statistical significance was not reached in this pilot study, a comparison of the mean results obtained from the two groups indicated a trend towards lower unmet needs in the intervention group at Time 3 with higher levels of empowerment revealed. Overall, those reporting no unmet needs at the completion of the study on the SF-SUNS (n=5, 9%) was very low. In contrast, a study of Canadian and Australian haematological survivors, one to 60 months' post-diagnosis, found 21% (n=71) reported no unmet needs (Hall, Campbell, et al., 2013). As a pilot study in the early survivorship phase, it is difficult to compare findings with larger studies with variable survivorship periods that found low levels of unmet needs in haematological survivor cohorts (Campbell et al., 2014; Hall, D'Este, et al., 2014).

The most endorsed concerns on the SCPTS were fear of recurrence, fatigue and cognition impairment. These findings are consistent with current research. A recent study of leukaemia and lymphoma survivors (n=477) reported the prevalence of fear of recurrence was higher in females and younger participants (Jones et al., 2015). This finding was supported by a study of different cancer types (n=2615) including lymphoma survivors (n=379), that found those in active follow-up and the early survivorship phase (0 to 5 years' post-diagnosis), experienced more fear of recurrence (van de Wal et al., 2016). Nonetheless, this study revealed satisfaction with information provision led to less reported fear of recurrence (van de Wal et al., 2016). This was reflected in the present study, where only one intervention participant recorded a high/very high level of unmet need for fear of recurrence at Time 2 and 3, compared with six control group participants at Time 2 and 3.

A recent study of Dutch HL survivors compared with a normative population revealed higher fatigue prevalence (41–43% vs 23–28%). Those with fatigue also had higher levels of anxiety (23% vs 13%) and depression (18% vs 12%) (Daniels et al., 2014). The authors suggested coping strategies may provide a clinically meaningful reduction in fatigue (Daniels et al., 2014). There may also be an association of fatigue with increasing age that may affect the ability to recover from fatigue (Kreissl et al., 2016). The present study found fatigue was still prevalent at nine months' post-treatment (Time 3), with participants continuing to report a moderate to very high unmet need.

Cognitive impairment is a condition that is not fully understood (Mojs et al., 2017), however, is described as a treatment side-effect (Zimmer et al., 2015). A recent review of psychological outcomes found cognitive decline can range

from mild attention, memory and thinking problems to severe impairment such as dementia (Mojs et al., 2017). A recent study of lymphoma patients (n=262) demonstrated significantly lower cognitive scores ($p .018$) and greater frequency of impairment when compared with healthy controls (32% vs 7%) (Krolak et al., 2017). This was supported by a smaller study (n=30 vs n=10 controls) which found a significant difference on objective and subjective cognition tests for lymphoma patients who were within 3 months of treatment completion (Zimmer et al., 2015). At the completion of the present study, cognition impairment remained an issue for many participants across both groups, however the control group reported more unmet need at the end of the study. This may indicate that normalisation, information and support may assist lymphoma survivors to cope with this condition.

Survivorship unmet needs

Participants in the intervention group demonstrated an increase in total scale median scores at Time 2, suggesting more unmet needs were evident in this group at this time point. However, all scores were lowest at Time 3 perhaps implying participants needs were met by study completion. Significantly, those participants aged >60 years had the lowest scores, and this may be due to their life stage where some practical issues such as finances, employment, relationship and emotional concerns are less of a concern than for younger age groups. Women in both groups had the highest Time 1 total scale median scores which concur with other Australian research indicating women had higher levels of unmet need (Lobb et al., 2009; Sanson-Fisher et al., 2000). In contrast, men in the intervention group at Time 3 had the highest median scores for the information domain, a finding reflected in a study of gender differences and survivorship follow-up which likewise found men had more unmet informational needs (Arden-Close et al., 2011). Unmet needs decreased across the study period suggesting intervention participants were

able to have their needs, issues and concerns resolved suggesting this may have been attributable to the nurse-led lymphoma survivorship model of care intervention. The control group scores were significantly higher in the 30–59 years age group suggesting this age group may require more support when treatment ends to facilitate return to “normal” functioning and may warrant further exploration in future research. This finding concurs with those of a study that reported follow-up services should account for the distinctive burden of supportive care needs in different age groups (Sharp et al., 2014). The majority of results in the control group (total scale and domain mean scores) decreased by Time 3, however, were higher than intervention group scores at Time 3. Although not statistically significant, likely due to this pilot study being underpowered, the researcher suggests these higher scores may reflect a lack of targeted support when treatment completed. Conversely, the relationships and emotional health domain mean scores increased over the study period. Talking about emotions and depression were endorsed as a moderate to high unmet need by the majority of participants in the control group and the researcher proposes this may be an area that requires support at treatment completion to assist in mitigating escalating or unresolved unmet need. Those with NHL had significantly higher scores in the financial and access and continuity of care domains than those with HL across both groups at all time points suggesting a need for targeted support to this cohort when treatment completes.

Psychological distress

Scores on the three domains of the DASS21 remained similar for both cohorts across the study. The majority of domain scores were below population norm scores outlined in the DASS scoring manual: depression <4.5; anxiety <3.5; and stress <7.0 (Lovibond & Lovibond, 1995) and suggests the lymphoma cohort under study had good psychological coping mechanisms. Participants

in the intervention group showed a decrease in all scores by Time 3. This downward trend suggested psychological distress concerns were no longer evident and likely resolved at study completion. The data revealed an increase in the intervention group mean scores at Time 2, and although they had decreased by Time 3, they were nonetheless higher than Time 1 scores. The researcher proposes this may be due to discussions around these issues in the nurse-led lymphoma survivorship clinic (NLSC) appointment. Anxiety and stress were the highest at Time 2, and stress continued to be elevated at Time 3, an area highlighted as a concern in research with cancer survivors (Marker, 2015).

Women in the control group, when compared with men, had higher total scale and anxiety median scores at Time 2, and higher depression scores at Time 1 and Time 2. This concurs with the findings from the SF-SUNS of unmet needs in the anxiety and depression domain. Although statistical significance was not reached, the direction of change revealed total scale mean scores decreased over the study period and remained higher in comparison with the intervention group mean scores. This was especially evident with anxiety being higher in the control group compared with the intervention group at Time 2. These findings concur with research that indicated depression and anxiety is a common psychological problem in haematology cancer survivors (Hall et al., 2016; Lobb et al., 2009; Mitchell et al., 2011).

Mental adjustment to cancer

Fighting spirit is described as a combination of optimism and confidence that the effects of cancer are controllable and the individual can actively deal with the situation (Wills & O'Carroll Bantum, 2012). Participants in the intervention group revealed significantly lower fighting spirit domain scores

at Time 1 and Time 2. These participants were given an opportunity to debrief about their diagnosis and treatment experiences and, therefore, the researcher suggests these participants may have felt they no longer had to 'fight' or 'beat' their cancer. Helplessness/hopelessness, defined as a sense of incapacity or 'giving into the cancer' (Czerw et al., 2015), showed a decrease from Time 1 to Time 3 in the intervention group and may indicate this group were not incapacitated by having had cancer. The anxious preoccupation domain can be understood to reflect preoccupation with the cancer that cannot be controlled by the individual (Czerw et al., 2015; Watson et al., 1994). The intervention group had a slight increase in median scores by Time 3 revealing this group were thinking about the cancer more. However, these participants were also aware this was their last appointment in the NLSC and may have been experiencing some anxiety about the completion of this individualised support. Participants with NHL in the intervention group had the lowest total scale, and median anxious preoccupation and cognitive avoidance (defined as a tendency to avoid actively thinking about the cancer and its implications (Watson et al., 1994)) domain scores, perhaps reflecting this group's ability to think beyond the cancer after treatment has been completed.

The 30–59 years age group in the control group had the highest median scores across all time points. Helplessness/hopelessness at Time 2, anxious preoccupation at Time 2 and Time 3, and cognitive avoidance at Time 1 and Time 3 had significantly higher median scores. These results may indicate that this age group, who continued with usual care, were not able to find ways to discuss their cancer concerns and were trying to actively avoid thinking about the cancer without success. Those control participants aged >60 years had significantly higher fatalism domain median scores at Time 2. The level of fatalism is said to impact whether an individual can control or

influence their cancer (Park, Edmondson, Fenster, & Blank, 2008), and may indicate the older age group felt they were not able to influence the diagnosis, perhaps due to age. Control participants with NHL had significantly higher median scores, especially in the fighting spirit domain at Time 3 suggesting the cancer was seen as a challenge they were still overcoming.

Fatalism, fighting spirit and anxious preoccupation mean scores decreased and helplessness/hopelessness and cognitive avoidance scores increased in the control group over the study. This may suggest a sense of powerlessness in coping with the cancer diagnosis, regardless of treatment completion and remission status. This is reflected in mean fatalism and fighting spirit scores which were lower than those of the intervention group. In addition, the suggestion of a sense of powerlessness is supported by the majority of the control group participants (compared with the intervention group) at Time 2 who significantly endorsed the items related to difficulty believing cancer had happened to them and trying to push all thoughts of cancer away, and at Time 3 indicating they did not want to think about cancer and were pushing thoughts of cancer away.

Self-empowerment

Participants in the intervention group demonstrated an increase in scores for self-empowerment from Time 1 through to Time 3. This study also found those >60 years of age, regardless of group allocation (intervention or control) were more empowered, especially compared with those in the 30–59 years age group. The researcher suggests this may, in part, be due to the life experiences and previous exposure to adversity older adults may have encountered. At Time 1 and Time 2 those with NHL, characteristically a disease of older age (Cancer Australia, 2017), had higher median scores. The

researcher suggests these participants may have already been more empowered due to age. Conversely, mean scores in the control group were lowest at Time 3. This finding suggests this group of participants felt less able to control aspects of their cancer and move on with their life, although further research is required to explore this trend.

The most endorsed items indicated the intervention group felt they had all the information they needed, were able to adapt and make changes to their lifestyle, felt health professionals included them in discussions and by Time 3 were more confident in their GP. The researcher suggests this may be due to the SCPTS sent to their GPs which outline future follow-up recommendations.

Nurse-led lymphoma survivorship model of care

While this pilot study was not sufficiently powered to demonstrate a significant effect between the two groups, the direction of change in the results suggests the nurse-led lymphoma survivorship model of care may be an effective intervention for targeted cancer cohorts. For some participants in the intervention, one or two appointments in the NLSC would have been sufficient to impart the SCPTS and give individualised and tailored resources as these survivors do not require intensive support (Campbell et al., 2014). However, those with high levels of unmet need after the provision of the SCPTS and resources may need more support. This was evidenced by the increase in needs at Time 2. These needs had diminished in the most part by Time 3 indicating a sustained follow-up may not be warranted.

Participants who utilised the motivational chart to make healthy lifestyle changes reported pressure to cease smoking or reduce alcohol during treatment. However, these participants indicated adequate support was not

provided at such a high-stress time. The participants acknowledged the motivational chart and support as a useful way to explore the unhealthy behaviour and their motivations in continuing. Likewise, these participants felt the motivational interviewing assisted them to be empowered to quit or reduce the unhealthy behaviours. Further study would be required to ascertain sustained change over a longer period than the study timeframe of six months.

Discussion of the Phase Four General Practitioner Evaluations

Data from the GP evaluations indicated the SCPTS had been received, read and in some cases prompted the GP to make an appointment (n=16, 89%) with the patient. However, not all GPs indicated they had discussed the SCPTS with their patient during the trial (n=11, 61%). Discussion of the SCPTS between participants and their GPs was encouraged; however, the participant could choose when and if they discussed the SCPTS during the trial. Five intervention participants indicated at the completion of the study they had not visited or discussed the SCPTS with their GP. As a copy of the SCPTS is held by the participant and his/her GP, it is envisaged the document could potentially be used at future appointments.

Of those GPs who completed the Likert-type scale, the majority (n=13, 81%) found the SCPTS useful and rated it as good to very good. Just over half of GP responders (n=10, 59%) requested further haematology or medically related information be included on the SCPTS, perhaps indicating insufficient information was communicated from the haematology department. As a treatment summary document, it was not the intent of the SCPTS to provide all health-related information. The majority of responders indicated they did not want further education on the SCPTS (n=9, 69%). The

present study did not address the management of other medical conditions, and this may be an area that would need consideration for future inclusion, particularly in older cancer participants who have an increased likelihood of co-morbidities.

Summary of the Phase Four Qualitative Interviews

In quantitative research, participants may not have an opportunity to articulate their perceptions, thoughts and feelings as they complete questionnaires with set responses. The researcher sought to avoid this limitation by including a qualitative sub-study (Phase Four) using a cohort of intervention participants to add depth and further explore some aspects of the quantitative data obtained (Creswell & Clark, 2011). This process of triangulating the data, using multiple methods of data collection, strengthened and supported the study outcomes as a more holistic understanding of the key findings was obtained from different sources (Sarantakos, 2013).

Additional support is particularly valuable when patients are transitioning from active treatment to life without treatment (Knott, Turnbull, Olver, & Winefield, 2012). Reality, however, suggests this period is characterised by the reduction or cessation of cancer care support in the acute setting (Rabin, Simpson, Morrow, & Pinto, 2011). The support conceptualised for the nurse-led lymphoma survivorship model of care and offered by an experienced cancer nurse was appreciated by participants at a time when previous cancer patients have expressed the fear they would be abandoned once treatment had completed (Lobb et al., 2009; Matheson et al., 2016; Monterosso et al., 2017). Participants who were interviewed highlighted both the importance of a safe environment to ask questions and expressed the importance of trust

and rapport developed between themselves and the researcher during the study. The majority of lymphoma survivors wanted to make healthy lifestyle behaviour changes; however, there were limited options that specifically target cancer survivors. Having an opportunity to discuss preferences and decisions with the researcher about individual goals and action plans was seen as very helpful. This can enhance self-efficacy leading to greater psychosocial well-being. This concurs with findings from a recent study which revealed a positive correlation between increased levels of self-efficacy and more emotional and functional well-being, alongside fewer cancer-related issues (Papadopoulou et al., 2017). Participants particularly liked how the SCPTS was personalised to them and they were able to document the issues and concerns most important to them.

Summary of the Test–retest Reliability Analysis

The SF-SUNS test–retest reliability sub-study added psychometric data for this measure in a lymphoma-specific cohort of survivors. The results demonstrated the majority of items achieved fair to good reliability intraclass correlation (ICC) scores. It is essential that survivorship-specific needs assessment measures detect clinically meaningful changes over time in the survivorship phase (DeVellis, 2012; McDowell, 2006; Streiner & Norman, 2003). An important consideration when issues and concerns are rapidly changing as survivors move beyond the diagnosis and treatment phases and begin to move forward with their lives. These results, now available in the published literature will allow other researchers an opportunity to make informed choices when choosing a survivorship-specific needs assessment measure for their cohorts.

Limitations of the Research

Specific limitations are addressed in each published manuscript. Limitations of the pragmatic RCT included the recruitment by chance of more males than females in the intervention group, and a disproportionate number of HL to NHL that did not reflect current lymphoma statistics (Cancer Australia, 2017). However, it is acknowledged this is a possibility when randomisation of groups occurs (Deaton & Cartwright, 2017). As a pilot study, a sample size calculation was not required, and it is acknowledged that 60 participants may not be adequate to see a true effect of the intervention. It must be highlighted the purpose of this pragmatic pilot RCT was to generate data that can be used to power future robust larger RCTs. This aim was achieved.

Fidelity of the intervention was maintained, and no control group participant received the intervention while on the study. It is unknown if survivorship information was imparted to control group participants by haematologists. This is considered unlikely however as needs of this group were higher than those of the intervention group.

The PhD candidate administered the intervention and entered the data from both groups. There is a potential for bias when the researcher evaluates their own service. Due to the constraints of a PhD which related to a lack of funding to employ an independent experienced cancer research nurse, a number of measures were employed to mitigate potential bias. Statisticians reviewed data and assisted with quantitative analysis to decrease the risk of bias in evaluation. Control group participants were only contacted by an independent member of the research team if this was required.

Alterations were made to how the NLSC appointments were conducted when haematologist appointments were altered. This was required to ensure timeframes were maintained. However, a strength of the NLSC intervention was its ability to be flexible to accommodate the requests of participants.

As a pragmatic RCT, there was a usual care group who did not receive the nurse-led lymphoma survivorship model of care. It is important when examining new models that a comparison group is provided, especially as research on the benefits of an SCPTS is limited. Future research to investigate the provision of the intervention to the usual care group after study timeframes are completed may provide valuable data on the benefits of delayed delivery compared with no delivery.

Assessment measures used in this study may not have captured all the concerns and issues that applied to lymphoma survivors. There were limitations to using the DASS21, for example, where a control group participant complained of a dry mouth it was unknown whether this was a sign of anxiety or an ongoing treatment effect. This was comparably true for the question related to lack of initiative which may have been related to fatigue rather than a sign of depression. Some participants expressed difficulty with answering particular questions on the Mini-MAC. Some participants at baseline indicated that some items, for example; 'I take one day at a time', 'I am apprehensive' or 'I have difficulty believing that this happened to me', both "applied" and "did not apply". Intervention participants who indicated similarly at the NLSC appointments were guided to reflect on how they felt at present, as per questionnaire instructions. Many participants at baseline needed to be reminded the assessment questionnaires were related to the present, not how they felt during treatment.

An economic evaluation of the cost of a nurse-led lymphoma survivorship model of care would have enhanced the research and added information on the viability of the model. This would correspondingly have examined the time and cost required for nurses to deliver this model of survivorship care. Likewise, an evaluation of lymphoma survivors' utilisation of the primary healthcare system from Medicare data could have examined if there was an increase in GP visits with the intervention group participants who were encouraged to see the GP compared with control group participants who were not given any post-treatment support. The time constraints of this PhD thesis prevented this lengthy form of evaluation. Further, as the study was only conducted with participants from one haematology department, it would be difficult to generalise the findings of this thesis to the other two public tertiary haematology departments in Perth Western Australia.

The time constraints of a PhD candidacy, as well as the significant size of this thesis, prevented an examination of the experience and needs of carers of RCT study participants. This is an important aspect of care and should be considered a potential future area for research. No data were collected from patients who declined the research. Therefore, it is unknown if these patients had more or diverse issues and unmet needs. Providing a nurse-led follow-up appointment to all lymphoma patients when they complete treatment as standard practice may contribute to supporting patients who would otherwise not seek assistance.

Finally, GP feedback could be improved with an investigation into whether and why some GPs did not receive the SCPTS. All medical centres were contacted if evaluations were not received with faxed copies being sent if medical practices indicated non-receipt. Whether the participant's GP did eventually receive the SCPTS and evaluation remains unknown. Further,

some GPs may have chosen not to return the evaluation. Nevertheless, the response rate for evaluation returns was considered acceptable at 64% (Livingston & Wislar, 2012).

Strengths of the Research

The major strength of this research and a key aspect was the tailored and personalised nature of the nurse-led lymphoma survivorship model of care, delivered by one experienced cancer nurse clinician (the PhD candidate). This ensured consistency and accuracy of all data. Information provision that is tailored to the patient's perceived needs is a significant factor in survivorship care, support and empowerment (Bulsara & Styles, 2013; Hall, D'Este, et al., 2014; Husson et al., 2013). Equally important was the early knowledge of late effects that may assist in timely follow-up with the GP when haematology department surveillance ends (Ng et al., 2011). An additional strength of this research was the lymphoma-specific cohort which allowed the researcher an opportunity to assess needs that were disease-specific (Oberoi et al., 2017). The nurse-led survivorship model of care was developed for lymphoma survivors in the early survivorship period, a time when studies have indicated there is an increase in distress as treatment completes (Girgis & Butow, 2009; Hewitt et al., 2005; Jefford et al., 2008) and survivors may feel abandoned by the treating team (Matheson et al., 2016; Monterosso et al., 2017).

Recent studies have indicated survivors want more detail and more information on healthy lifestyle behaviours, psychological support and resources (Keesing, McNamara, & Rosenwax, 2015; Mayer, Birken, et al., 2015). A strength of the conceptualised model was to develop information that was delivered as part of the general health aspect of the SCPTS and

within the resource pack developed for the study. GP evaluations on the SCPTS indicated a content rating of good to very good from the majority of GP respondents. Therefore, the researcher suggests the nurse-led lymphoma survivorship model of care was able to accommodate the needs of both survivors and GPs.

Assessment measures were utilised to assess and evaluate survivorship, distress, adjustment and coping and empowerment post-treatment at three time points. This assisted with discussion and targeting of resources during the nurse-led lymphoma survivorship clinic appointments for the intervention group. It may have also assisted those in the usual care (control) group to identify areas they may have discussed with their haematologist or GP. The unique lymphoma SCPTS was patient-centred and allowed intervention participants an opportunity to seek support on the issues and health goals that were important to them at their life stage. This has not been a feature of any SCPTS found in the published literature at the time of development. Motivational interviewing techniques require a particular skill set, and fortunately, the researcher was competent in this area. Utilising this skill and assisting the intervention participants to understand the impact of continuing unhealthy lifestyle behaviours, was an important promoter for change that they were empowered to make. This was an important element of the conceptual framework developed when the research was planned to aid recovery of health and well-being and engagement in healthy lifestyle behaviours to improve quality of life.

The research allowed participants an opportunity to debrief after a life-changing and often traumatic experience, such as a cancer diagnosis. This was an aspect that was highlighted in the qualitative interviews and anecdotally to the researcher during the face-to-face appointments. The

nurse-led lymphoma survivorship model of care provided normalisation of some of the long-term effects such as fatigue, fear of recurrence and/or cognitive impairment, with provision of further information. This was likewise perceived by many participants as missing from haematology follow-up care. The researcher suggests debriefing and normalisation, along with information, resources and support may help to mitigate these issues continuing in the longer-term.

Lastly, an important strength was the use of and collaboration with the haematology survivorship research advisory committee which consisted of academic, clinical health and community support group professionals and lymphoma survivor consumers. The input of the consumers provided significant insight into current lymphoma post-treatment follow-up and on gaps they perceived in their own cancer survivorship journey.

Chapter Summary

This chapter summarises the key findings from the four phases of this thesis study. In keeping with a pilot pragmatic RCT design, the small numbers of participants recruited limited the power of this study to potentially demonstrate statistically significant results. Nevertheless, this study provides a valuable contribution for future rigorous testing of nurse-led survivorship models of care to transition patients from treatment into the survivorship phase. The large body of work presented in this PhD thesis by publication exceeds the minimum requirement of four published manuscripts. The final publication, currently undergoing preparation for publication will report the LMM data from the pragmatic pilot RCT and provide evidence to generate sample size calculations to support future RCT studies.

Providing individualised and tailored information, support, resources and a patient-centred survivorship care plan and treatment summary in the early survivorship period may lead to less unmet needs and better recovery of health and well-being in the future.

The final chapter will conclude this thesis and discuss the implications of this type of research. Furthermore, it will provide recommendations for clinical nursing, future research and education in survivorship care for nurses who are a valuable and integral component of high-quality supportive survivorship care.