European Journal of Oncology Nursing 40 (2019) 53–62

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Care After Lymphoma (CALy) trial: A phase II pilot pragmatic randomised controlled trial of a nurse-led model of survivorship care

Karen Taylor[a,b,*], Paola Chivers[c], Caroline Bulsara[a,c], David Joske[d,e], Max Bulsara[c], Leanne Monterosso[a,f,g]

[a] School of Nursing and Midwifery, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[b] Western Australia Cancer and Palliative Care Network, Perth, Australia
[c] Institute for Health Research, University of Notre Dame Australia, Fremantle, Western Australia, Australia
[d] Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia
[e] School of Medicine, University of Western Australia, Crawley, Western Australia, Australia
[f] Centre for Nursing and Midwifery Research, St John of God Murdoch Hospital, Western Australia, Australia
[g] School of Nursing, Edith Cowan University Joondalup, Western Australia, Australia

ARTICLE INFO

Keywords:
Lymphoma
Survivorship
Nurse-led model of care
Randomised controlled trial

ABSTRACT

Purpose: Post-treatment follow-up for lymphoma potentially fails to address the supportive care needs of survivors. A nurse-led lymphoma survivorship model of care was developed and tested in a phase II pilot pragmatic randomised controlled trial (RCT). The intervention comprised three face-to-face appointments, delivery of tailored resources and an individualised survivorship care plan and treatment summary (SCPTS), shared with the general practitioner (GP).

Method: Three months' post-treatment completion, eligible lymphoma patients were randomised 1:1 to usual care (control) or usual care plus intervention. Survivorship unmet needs (Short-Form Survivor Unmet Needs Survey), distress (Depression Anxiety Stress Scale 21), adjustment to cancer (Mini-Mental Adjustment to Cancer scale) and self-empowerment (Patient Empowerment Scale) were assessed at baseline, three and six months. Univariate and multivariate analyses examined changes within and between groups at the three time points. A GP evaluation survey sought information on the perceived utility of the SCPTS.

Results: Statistical significance was set at 0.05 (2-tailed). Although not statistically significant, by study completion, intervention participants (n = 30), reported less unmet needs (M = 21.41 vs M = 25.72, p = .506), less distress ((M = 13.03 vs M = 15.14, p = .558) and an increase in empowerment (M = 50.21 vs M = 47.21, p = .056) compared with control participants (n = 30). The SCPTS was rated good to very good by a majority of GPs (n = 13, 81%).

Conclusions: The nurse-led lymphoma survivorship model of care may be a helpful intervention for lymphoma patients who had completed treatment. Survivors require individualised and tailored support and resources. A tailored SCPTS may promote survivor self-management and increase GP engagement.

1. Introduction

Lymphomas are lymphatic system cancers (Cancer Australia, 2018) broadly categorised into two main types: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). Globally, North America has the highest incidence of lymphoma, with an estimated 83,180 new cases in the USA in 2018 (Siegel et al., 2018), followed by Australia, with an estimated 6,232 cases in 2017 (Australian Institute of Health and Welfare, 2017). This equates to approximately 4.6% of all cancer cases in both countries (Cancer Australia, 2018; Siegel et al., 2018). Due to the advent of improved treatment and supportive care options such as chemotherapy, radiotherapy, haematopoietic stem cell transplants and targeted therapies, survival at five years in Australia is approximately 76% (Australian Institute of Health and Welfare, 2017), similar to the USA (Siegel et al., 2018). With improved remission rates, quality of life and well-being can be impacted by long-term and late effects (Leeuwen and Ng, 2017; Sarker et al., 2017). These can include persistent physical effects such as fatigue and cognition impairment (de Lima et al., 2018; Krolak et al., 2017; Leeuwen and Ng, 2017; Linendoll et al., 2016); psychosocial effects such as fear of recurrence, depression, anxiety and

* Corresponding author. Western Australia Cancer and Palliative Care Network, 4th Floor A Block, Verdun Street, Nedlands, Western Australia, 6009, Australia.
E-mail address: Karen.Taylor@health.wa.gov.au (K. Taylor).

https://doi.org/10.1016/j.ejon.2019.03.005
Received 8 September 2018; Received in revised form 21 March 2019; Accepted 25 March 2019
1462-3889/ © 2019 Elsevier Ltd. All rights reserved.

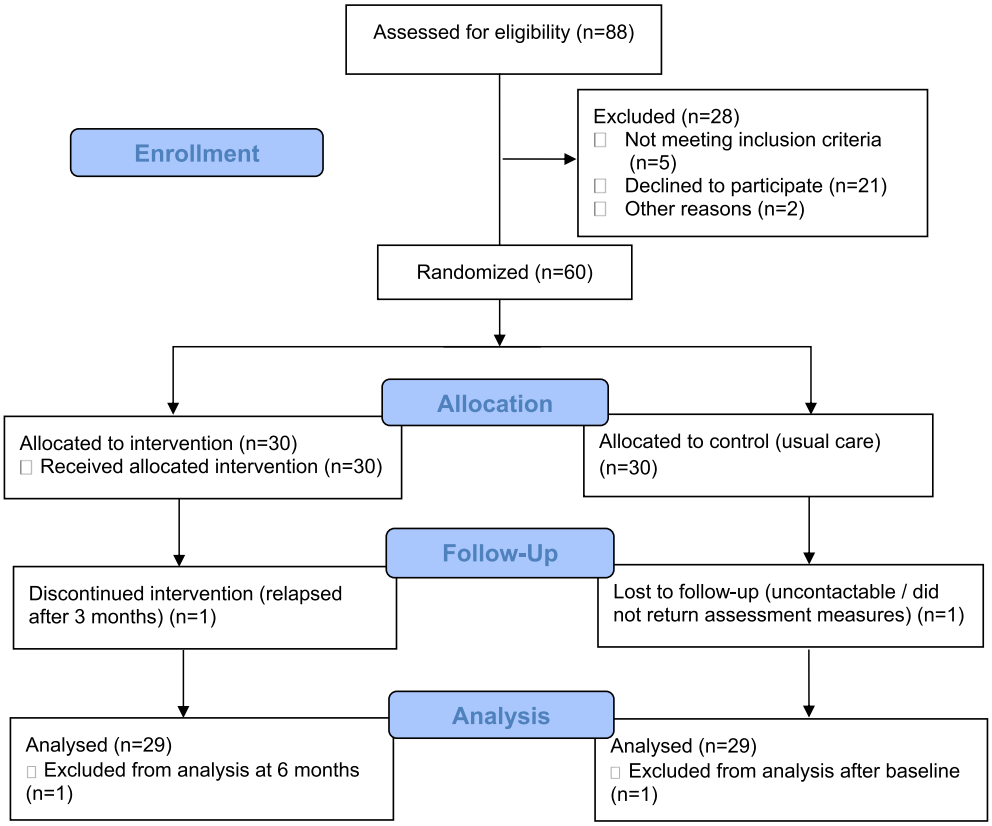

Fig. 1. CONSORT Flow Diagram for the current trial.

distress (Hall et al., 2016; van de Wal et al., 2016); along with practical concerns such as employment and finances (Arboe et al., 2017; Mojs et al., 2017). Survivors also have an increased risk of developing other diseases such as cardiovascular disease (Leeuwen and Ng, 2017) and second cancers (Leeuwen and Ng, 2017; Schaapveld et al., 2015), therefore survivors need an awareness of these potential risks to ensure timely follow-up occurs (Ng et al., 2011).

Follow-up after treatment completion has traditionally been haematologist-led (Taylor et al., 2015), focusing more on recurrence surveillance (Molassiotis et al., 2017) than tailored support and information needs (Earle and Ganz, 2012; Jefford et al., 2008). Our recent focus group study with 17 lymphoma survivors, indicated a post-treatment follow-up appointment to transition with individualised and tailored support could provide a more flexible, patient-centred approach to survivorship care (Monterosso et al., 2017). Recent studies have demonstrated the potential of nurse-led survivorship models of care to transition patients into the survivorship phase (Howell et al., 2012; Jefford et al., 2016; John and Armes, 2013). Further, the use of a survivorship care plan and treatment summary (SCPTS) has been recommended nationally and internationally (Clinical Oncology Society of Australia, 2016; Klemanski et al., 2016; MacMillan Cancer Support & NHS Improvement, 2010) to facilitate survivorship follow-up care. A written, individualised summary of treatment, with tailored information and resources for surveillance, late effects screening and the promotion of healthy lifestyle behaviours, may be an effective way to guide follow-up care (Taylor and Monterosso, 2015). It may also encourage survivors to take responsibility for the management of their health, ongoing symptoms and well-being, which can improve quality of life and self-efficacy (Kuijpers et al., 2013).

The aim of the Care After Lymphoma (CALy) phase II pilot study was to use a pragmatic randomised controlled trial (RCT) design to develop and evaluate an evidence-based nurse-led lymphoma survivorship model of care intervention. Three fundamental components comprised the intervention: 1) administration of assessment measures to assess patient-reported concerns, adjustment to cancer and empowerment; 2) delivery of an individualised SCPTS to encourage participants to identify their own concerns, health goals and actions, with a copy sent to the general practitioner (GP); and 3) provision of evidenced-based tailored information, support and resources to address identified issues and promote healthy lifestyle behaviours. The primary outcome was the effect of the model of care on self-reported unmet informational, practical and emotional needs, distress (depression, anxiety and/or stress); and self-management and mental adjustment to cancer survivorship in the intervention group compared with participants in the usual care (control) group. The secondary outcome was to evaluate the perceived utility of the SCPTS by the intervention participants' GPs.

2. Methods

2.1. Design

A pragmatic RCT design was chosen to understand the real-world implications of the intervention in conditions closely aligned with usual follow-up care (Thorpe et al., 2009). The framework was developed using the Consolidated Standards of Reporting Trials (CONSORT) statement and checklist (Moher et al., 2010; Schulz et al., 2010). Human research ethics approval was obtained (UNDA 015007F & SCGH 2015-020) and the RCT registered with the Australian New Zealand Clinical Trials Registry (ACTRN1261500530527). Study development and the full study protocol have been published (Taylor et al., 2016).

2.2. Recruitment process

Lymphoma participants were recruited from a large, tertiary comprehensive cancer centre in Western Australia. Trial eligibility included:

a confirmed diagnosis of HL or NHL; completed first-line curative intent chemotherapy or second-line curative intent autologous stem cell transplant within the previous three months; no evidence of lymphoma disease on mid-treatment and/or post-treatment PET scan; over 18 years of age; and ability to understand and read English. Exclusion criteria were: no chemotherapy; treatment or follow-up at another hospital; cognitive or diagnosed acute mental health condition precluding informed consent; diagnosis of a secondary cancer or other medical condition requiring treatment. The survivorship cancer nurse coordinator (CNC) conducting the study had over 20 years haematology/bone marrow transplant nursing care experience. She approached eligible patients after treatment completion to discuss and provide study information. The CONSORT diagram (Moher et al., 2010) depicting the flow of participants through the trial is presented in Fig. 1. Computer-generated random numbers were generated and linked to group allocation by an independent statistician. Participants were randomised 1:1 into the intervention or control groups after informed consent and baseline assessment. Recruitment commenced in July 2015 and was completed in January 2017. All participants had completed study participation by October 2017.

2.3. Data collection

Baseline demographic data was collected three months after treatment completion and included: lymphoma type, stage and treatment; date of and time since diagnosis; comorbidities; gender; age; marital status; age of children (if any); postcode; occupation; education and income level; smoking status, alcohol consumption and weight. Four assessment measures were chosen and administered at baseline (Time 1), three months post-baseline (Time 2) and six months post-baseline (Time 3). Permission was sought and granted for use of all the measures during this study. Fig. 2 indicates the participant flow and timing of measures throughout the RCT.

2.3.1. Assessment measures

The Short-Form Survivor Unmet Needs Survey (SF-SUNS) (Campbell et al., 2014) assessed the gap between cancer survivors' self-reported concerns and level of support required in four domains. Each item was scored from 0 (no unmet need) to 4 (very high unmet need), therefore total scale scores could range from 0 to 120. Higher scores indicated more unmet needs. The Depression, Anxiety, Stress Scale (DASS21) (Lovibond and Lovibond, 1995) measured the multiple dimensions of depression, anxiety and stress and was scored according to: 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). Total scale scores could range from 0 to 63, with higher scores a representation of a higher level of distress. The Mini Mental Adjustment to Cancer scale (Mini-MAC) (Watson et al., 1994) was used to measure five cancer-specific coping strategies. The scale was scored from 1 (definitely does not apply to me) to 4 (definitely applies to me) and total scale scores could range from 29 to 116. Higher scores in a domain indicated an escalation of behaviour characteristic of that coping strategy. The Patient Empowerment Scale (PES) (Bulsara and Styles, 2013) measured the level of a patient's coping ability and perceived self-efficacy in managing their illness and making decisions about support strategies. It was scored 1 (strongly disagree) to 4 (strongly agree), thus total scale scores could range from 15 to 60. Higher scores indicated more self-empowerment. All measures reported good to excellent reliability and validity with haematological cancer participants and were psychometrically sound. Responses to the SF-SUNS, DASS21, Mini-MAC and PES used Likert-type scales and were scored according to the algorithms in the instrument manuals. Missing data was minimal and accounted for less than 1.5% of the total data.

2.4. Control group

Participants in this group received follow-up care as per haematologists' usual practice. Three and six months after baseline, the four assessment measures were posted with an explanation letter to complete and return assessments via the addressed reply-paid envelope. A member of the research team called participants who had not returned assessments after two weeks, to encourage completion and return of assessments.

2.5. Intervention group

Participants in this group received: usual haematology follow-up; three appointments in the nurse-led lymphoma survivorship clinic (NLSC) with the CNC; an individualised SCPTS; and resource pack.

2.5.1. Nurse-led lymphoma survivorship clinic (NLSC)

Appointments in the NLSC were made for 60 min and were conducted in a private clinic room, coinciding with haematologist appointments to decrease travel burden to the hospital. Participants were encouraged to discuss their treatment experience and normalise their concerns during the first appointment. Guided by responses from the baseline assessment measures, participants were encouraged to indicate where most concerns and issues transitioning into the survivorship phase were. The SCPTS was discussed and completed. Participants were encouraged to discuss the follow-up recommendations with their GP. The resource pack contents were explained and information on how to access support provided. The second and third NLSC appointments involved: completion of the four assessment measures; discussion of previous and new unmet needs (if any); provision of applicable written information, resources and support. Participants were asked if they had discussed the SCPTS with their GP.

2.5.2. Survivorship care plan and treatment summary (SCPTS)

A SCPTS was developed for this study (Taylor et al., 2016) and comprised: an individualised treatment summary; potential late effects; participant-derived main concerns, health goals and actions; and general health and screening information. The treatment summary and potential late effects were drafted by the CNC, then reviewed and signed by the treating haematologist prior to the first appointment. Participant-derived main concerns, health goals and actions were recorded at the first NLSC. Copies of the completed SCPTS were distributed to the participant, their GP and their hospital record. Motivational interviewing techniques were used to assess for readiness to make behavioural changes from unhealthy lifestyle behaviours and to guide how change would be enacted, along with encouragement of changes already attempted or made. A motivational chart assisted the participant to record likes and dislikes of specific health behaviours and reasons for making or not making changes. The chart likewise encouraged the participant to record the benefits and/or issues that might arise when making changes to their lifestyle.

2.5.3. Resource pack

All participants received two generic information booklets for cancer survivors; *Living Well After Cancer* (Bell and Fagan, 2015) and *Exercise for People Living with Cancer* (Bruce, 2015). Fact sheets included: new insurance policies (Cancer Council Australia, 2015); Australian guide to healthy eating (Australian Government, 2015a); coping with fear of recurrence (American Society of Clinical Oncology, 2015); coping with cancer fatigue (Cancer Council Australia, 2015); a cancer survivor exercise program (Edith Cowan University, 2015); coping with memory and concentration impairment (developed by researcher); and Cancer Council WA "Life Now" information and dates (Cancer Council Australia, 2015). Tailored information was provided based on responses to baseline measures or requested by the participant. This could include: "*Cancer and Your Finances*" (Bruce, 2015); "*Sexuality, Intimacy and Cancer*" (Bruce, 2015); Cancer Council Pro Bono programs (legal, financial and workplace advisory) (Cancer Council Australia, 2015); quit smoking (Cancer Council Australia, 2015); motivational chart

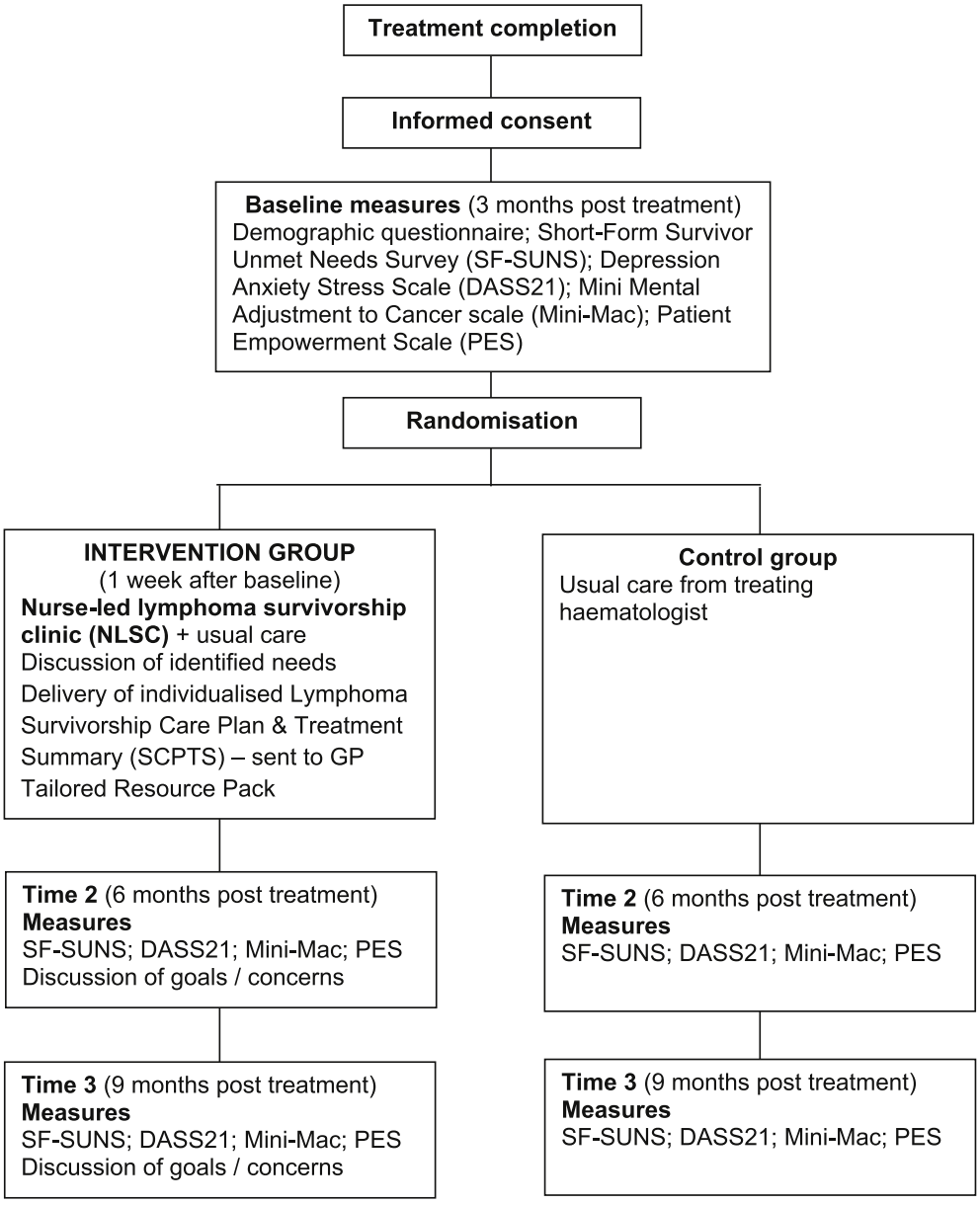

Fig. 2. Study participant flow and timing of measures.

(developed by researcher); and mental health plan information (Australian Government, 2015b). A checklist was created for each participant recording the resources provided.

2.6. General practitioner evaluations

A 16-item evaluation for GPs was developed in consultation with two GPs to assess the utility of the SCPTS. Seven yes/no/not applicable items ascertained whether GPs received and used the SCPTS. A Likert-type scale (1 = very poor, 2 = poor, 3 = adequate, 4 = good, 5 = very good) was used to rate the elements of the SCPTS (4 items). Five open-ended items allowed further comment on the SCPTS and if further haematology education was desired. The evaluation was sent with a cover letter and a further copy of the SCPTS upon study completion (approximately 6-months). Non-responding GPs were called by the CNC after two weeks with a reminder to complete and post, email or fax back the evaluation.

2.7. Ethical considerations

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. Participants were assured raw data would remain confidential and would not be shared. De-identified data is available on reasonable request. This research was approved by the ethics committees of the University of Notre Dame Australia (015007F) and Sir Charles Gairdner Hospital (2015-020).

2.8. Data analysis

Quantitative data were analysed using IBM SPSS version 25 (IBM Corp, 2017). Descriptive statistics were used for demographic variables. Statistical significance was set at alpha 0.05 (2-tailed). The degree of sample generalisation between groups (control and intervention) was

ascertained and reported using a Pearson Chi-square test, or Fisher's Exact Test where required. Analysis was by intention to treat, unanswered items on questionnaires were recorded. Within each group, paired *t*-test on the total scale and domain scores of each instrument were made between Time 1 compared to Time 2 and Time 3. Independent t-tests (or non-parametric Mann Whitney *U* Test) were used to assess the group differences on the four assessment measures including total scale and domain scores at each time point.

Linear Mixed Modelling (LMM) with Bonferroni post-hoc comparisons were used to examine change in repeated measures over the six months. LMM is suitable for data where; multiple measures are repeatedly taken from the same individuals, data is not necessarily normally distributed, and permits missing data points (missing at random) (West et al., 2015). Each assessment measure and its domains were treated as a separate dependent variable model. Covariates were treated as fixed effects and included group (control versus intervention), time (1, 2 and 3), with cofounders of age, gender and lymphoma type. Individuals were treated as a random effect. Group x time and gender × time interactions were examined for each model and were included in the final reported model only if statistically significant. Final model residuals were assessed for normality and were not violated, although a slight deviation in the tails was noted for some models.

GP evaluations were analysed using descriptive statistics and qualitative content analysis for open-ended items.

3. Results

3.1. Participants

Of 88 eligible patients (Fig. 1), 60 consented to participate in the trial (68%). Twenty-eight patients who either did not meet the inclusion criteria (n = 5) or declined to participate (n = 21) had comparable demographic characteristics (obtained from their medical records) with those of participants: more males (n = 16, 58%); a similar age range (24–82 years, *M* = 63 years, *SD* = 14); in a relationship (n = 20, 67%), and NHL diagnosis (n = 24, 80%). Demographic and disease characteristics of study participants are shown in Table 1. Groups were similar apart from gender differences, with more males (73%) randomised to the intervention group, and more females randomised to the control group (60%). Gender differences were controlled for during subsequent analyses.

3.2. Assessment measures

All participants completed all items on the SF-SUNS, DASS21 and Mini-MAC. Most participants completed all items on the PES. The frequently unanswered PES item was “complementary therapies help me cope with my illness” (n = 12, 48%). Cronbach's alpha results were high: SF-SUNS = 0.70–0.96; DASS21 = 0.79–0.94; Mini-MAC = 0.58–0.90; and PES = 0.75–0.79.

3.3. Fidelity

3.3.1. Control group

No participant in the control group received the SCPTS nor the resource pack (developed by the researcher) during the study. Control participants may have accessed other forms of information and support in the public domain, however this was considered usual care. Twenty-nine participants (97%) completed all time points.

3.3.2. Intervention group

All participants completed the first NLSC appointment face-to-face. The average time of consultation was 64.28 min (range 20–120 min) and the average time from baseline was 9.63 days (range 0–56 days). Four participants (13%) requested the first NLSC appointment on the

Table 1
Demographic characteristics for RCT participants (n = 60).

Characteristics	Intervention n = 30	Control n = 30	Group Difference	
	N (%)	N (%)	Pearson Chi Square	P value
Gender			6.79	**.018**
Male	22 (73)	12 (40)		
Female	8 (27)	18 (60)		
Age group - years			0.89	.712
18-29	8 (27)	5 (16)		
30-59	12 (40)	14 (47)		
60-86	10 (33)	11 (37)		
Lymphoma diagnosis			2.86	.158
Non-Hodgkin	18 (60)	24 (80)		
Hodgkin	12 (40)	6 (20)		
Time since diagnosis - months			0.29	.789
5–8 months	20 (67)	18 (60)		
> 9 months	10 (33)	12 (40)		
Marital status			5.14*	.273
Single	9 (30)	5 (16)		
Married/defacto	17 (57)	20 (67)		
Divorced/separated	4 (13)	2 (7)		
Widowed	0 (0)	3 (10)		
Children < 25 (living at home)^	12 (40)	9 (30)		
Adult children	9 (30)	13 (43)		
No Children	9 (30)	8 (27)		
Highest level of education			1.56	.498
Secondary school or less	7 (23)	11 (37)		
Trade/vocational college	9 (30)	9 (30)		
University	14 (47)	10 (33)		
Employment status#			1.09	.435
Working	15 (50)	12 (40)		
Not working	15 (50)	18 (60)		
Retired	7 (23)	9 (30)		
No return to work date	5 (16)	5 (16)		
Looking for work	2 (7)	4 (13)		
Sick pension	1 (3)	0 (0)		
Level of Income			4.10*	.586
$0-$30,000	13 (43)	15 (50)		
$30,001-$70,000	7 (23)	6 (20)		
$70,001–100,000	4 (13)	5 (16)		
$100,001-$130,000	2 (7)	1 (3)		
> $130,001	4 (13)	1 (3)		
prefer not to answer	0 (0)	2 (7)		
Residence			0.48*	.731
Metropolitan	24 (80)	26 (87)		
Regional	6 (20)	4 (13)		

(*continued on next page*)

Table 1 (*continued*)

Characteristics	Intervention n = 30	Control n = 30	Group Difference	
	N (%)	N (%)	Pearson Chi Square	P value
Lifestyle factors^				
Current smoker	4 (13)	3 (10)		
Quit < 12 months	2 (7)	2 (7)		
Quit > 12 months	5 (16)	5 (16)		
Never smoked	19 (63)	20 (67)		
Alcohol consumption				
Current	17 (57)	19 (63)		
Occasional < 1 drink/week	9 (30)	10 (33)		
2–3 drinks/week	6 (20)	3 (10)		
4–5 drinks/week	1 (3)	0 (0)		
6–7 drinks/week	0 (0)	3 (10)		
Binge on weekends	1 (3)	0 (0)		
2–3 drinks/night	0 (0)	3 (10)		
Never	13 (43)	11 (37)		
Weight				
Underweight (< 50 kg)	1 (3)	0 (0)		
Overweight (> 95 kg)	5 (16)	6 (20)		

Bolded indicated statistical significance p < .05; *Fisher's Exact test result reported; #Analysis from two groups – 'working' and 'not working'; ^Subjective data not analysed.

same day as baseline. Two participants (6%) missed their appointment and were seen 31 and 56 days later. Reasons for delays related to work and family commitments. The second and third NLSC consultation average times were 46.13 min (range 19–90 min) and 44.31 min (range 15–70 min) respectively. Four participants (13%) completed the third NLSC by telephone after haematologist appointments were cancelled and moved to a future date. Distance to the hospital was a barrier for these four patients to attend the nurse-led clinic, and these participants requested the opportunity to complete the final time point when it was due rather than delay this point of data collection. Requested information was emailed or posted. Twenty-nine participants (97%) completed all time points.

3.4. Nurse-led lymphoma survivorship model of care

3.4.1. Concerns and health goals on SCPTS

Half the participants identified fear of recurrence (n = 15, 50%), and one third identified fatigue (n = 10, 33%) and/or cognitive impairment (n = 9, 30%) as participant-derived concerns on the SCPTS. As self-reported on the SF-SUNS at Time 3: one participant (3%) continued to report a very high level of fear of recurrence; 10 participants (34%) reported fatigue as a moderate to high unmet need; and 15 participants (52%) reported cognition impairment as a moderate to high unmet need. The majority of participants (n = 25, 83%) recorded a goal to increase or start physical exercise and over half wanted to make healthy lifestyle changes (n = 16, 53%). Four participants (13%) used the motivational chart to assist with smoking cessation. Three participants (10%) had quit smoking by study completion. Two participants (6%) used the chart to address excessive alcohol intake and by study completion, one participant indicated complete abstinence and the other a reduction in intake.

3.4.2. Survivorship unmet needs (SF-SUNS)

Intervention group mean scores were highest at Time 1 ($M = 27.33$) and continued to decrease over the study period. Independent t-tests, demonstrated higher mean scores in the control group compared with the intervention group (Table 2). The relationships and emotional health domain scores for the control group increased over the study period. All scores had a small effect size and no results were significant.

Individual items assessed on the SF-SUNS indicated the intervention group at Time 1 reported a higher level of need for finding information about complementary or alternative therapies ($M = 0.87$) than the control group ($M = 0.27$; $p = .014$). Time 3 results indicated the control group felt less able to speak to others about their emotions ($M = 1.10$ vs $M = 0.21$; $p < .001$) or deal with feeling depressed ($M = 1.24$ vs $M = 0.62$; $p = .047$).

LMM analysis, adjusting for gender, lymphoma type and age, reported group (control or intervention), time (1, 2 or 3), and lymphoma type (NHL or HL) were not significantly associated with the SF-SUNS. The LMM for the information domain reported a significant effect for time, showing Time 1 scores were higher ($\beta = 0.76$, 95% CI = 0.10–1.42, $p = .025$). The financial domain LMM reported those with NHL had higher scores compared to those with HL ($\beta = 5.70$, 95% CI = 1.40–10.00, $p = .010$). The access and continuity of care domain LMM reported those with NHL had higher scores compared to those with HL ($\beta = 3.05$, 95% CI = 0.47–5.62, $p = .021$) and as age increased, unmet needs in this domain decreased ($\beta = -0.06$, 95% CI = −0.12-0.00, $p = .039$). The relationships and emotional health domain LMM reported women had more unmet needs compared to males ($\beta = -8.20$, 95% CI = −14.39 to -2.02, $p = .010$).

3.4.3. Distress (DASS21)

No statistically significant group differences at each time point (independent t-tests) or between time points (paired sample t-tests) were found (Table 2).

Similarly, LMMs examining DASS21 total scale score and domains, adjusting for gender, lymphoma type and age, reported no significant group or time effects. However, women reported significantly higher scores compared with men for all DASS21 models: Total scale ($\beta = -8.75$, 95% CI = −15.60 to -1.90, $p = .013$); depression ($\beta = -2.92$, 95% CI = −5.58 to -0.26, $p = .032$); anxiety ($\beta = -2.70$, 95% CI = −4.61 to -0.78, $p = .007$); and stress ($\beta = -3.16$, 95% CI = −5.99 to -0.33, $p = .029$).

3.4.4. Mental adjustment to cancer (Mini-MAC)

Intervention group, total scale and domain mean scores decreased from Time 1 to Time 3, with the exception of cognitive avoidance domain mean score which was highest at Time 2 ($M = 8.80$; $p = .043$) (Table 2). Evaluation of individual items revealed significant differences, indicating the control group struggled more with having a cancer diagnosis ($M = 2.76$ vs $M = 2.20$; $p = .035$) at Time 2, and trying not to think about it at Time 2 ($M = 2.59$ vs $M = 2.03$; $p = .034$) and Time 3 ($M = 2.48$ vs $M = 1.97$; $p = .042$).

LMM analysis adjusting for gender, lymphoma type and age, reported group, gender and lymphoma type were not significant contributors. LMMs: total scale ($\beta = 2.93$, 95% CI = 0.46–5.40, $p = .020$); fatalism ($\beta = -0.69$, 95% CI = 0.05–1.33, $p = .035$); and fighting spirit ($\beta = -0.83$, 95% CI = 0.08–1.58, $p = .029$) revealed higher scores at Time 1. In addition, fatalism domain scores increased as age increased ($\beta = -0.06$, 95% CI = 0.02–0.11, $p = .005$). A significant interaction between group and time was found in the fighting spirit domain model, reporting the control group had a higher fighting spirit domain score at Time 2 ($\beta = -1.06$, 95% CI = 0.01–2.12, $p = .049$). No significant results were found in the LMMs for other domains.

3.4.5. Patient empowerment (PES)

The highest level of self-empowerment in the intervention group was at Time 2 and Time 3, however these were not significant (Table 2). Control group results identified a significant decrease in the level of self-empowerment from Time 1 to Time 2 ($p = .005$). The highest self-empowerment scores were identified in the intervention group compared with the control group at Time 2 ($M = 49.50$ vs $M = 45.79$; $p = .016$).

Individual items on the PES revealed the control group felt less adept at making lifestyle changes at Time 2 ($M = 3.03$ vs $M = 3.40$;

Table 2
Descriptive data of the multi-item measures by group at each time point and between time points.

Measure	Baseline (Time 1)#			3 months (Time 2)#			6 Months (Time 3)#			Time differences^			
	Control Group*	Intervention Group*	P value (Cohen's *d*)	Control Group*	Intervention Group*	P value (Cohen's *d*)	Control Group*	Intervention Group*	P value (Cohen's *d*)	Time 1 – Time 2		Time 1 – Time 3	
										Control	Intervention	Control	Intervention
SF-SUNS[a]	26.53 (21.84)	27.33 (20.63)	.885 (−.04)	28.62 (27.82)	26.27 (22.81)	.723 (.09)	25.72 (25.99)	21.41 (22.95)	.506 (.18)	*t* (28) −0.46 *p* .648	*t* (29) 0.39 *p* .698	*t* (28) 0.32 *p* .753	*t* (28) 1.99 *p* .057
Information	3.30 (2.58)	2.97 (3.18)	.657 (.12)	3.21 (3.29)	2.33 (2.01)	.221 (.27)	2.76 (2.82)	1.97 (2.34)	.249 (.31)	*t* (28) 0.43 *p* .673	*t* (29) 1.20 *p* .240	*t* (28) 1.36 *p* .185	*t* (28) 1.52 *p* .139
Financial concerns	7.03 (6.13)	6.70 (5.93)	.831 (.05)	6.38 (8.38)	7.63 (7.58)	.549 (−.16)	6.28 (7.77)	5.76 (6.36)	.782 (.07)	*t* (28) 0.62 *p* .538	*t* (29) −0.89 *p* .383	*t* (28) 0.68 *p* .505	*t* (28) 1.02 *p* .317
Access and continuity of care	2.60 (4.35)	3.97 (5.88)	.310 (.27)	3.28 (4.32)	2.40 (3.43)	.391 (.23)	2.34 (2.87)	2.24 (4.75)	.920 (.03)	*t* (28) −0.98 *p* .338	*t* (29) 1.88 *p* .070	*t* (28) 0.34 *p* .737	*t* (28) 2.47 *p* **.020**
Relationships and emotional health	13.60 (11.51)	13.70 (10.87)	.973 (.01)	15.76 (13.79)	13.90 (12.75)	.593 (.14)	14.34 (14.10)	11.45 (12.28)	.408 (.22)	*t* (28) −0.93 *p* .361	*t* (29) −0.19 *p* .907	*t* (28) −0.22 *p* .826	*t* (28) 1.32 *p* .199
DASS21[b]	15.57 (13.91)	12.67 (12.01)	.391 (.22)	14.17 (13.67)	15.63 (15.61)	.704 (−.10)	15.14 (13.76)	13.03 (13.40)	.558 (.16)	*t* (28) 0.75 *p* .462	*t* (29) = −1.53 *p* .136	*t* (28) 0.24 *p* .812	*t* (28) - 0.19 *p* .853
Depression	4.33 (5.37)	4.03 (4.75)	.819 (.06)	4.59 (5.44)	5.30 (5.78)	.627 (−.13)	4.83 (5.56)	4.14 (5.38)	.633 (.13)	*t* (28) −0.28 *p* .79	*t* (29) = −1.58 *p* .13	*t* (28) −0.58 *p* .57	*t* (28) −0.06 *p* .95
Anxiety	4.60 (5.05)	3.47 (3.36)	.310 (.27)	3.63 (4.18)	3.53 (3.67)	.932 (.02)	3.55 (3.95)	3.45 (3.93)	.921 (.03)	*t* (28) 1.22 *p* .232	*t* (29) −0.14 *p* .888	*t* (28) 1.38 *p* .179	*t* (28) −0.06 *p* .892
Stress	6.63 (5.15)	5.17 (5.05)	.270 (.29)	5.97 (5.69)	6.80 (6.97)	.617 (−.13)	6.76 (5.82)	5.66 (5.75)	.471 (.19)	*t* (28) 0.67 *p* .510	*t* (29) −1.85 *p* .074	*t* (28) −0.22 *p* .825	*t* (28) −0.65 *p* .522
Mini-MAC[c]	68.47 (12.74)	65.30 (12.62)	.337 (.25)	67.72 (15.22)	64.27 (13.44)	.359 (.24)	65.38 (15.52)	62.59 (15.03)	.489 (.18)	*t* (28) 0.51 *p* .614	*t* (29) = 0.61 *p* .547	*t* (28) 1.81 *p* .081	*t* (28) 1.35 *p* .188
Fatalism	14.27 (3.29)	14.13 (3.03)	.871 (.04)	13.79 (3.58)	14.30 (2.81)	.547 (−.16)	13.28 (3.56)	13.76 (3.44)	.603 (−.14)	*t* (28) 0.80 *p* .428	*t* (29) −0.39 *p* .701	*t* (28) 1.94 *p* .062	*t* (28) 1.13 *p* .267
Fighting spirit	12.47 (2.13)	12.40 (2.59)	.914 (.03)	12.07 (2.61)	11.33 (2.32)	.257 (.30)	11.24 (2.91)	11.55 (2.43)	.661 (−.12)	*t* (28) 0.96 *p* .345	*t* (29) 2.80 *p* **.009**	*t* (28) 3.50 *p* **.002**	*t* (28) 2.13 *p* **.042**
Helplessness/ hopelessness	12.47 (4.31)	12.77 (4.88)	.802 (−.07)	12.66 (4.76)	12.83 (4.79)	.887 (−.03)	12.62 (4.41)	12.00 (4.74)	.608 (.14)	*t* (28) −0.04 *p* .968	*t* (29) 1.11 *p* .909	*t* (28) 0.00 *p* 1.00	*t* (28) 1.39 *p* .176
Anxious preoccupation	19.47 (5.34)	17.27 (5.84)	.133 (.40)	18.66 (5.68)	17.00 (6.07)	.284 (.28)	18.10 (6.14)	16.76 (6.34)	.415 (.22)	*t* (28) 1.46 *p* .154	*t* (29) 0.33 *p* .742	*t* (28) 2.20 *p* **.037**	*t* (28) 0.65 *p* .521
Cognitive avoidance	9.80 (3.13)	8.73 (3.17)	.195 (.03)	10.55 (3.25)	8.80 (3.26)	**.043** (.54)	10.14 (3.06)	8.52 (3.94)	.086 (.46)	*t* (28) −1.68 *p* .105	*t* (29) −0.14 *p* .888	*t* (28) −0.73 *p* .474	*t* (28) 0.16 *p* .876
PES[d]	48.77 (6.03)	48.33 (5.11)	.765 (.80)	45.79 (5.85)	49.50 (5.63)	**.016** (−.65)	47.21 (6.07)	50.21 (5.63)	.056 (−.50)	*t* (28) 3.06 *p* **.005**	*t* (29) −1.45 *p* .158	*t* (28) 1.41 *p* .170	*t* (28) −1.97 *p* .059

Note. *Data given as mean (SD); # Independent *t*-test results; ^ Paired samples *t*-test results; [a]Higher scores represent higher levels of need; [b]Higher scores represent higher levels of psychological need; [c]Higher scores represent more endorsement of the domain trait; [d]Higher scores represent more empowerment; SF-SUNS, Short Form Survivor Unmet Needs Survey; DASS21, Depression, Anxiety Stress Scale; Mini-MAC, Mental Adjustment to Cancer Scale; PES, Patient Empowerment Scale; Cohen's *d*: 0.2 = small effect, 0.5 = moderate effect, 0.8 = large effect.

p = .048) and Time 3 (M = 2.83 vs M = 3.34; p = .022) and at Time 1 indicated a need for support from family and friends (M = 3.77 vs M = 3.43; p = .047). This was in contrast to the intervention group where results indicated they had all the information they needed to manage their health (M = 3.47 vs M = 3.03; p = .008) and make lifestyle change at Time 2 (M = 3.30 vs M = 2.86; p = .023) and Time 3 (M = 3.34 vs M = 2.83; p = .022). The intervention group at study completion had more confidence in their GP (M = 3.59 vs M = 3.03; p = .014).

The LMM for the PES, adjusting for gender, lymphoma type and age, reported no significant group, lymphoma, gender or time effects. However, a significant group × time interaction was reported indicating Time 1 scores were higher in the control group (β = 3.21, 95% CI = 068-5.74, p = .013) which then decreased over the study period.

3.5. GP evaluation results

Twenty-eight GPs of intervention group participants were sent the SCPTS evaluation (two participants did not have a GP) and 18 evaluations returned (64%). Five participants did not see their GP during the study. Of the non-responding GPs (n = 10, 36%), seven were male and eight had metropolitan medical practices.

Of the responding GPs, 11 (61%) were male, and the majority were metropolitan based (n = 16, 89%). Sixteen (89%) GPs had read the SCPTS and seen their patients within the last six months, however only 11 (61%) indicated they had discussed the SCPTS with their patient. Sixteen GPs completed the Likert-type scale on the usefulness of the SCPTS with responses ranging from adequate to very good (maximum score). The majority of GP responses (n = 13, 81%) to the SCPTS was good to very good (M = 4.19).

An open-ended section requested further information GPs would like on the SCPTS. Ten (56%) GPs provided responses which included a desire for more information on treatment, chemotherapy agents, frequency of haematologist review, side effect management and what was required of the GP. Six GPs (34%) responded to the question on unnecessary information and all indicated no information needed to be removed. Over half of GP respondents (n = 10, 56%) made additional comments pertaining to the SCPTS. Responses were dichotomised as: positive (“This was excellent. Concise and brief”, “Great idea”); neutral (“I did not ring [patient] when I got the plan”, “Diagnosed lymphoma, not seen him since”, “nothing further to add”); or negative (“I expect a letter with instructions”, “further comments are pointless”). In response to further education requirements, n = 13 (72%) responded. Four GPs indicated they would like further education on other haematology malignancies, case studies and post-treatment vaccinations.

4. Discussion

This pilot RCT suggests the nurse-led lymphoma survivorship model of care may be an effective intervention for targeted cancer cohorts. The most endorsed concerns on the SCPTS were fear of recurrence, fatigue and cognition impairment, and these findings are consistent with current research. A study of different cancer types in the early survivorship phase (n = 2615) including lymphoma survivors (n = 379), revealed higher fear of recurrence levels which could be mitigated with satisfactory information provision (van de Wal et al., 2016). This was reflected in the present study where only one participant self-reported a very high unmet need at study completion. Furthermore, our study found fatigue was still prevalent at study completion, a finding consistent with a recent study of Dutch HL survivors, where higher fatigue prevalence was revealed in comparison to a normative population (41%–43% vs 23%–28%) (Daniels et al., 2014). Likewise, a recent study of lymphoma patients (n = 262) demonstrated significantly lower cognitive scores and greater frequency of impairment when compared with healthy controls (32% vs 7%) (Krolak et al., 2017). Our study reported cognition impairment remained an issue at study completion.

Providing an opportunity for lymphoma survivors to name and discuss their concerns was the point of difference to the usual care provided in the study setting which is provided at haematologist follow-up appointments, and is brief and medically-focused. A nurse-led intervention, as in our study, may assist in normalising concerns experienced whilst providing resources and support during the survivorship period. This was explored in a recent SCP systematic review of 24 clinical studies (13 RCTs), which found outcomes were more positive for cancer survivors when personalised discussion accompanied delivery of a SCP (Jacobsen et al., 2018).

While statistical significance was not an aim of this pilot study, a comparison of the mean results of the intervention group scores on the SF-SUNS, DASS21 and Mini-MAC fighting spirit and helplessness/hopelessness domains indicated a downward trend over the study period. Equally, intervention group self-empowerment scores increased. This may suggest intervention participants were able to have their issues and concerns resolved which may have been attributed to the nurse-led lymphoma survivorship model of care. This may also be reflected in the most endorsed PES items, indicating this 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 six months were more confident in their GP. It is difficult to compare these findings with other published nurse-led survivorship research due to variations in study rigor, assessment measures used, intervention protocols and time since treatment completion (Carey et al., 2012; Jefford et al., 2016). Conversely, the mini-MAC items identified that amongst the control group, participants had difficulty believing cancer ‘had happened to them’ and difficulty trying to ‘push all thoughts of cancer away’ and in addition had higher fighting spirit domain scores. As stated, this pilot study was likely underpowered to reflect statistical significance. We suggest these results may indicate control group participants felt less able to control aspects of their cancer and move on with their life due to a lack of targeted support when treatment ended. A similar finding was reflected in a qualitative study of lymphoma survivors who perceived a lack of support after treatment completion with specialist-led follow-up (Monterosso et al., 2017).

Women in both groups had the highest scores on the SF-SUNS at baseline which concurs with other Australian research indicating women identify higher levels of unmet need (Lobb et al., 2009; Sanson-Fisher et al., 2000). Likewise, women had higher scores across all domains of the DASS21, especially control group women. These findings correspond with previous 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). In contrast, men had higher information needs at study completion, a finding reflected in a study of gender differences during survivorship follow-up which revealed men had more unmet informational needs (Arden-Close et al., 2011).

Targeting individual needs is important; study findings may suggest that women may need more to time to assess and explore a range of needs when treatment ends, whereas men may benefit from early assessment of information needs.

Significantly, participants aged > 60 years had the lowest SF-SUNS scores, possibly due to their life stage where some practical issues such as finances, employment, relationship and emotional needs are less of a concern. This age group, regardless of group allocation were also more empowered, perhaps due to life experiences and previous exposure to adversity. However, significantly higher fatalism domain scores were noted, which may indicate older age was associated with a perceived inevitability of a cancer diagnosis. In contrast, findings from our study suggest those under 60 years of age require more support when treatment completes to return to their normal functioning (Sharp et al., 2014). Understanding the support needs across different age groups may enable institutions to assess and direct resources that are age and life stage-relevant. Likewise, 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.

Data from the GP evaluations indicated the majority had received and read the SCPTS and found it useful. However, not all GPs discussed it with their patient. Likewise, five intervention participants indicated they had not seen their GP during the trial. 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. Over half of GP responders requested additional medically-related information be included on the SCPTS, perhaps indicating insufficient information is communicated during treatment. As a treatment summary, it was not the intent of the SCPTS to provide all health-related information.

Findings from this pilot study may guide the development of future research that explores the differing needs of men and women and how these can be best addressed in the survivorship phase. Likewise, age and life stage are important indicators of the resources and support that may be required by lymphoma survivors. Utilising mechanisms such as an individualised SCPTS to allow patient-identified concerns to be addressed requires larger long-term studies to determine if statistically significant findings are also of clinical significance in the survivor cohort. Further investigation of GP and primary care service utilisation by survivors, including information provided to GPs during treatment and upon completion would add to the body of knowledge and its utility in this area.

4.1. Limitations

As a pilot study, a sample size calculation was not required, consequently, it is acknowledged 60 participants may be inadequate to see a true effect of the intervention. However, the study has provided evidence that could be used by future researchers to estimate sample sizes for larger RCTs. There were disproportionate numbers of men to women and HL to NHL in the intervention group that did not reflect current lymphoma statistics (Cancer Australia, 2018), which can occur with randomisation (Deaton and Cartwright, 2017). It is unknown if survivorship information was imparted to control participants by haematologists, however, as needs were higher, it was unlikely. Alterations were made to the NLSC to accommodate participants when appointments were altered, nonetheless, a strength of the intervention was its flexibility. The motivational chart and motivational interviewing techniques was acknowledged as useful in assisting to quit or reduce unhealthy behaviours, however further research is required to ascertain sustained change over time.

5. Conclusion

Testing of a nurse-led lymphoma survivorship model of care by a pragmatic randomised controlled trial has not been published to date, therefore this study represents an original contribution to lymphoma survivorship supportive care and knowledge. Whilst 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 adjunct to traditional follow-up by providing individualised and tailored supportive care after treatment completion to targeted cancer cohorts. Whilst statistical significance may be demonstrated in a future adequately powered large-scale RCT, clinical significance of this nurse-led lymphoma survivorship model of care should also be explored and could include clinically-relevant information such as confidence intervals and effect sizes. Our findings provide the data to support the calculation of sample sizes for such future robust clinical trials.

The SCPTS allowed participants a voice in reporting issues, concerns and goals that were important to them. GPs supporting patients in the intervention found the SCPTS useful and rated it highly. Participants who have had their needs and concerns acknowledged and addressed post-treatment may feel more able to reintegrate and adapt to a new normal in all aspects of their future and this would be a worthwhile area for further study. Future multisite research with larger cohorts should include economic evaluations of the best provider of services, for example medical versus nurse-led support, along with outcome measures that assess long-term health care utilisation and the impact on long-term quality of life. Encouraging active participation in health and well-being as well as a greater emphasis on GP involvement through the SCPTS, may provide direction to GPs for future management of late effects that may not be occurring at the present time. This may lead to earlier interventions, which would provide clinically significant data for future survivorship research.

Conflicts of interest

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

Funding

This research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors. The PhD student was supported though an Australian Government Research Training Program Scholarship and the University of Notre Dame Australia (Fremantle), Australian Government's Collaborative Research Networks (CRN) program.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2019.03.005.

References

American Society of Clinical Oncology, 2015. Coping with Fear of Recurrence. https://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence, Accessed date: 1 April 2015.

Arboe, B., Olsen, M.H., Goerloev, J.S., Duun-Henriksen, A.K., Johansen, C., Dalton, S.O., Brown, P.D.N., 2017. Return to work for patients with diffuse large B-cell lymphoma and transformed indolent lymphoma undergoing autologous stem cell transplantation. Clin. Epidemiol. 9, 321–329.

Arden-Close, E., Absolom, K., Greenfield, D., Hancock, B., Coleman, R., Eiser, C., 2011. Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. Psycho Oncol. 20, 1202–1210.

Australian Government, 2015a. Australian Guide to Healthy Eating. Department of Health and Ageing. www.eatforhealth.gov.au, Accessed date: 1 April 2015.

Australian Government, 2015b. Better Access to Mental Health Care. www.health.gov.au/internet/main/publishing.nsf/Content/mental-ba, Accessed date: 1 April 2015.

Australian Institute of Health and Welfare, 2017. Cancer in Australia 2017. Cancer Series no.101. Cat. No. CAN 100. AIHW, Canberra.

Bell, J., Fagan, M., 2015. Living Well after Cancer. Cancer Council Australia.

Bruce, J., 2015. Cancer and Your Finances; Exercise for People Living with Cancer; Sexuality, Intimacy and Cancer. Cancer Council Australia.

Bulsara, C., Styles, I., 2013. Development of a cancer related patient empowerment scale using the polytomous rasch measurement model. Cancer Clin. Oncol. 2, 1–16.

Campbell, H.S., Hall, A.E., Sanson-Fisher, R.W., Barker, D., Turner, D., Taylor-Brown, J., 2014. Development and validation of the short-form survivor unmet needs survey (SF-SUNS). Support. Care Canc. 22, 1071–1079.

Cancer Australia, 2018. Lymphoma in Australia. Australian Government. https://lymphoma.canceraustralia.gov.au/statistics, Accessed date: 2 February 2018.

Cancer Council Australia, 2015. Quit Smoking; Pro Bono Programs; Life Now; Coping with Cancer Fatigue; New Insurance Policies. Cancer Council Australia.

Carey, M., Lambert, S., Smits, R., Paul, C., Sanson-Fisher, R., Clinton-McHarg, T., 2012. The unfulfilled promise: a systematic review of interventions to reduce the unmet supportive care needs of cancer patients. Support. Care Canc. 20, 207–219.

Clinical Oncology Society of Australia, 2016. Model of Survivorship Care: Critical Componenets of Cancer Survivorship Care in Australia Position Statement.

Daniels, L.A., Oerlemans, S., Krol, A.D., Creutzberg, C.L., van de Poll-Franse, L.V., 2014. Chronic fatigue in Hodgkin lymphoma survivors and associations with anxiety, depression and comorbidity. Br. J. Canc. 110, 868–874.

de Lima, F.D., Bottaro, M., de Oliveria Valeriano, R., Criuz, L., Battaglini, C.L., Vieira, C.A., de Oliveria, R.J., 2018. Cancer-related fatigue and muscle quality in Hodgkin's lymphoma survivors. Integr. Cancer Ther. 17, 299–305.

Deaton, A., Cartwright, N., 2017. Understanding and misunderstanding randomized controlled trials. Soc. Sci. Med. https://doi.org/10.1016/j.socscimed.2017.12.005.

Earle, C.C., Ganz, P.A., 2012. Cancer survivorship care: don't let the perfect be the enemy of the good. J. Clin. Oncol. 30, 3764–3768.
Edith Cowan University, 2015. Vario Wellness Clinic. , Accessed date: 1 April 2015.
Hall, A.E., Sanson-Fisher, R.W., Carey, M.L., Paul, C., Williamson, A., Bradstock, K., Campbell, H.S., 2016. Prevalence and associates of psychological distress in haematological cancer survivors. Support. Care Canc. 24, 4413–4422.
Howell, D., Hack, T., Oliver, T., Chulak, T., Mayo, S., Aubin, M., Chasen, M., Earle, C., Friedman, A., Green, E., Jones, G., Jones, J., Parkinson, M., Payeur, N., Sabiston, C., Sinclair, S., 2012. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. J. Canc. Surviv. 6, 359–371.
IBM Corp, 2017. Released 2017. IBM SPSS Statistics for Macintosh, Version 25.0. IBM Corp, Armonk, NY.
Jacobsen, P.B., DeRosa, A.P., Henderson, T.O., Mayer, D.K., Moskowitz, C.S., Paskett, E.D., Rowland, J.H., 2018. Systematic review of the impact of cancer survivorship care plans on health outcomes and health care delivery. J. Clin. Oncol. 36, 2088–2100.
Jefford, M., Gough, K., Drosdowsky, A., Russell, L., Aranda, S., Butow, P., Phipps-Nelson, J., Young, J., Krishnasamy, M., Ugalde, A., King, D., Strickland, A., Franco, M., Blum, R., Johnson, C., Ganju, V., Shapiro, J., Chong, G., Charlton, J., Haydon, A., Schofield, P., 2016. A randomized controlled trial of a nurse-led supportive care package (SurvivorCare) for survivors of colorectal cancer. Oncol. 21, 1014–1023.
Jefford, M., Karahalios, E., Pollard, A., Baravelli, C., Carey, M., Franklin, J., Aranda, S., Schofield, P., 2008. Survivorship issues following treatment completion - results from focus groups with Australian cancer survivors and health professionals. J. Canc. Surviv. 2, 20–32.
John, C., Armes, J., 2013. Developing a nurse-led survivorship service for patients with lymphoma. Eur. J. Oncol. Nurs. 17, 521–527.
Klemanski, D.L., Browning, K.K., Kue, J., 2016. Survivorship care plan preferences of cancer survivors and health care providers: a systematic review and quality appraisal of the evidence. J. Canc. Surviv. 10, 71–86.
Krolak, D., Collins, B., Weiss, L., Harris, C., Van der Jagt, R., 2017. Cognitive function and its relationship to other psychosocial factors in lymphoma survivors. Support. Care Canc. 25, 905–913.
Kuijpers, W., Groen, W.G., Aaronson, N.K., 2013. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. J. Med. Internet Res. 15, e37.
Leeuwen, F.E., Ng, A.K., 2017. Late sequelae in Hodgkin lymphoma survivors. Hematol. Oncol. 35, 60–66.
Linendoll, N., Saunders, T., Burns, R., Nyce, J.D., Wendell, K.B., Evens, A.M., Parsons, S.K., 2016. Health-related quality of life in Hodgkin lymphoma: a systematic review. Health Qual. Life Outcomes 14, 114.
Lobb, E.A., Joske, D., Butow, P., Kristjanson, L.J., Cannell, P., Cull, G., Augustson, B., 2009. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. Patient Educ. Counsel. 77, 103–108.
Lovibond, S.H., Lovibond, P.F., 1995. Manual for the Depression Anxiety Stress Scales, second ed. Psychology Foundation University of New South Wales, Sydney.
MacMillan Cancer Support, NHS Improvement, 2010. The National Cancer Survivorship Initiative Vision. Department of Health UK, London.
Mitchell, A.J.D., Chan, M.M., Bhatti, H.M., Halton, M.M., Grassi, L.P., Johansen, C.P., Meader, N.P., 2011. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. Lancet Oncol. 12, 160–174.
Moher, D., Hopewell, S., Schulz, K.F., Montori, V., Gøtzsche, P.C., Devereaux, P.J., Elbourne, D.D., Egger, M.M., Altman, D.G., 2010. CONSORT 2010 Explanation and Elaboration: updated guidelines for reporting parallel group randomised trial. Br. Med. J. 340, c869.
Mojs, E., Warchol-Biedermann, K., Samborski, W., 2017. What do we know about psychological outcomes of lymphoma in adults? Eur. Psychol. 22, 121–131.
Molassiotis, A., Yates, P., Li, Q., So, W.K.W., Pongthavornkamol, K., Pittayapan, P., Komatsu, H., Thandar, M., Li, M.S., Titus Chacko, S., Lopez, V., Butcon, J., Wyld, D., Chan, R.J., 2017. Mapping unmet supportive care needs, quality-of-life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: results from the international STEP study. Ann. Oncol. 28, 2552–2558.
Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., Stratton, K., Joske, D., 2017. A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. Eur. J. Oncol. Nurs. 28, 62–68.
Ng, A., LaCasce, A., Travis, L.B., 2011. Long-term complications of lymphoma and its treatment. J. Clin. Oncol. 29, 1885–1892.
Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., Cook, P., 2000. The unmet supportive care needs of patients with cancer. Supportive care review group. Cancer 88, 226–237.
Sarker, S.-J., Smith, S.K., Chowdhury, K., Ganz, P.A., Zimmerman, S., Gribben, J., Korszun, A., 2017. Comparison of the impact of cancer between British and US long-term non-Hodgkin lymphoma survivors. Support. Care Canc. 25, 739–748.
Schaapveld, M., Aleman, B.M., Eggermond, A.M.v., Janus, C.P., Krol, A.D., Maazen, R.W.M.v.d., Roesink, J., Raemaekers, J.M.M., Boer, J.P.d., Zijlstra, J.M., Imhoff, G.W.v., Petersen, E.J., Poortmans, P.M.P., Beijert, M., Lybeert, M.L., Mulder, I., Visser, O., Louwman, M.W., Krul, I.M., Lugtenburg, P.J., Leeuwen, F.E.v., 2015. Second cancer risk up to 40 years after treatment for Hodgkin's lymphoma. N. Engl. J. Med. 373, 2499–2511.
Schulz, K.F., Altman, D.G., Moher, D., 2010. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. Br. Med. J. 340, c332.
Sharp, L., Deady, S., Gallagher, P., Molcho, M., Pearce, A., Thomas, A.A., Timmons, A., Comber, H., 2014. The magnitude and characteristics of the population of cancer survivors: using population-based estimates of cancer prevalence to inform service planning for survivorship care. BMC Canc. 14, 1–10.
Siegel, R.L., Miller, K.D., Jemal, A., 2018. Cancer statistics, 2018. CA: Canc. J. Clin. 68, 7–30.
Taylor, K., Chan, R.J., Monterosso, L., 2015. Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review. Support. Care Canc. 23, 1447–1458.
Taylor, K., Joske, D., Bulsara, M., Bulsara, C., Monterosso, L., 2016. Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. BMJ Open 6, 1–10.
Taylor, K., Monterosso, L., 2015. Survivorship care plans and treatment summaries in adult patients with hematologic cancer: an integrative literature review. Oncol. Nurs. Forum 42, 283–291.
Thorpe, K.E., Zwarenstein, M., Oxman, A.D., Treweek, S., Furberg, C.D., Altman, D.G., Tunis, S., Bergel, E., Harvey, I., Magid, D.J., Chalkidou, K., 2009. A pragmatic–explanatory continuum indicator summary (PRECIS): a tool to help trial designers. J. Clin. Epidemiol. 62, 464–475.
van de Wal, M., van de Poll-Franse, L., Prins, J., Gielissen, M., 2016. Does fear of cancer recurrence differ between cancer types? A study from the population-based PROFILES registry: PROFILES - fear of cancer recurrence in cancer survivors. Psycho Oncol. 25, 772–778.
Watson, M., Law, M., dos Santos, M., 1994. The mini-MAC: further development of the mental adjustment to cancer scale. J. Psychosoc. Oncol. 12, 33–46.
West, B.T., Welch, K.B., Galecki, A.T., 2015. Linear-Mixed Models—A Practical Guide Using Statistical Software, second ed. Taylor and Francis/CRC Press, Boca Raton, Florida.