Seminars in Oncology Nursing 40 (2024) 151592

Contents lists available at ScienceDirect

Seminars in Oncology Nursing

journal homepage: https://www.journals.elsevier.com/seminars-in-oncology-nursing

Supporting Cancer Survivors Following Treatment for Non-Hodgkin's and Hodgkin's Lymphoma: A Pilot Study Assessing the Feasibility and Process Outcomes of a Nurse-Led Intervention

Amy J. Spooner[a,b], Jane Turner[c], Elise Button[a,b,d], Patsy Yates[a,b,d], Glen Kennedy[d,e], Jason Butler[d], Natalie Bradford[a,b,f], Alexandre Chan[g], Nicolas H. Hart[a,b,h,i,j,k], Raymond J. Chan[a,b,h,m,*]

[a] School of Nursing, Queensland University of Technology, Brisbane Australia
[b] Cancer and Palliative Care Outcomes Centre, Faculty of Health, Queensland University of Technology, Brisbane Australia
[c] Faculty of Medicine, University of Queensland, Brisbane Australia
[d] Cancer Care Services, Royal Brisbane and Women's Hospital, Metro North Hospital and Health Service, Brisbane, Australia
[e] Mater Cancer Care Centre, Mater Health, Brisbane, Australia
[f] Youth Cancer Services, Queensland Children's Hospital, Brisbane, Australia
[g] School of Pharmacy and Pharmaceutical Sciences, University of California, Irvine, United States of America
[h] Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia
[i] Human Performance Research Centre, INSIGHT Research Institute, Faculty of Health, University of Technology Sydney, Sydney, Australia
[j] School of Medical and Health Sciences, Edith Cowan University, Perth, Australia
[k] Institute for Health Research, University of Notre Dame Australia, Perth, Australia
[m] Division of Cancer Services, Princess Alexandra Hospital, Metro South Hospital and Health Service, Brisbane, Australia

ARTICLE INFO

Key Words:
Survivorship
Lymphoma
Non-Hodgkin's
Hodgkin's
Nurse-led
Shared care

ABSTRACT

Objective: Lymphoma is the sixth most common cancer in Australia and comprises 2.8% of worldwide cancer diagnoses. Research targeting development and evaluation of post-treatment care for debilitating complications resulting from the disease and its treatment is limited. This study aimed to assess the feasibility and acceptability of a nurse-led survivorship intervention, post-treatment in Hodgkin's and non-Hodgkin's lymphoma survivors.

Methods: A single-center, prospective, 3-arm, pilot, randomized controlled, parallel-group trial was used. People with lymphoma were recruited and randomized to the intervention (ENGAGE), education booklet only, or usual care arm. Participants receiving ENGAGE received an educational booklet and were offered 3 consultations (via various modes) with a cancer nurse to develop a survivorship care plan and healthcare goals. Participant distress and intervention acceptability was measured at baseline and 12-wk. Acceptability was measured via a satisfaction survey using a 11-point scale. Feasibility was measured using participation, retention rates, and process outcomes. Data were analyzed using descriptive statistics.

Results: Thirty-four participants with HL and NHL were recruited to the study (11 = intervention, 11 = information only, 12 = usual care). Twenty-seven participants (79%) completed all time points from baseline to 12 wk. Seven (88%) of the 8 participants receiving ENGAGE completed all consultations using various modes to communicate with the nurse (videoconference 14/23, 61%; phone 5/23, 22%; face-to-face 4/23, 17%). Participants who completed the intervention were highly satisfied with ENGAGE.

Conclusion: The ENGAGE intervention is feasible and highly acceptable for lymphoma survivors. These findings will inform a larger trial assessing effectiveness and cost effectiveness of ENGAGE.

Lymphomas are neoplasms originating in the lymphatic system, covering a wide spectrum of diseases, from chronic and slow growing, to acute and aggressive. The incidence of lymphomas has risen over the past 20 y, representing the sixth most diagnosed cancer across all age groups in Australia.[1] Worldwide, across 185 countries the incidence of lymphoma is 0.4% for Hodgkin's lymphoma (HL) and

* Address correspondence to: Raymond J. Chan, RN, PhD, GAICD, FAAN, FACN, NHMRC, Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Sturt Rd, Bedford Park, 5042, Australia.
E-mail address: raymond.chan@flinders.edu.au (R.J. Chan).

https://doi.org/10.1016/j.soncn.2024.151592

Layperson Summary

What we investigated

This study tested a post-treatment intervention for lymphoma survivors and compared it to lymphoma survivors that received usual care and an educational booklet or usual care only.

Why we investigated it

Lymphoma is one of the top 10 cancers diagnosed in Australia. Although advances in treatment have led to an increased survival rate, treatment is complex and can often cause side effects that last long after treatment has finished. Post-treatment care of side effects is common in people surviving breast, prostate, or colorectal cancer however, post-treatment care for lymphoma survivors is limited.

How we did our research

Participants were randomised to one of three groups (usual care + educational booklet + three consultations with an oncology nurse) for the length of the study. The aim of the study was to identify whether participants that received the intervention were satisfied, attended, and participated in consultations with an oncology nurse.

What we have found

Participants had differing levels of readiness to participate in post-treatment care and nurses are well positioned to assess when and how participants would like to receive post-treatment care. Participants were very satisfied with nurse-led consultations and chose various ways (in person, phone and telehealth) to communicate with the nurse.

What it means

The results support further development of this nurse-led model in a larger study to support lymphoma survivors' post-treatment.

2.8% for non-Hodgkin's lymphoma (NHL) with the highest incidence reported in Australia and New Zealand.[2] Treatment is complex and debilitating, and can be provided through multiagent chemotherapy, and/ or radiation therapy, and/or hematopoietic stem cell transplantation, resulting in immune suppression with increased risk of opportunistic infections.[3] Advances in treatments have seen increasing numbers of people surviving lymphoma more than 5 y following curative treatment.[1,4,5] Unfortunately, survival from lymphoma does not guarantee full restoration of health, with many people continuing to experience debilitating complications and impaired quality of life (QoL) for years after treatment as a result of their disease and aggressive treatment.[4,6]

Emerging evidence concerning the short-term and long-term physical, emotional, and social impact of hematological malignancies and their treatment highlight the potential for comprehensive clinical interventions to reduce distress and improve QoL.[7,8] Interventions can focus on the specific needs of lymphoma survivors including management of cancer-related fatigue, optimizing diet and exercise, and impacts on fertility, sexual function, body image, which can affect adjustment to normal life, depression, anxiety, fear of cancer recurrence, or other unaddressed informational needs.[8-10] Adults who have completed treatment for hematological malignancies further highlight the need for good care co-ordination and communication between treating doctors at the end of their treatment.[9] These findings indicate a need for a well-coordinated approach to survivorship

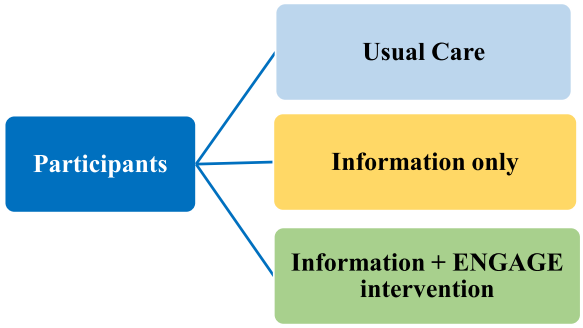

FIG 1. ENGAGE trial study arms.

care for people with hematological malignancies at the end of their treatment.[9] Survivorship models of care have focused predominantly on those with breast cancer, prostate cancer, or colorectal cancer to date, with relative neglect of people with hematological malignancies including those with HL and NHL, particularly in the post-treatment phase.[8]

Given the complex needs of lymphoma survivors, it is important to consider how nurse-led care may value add to the traditional medical-led models.[11] Several studies suggest nurses are well-placed to deliver survivorship care because of their central role in providing information that is holistic and individualised.[12,13] A phase II, pilot randomized controlled trial (RCT) in 60 lymphoma survivors indicated that a nurse-led survivorship model led to fewer reported unmet needs, less distress and increased empowerment.[14,15] Given the increasing number of cancer survivors within the healthcare system, and escalating associated healthcare costs, supportive interventions that are effective and cost-effective are urgently needed.[16]

Importantly, ensuring access to such supportive interventions for all survivors is an important priority. Telehealth interventions have been shown to improve service efficiency and reduce costs related to travel.[17,18] In many clinical specialties, videoconferencing is an accepted alternative for face-to-face consultations that has been demonstrated to be an efficient and economical method for increasing access to quality care.[17,19] Incorporating videoconferencing into models of care potentially enables more people to receive personalized care in a location convenient to the cancer survivor and clinician. The aim of this study was to examine the feasibility and acceptability of delivering a telehealth-enabled and tailored nurse-led survivorship care intervention in HL and NHL survivors to inform future large, multi-site, pragmatic RCTs.

Methods

This study, *a pilot randomized controlled trial of a nurse-led survivorship intervention for EmpoweriNG pAtients with HodGkin's and Non-Hodgkin's lymphoma after trEatment (ENGAGE),* adhered to the CONSORT statement for reporting RCTs,[20] and was approved by the Royal Brisbane and Women's Hospital (RBWH) Human Research Ethics Committee (HREC/16/QRBW/372). The trial was prospectively registered on the Australian and New Zealand Clinical Trials Registry (ACTRN12617000068369).

Trial Design

This single-site, prospective, 3-arm, pilot, RCT, parallel-group trial spanned 12-wk in duration, with pre- and postintervention assessments. Study arms included: (1) usual care; (2) information only: educational booklet and (3) ENGAGE intervention and information: a nurse-led, tailored, survivorship care intervention and educational

booklet (Fig. 1). Feasibility (i.e., recruitment and retention) and acceptability (to participants) of the ENGAGE survivorship intervention was assessed.

Participants

Cancer survivors were eligible if they were 18 y of age or older; within 12 wk following curative-intent treatment (chemotherapy with/without radiation and/or autologous hematopoietic stem cell transplantation) completion for HL or NHL; expected to remain in remission for 2 or more years as judged by their treating clinician; able to speak and read English; ambulatory at the time of recruitment and had an Eastern Cooperative Oncology Group (ECOG) performance status ≤ 1. For people receiving chemotherapy or radiotherapy without hematopoietic stem cell transplantation, the last day of chemotherapy or radiotherapy was considered treatment completion. For people completing hematopoietic autologous stem cell transplantation, treatment completion was defined as day of hospital discharge post-transplant. Cancer survivors were excluded if they had received allogeneic stem cell transplantation as they often have high requirements of acute care needs for a longer period post transplantation. People with severe mental, cognitive, or physical conditions, (advised by the treating hematologist) that would limit the cancer survivors' ability to participate were also excluded.

Study Setting

Royal Brisbane and Women's Hospital (Brisbane, QLD, Australia), a tertiary public teaching hospital in Australia, from April 2017 to July 2018. Eligible cancer survivors were identified through screening people in hematology clinics, attending multidisciplinary team meetings, and through nurse care coordinator referrals.

Interventions

All participants received usual care which involved routine medical follow-up from their hematologist for surveillance purposes and supportive care as required. Participants receiving information only, or the ENGAGE intervention, received an evidence-based educational booklet with information and guidance for post-treatment survivorship care additional to usual care. The educational booklet was only available to participants randomized to information only, or the ENGAGE intervention. Following study completion, the booklet was made openly available through the Leukemia Foundation. Participants receiving the ENGAGE intervention were also provided with nurse-led consultations via telehealth (videoconference or phone) or face-to-face, depending on the participant's preference within 12 wk following treatment completion. As this was a pilot study, approval was obtained to extend the participant eligibility period from 4 wk to 12 wk following treatment completion to accommodate people who experienced acute issues within the first 4 wk limiting their participation. To minimize contamination effects, cancer care nurses employed in the study were advised not to provide additional education to participants in the information only arm or the usual care arm or discuss the intervention with other nurses.

Educational Booklet

An evidence-based educational booklet was developed for this study based on an extensive literature review and previous pilot work (See supplementary file).[21] This booklet included information on management and coping strategies for fatigue, depressed mood and anxiety, fear of cancer recurrence, identifying signs of cancer recurrence, returning to work, financial issues, getting help at home, sexuality and fertility, healthy diet recommendations, maintaining positive relationships and self-image, and information on support groups and contacts to obtain further support. The booklet was reviewed by the research team which included a multidisciplinary team of clinicians currently caring for people with HL and NHL and a person who had survived lymphoma. Additional reviews with cancer survivors were coordinated through the Leukemia Foundation (the leading national, non-profit, patient advocacy group for hematological malignancies in Australia). Each recommendation in the booklet was graded according to the National Health and Medical Research Council hierarchy of research evidence.[22] The evidence-grading information was removed in the final patient version of the booklet to allow ease of use. The booklet readability was at a sixth-grade level.[23,24] Following completion of this study, the educational booklet has been published on the Leukemia Foundation website (Living-well-after-treatment-booklet-1.pdf (leukaemia.org.au)).[25]

The ENGAGE Intervention

The ENGAGE intervention was developed with guidance from 2 key frameworks: the self-efficacy model,[26,27] and the Capabilities for Supporting Prevention and Chronic Condition Self-Management (CSPCCSM) framework.[28] Self-efficacy is a valuable construct that can explain numerous behavioral and symptom outcomes of people with cancer, including self-management behaviors,[29,30] symptom severity,[30,31] and symptom experiences.[31] Motivational interviewing[32] and self-efficacy enhancement techniques (ie, performance accomplishment, vicarious experience, verbal persuasion and attention to physiological states) also underpin the intervention as these have been demonstrated to lead to behavior change.[33,34]

The ENGAGE intervention spanned 12-wk and involved one-on-one consultations between trained cancer nurses and participants, either face-to-face or via telehealth (phone or videoconference) depending on participant preference. Nurse training in motivational interviewing, self-efficacy enhancement techniques and videoconference was delivered by an investigator who is a Professor of Psychiatry with expertise in psycho-oncology, and informed by the CSPCCSM framework,[28] to ensure nurses were confident and capable of delivering the interventions via telehealth. The same investigator provided ongoing clinial supervision to the nurses after their first 10 consultations and every 3 mo thereafter. After group allocation, participants were trained in the effective management of a videoconference call and hardware and videoconference connectivity testing were undertaken.

Prior to the initial consultation, the intervention cancer nurse met with the participant's treating hematologist to discuss their planned follow-up care, develop a schedule of medical follow-ups, referrals, cancer surveillance, and late effects monitoring plan (frequency of follow-up and the clinician responsible) which were documented in the survivorship care plan (Fig. 2). The intervention cancer nurse included the participant's general practitioner (GP) contact details, health professional contacts, participant medical history, cancer diagnosis and treatment summary (received and ongoing) in the care plan. The initial nurse-led consultation (1 h) utilized a structured approach to undertake collaborative goal setting with the participant. This strategy involved identifying up to 4 key distressing issues through discussing the participant's responses to the distress thermometer (DT) survey which was undertaken at baseline and prior to each consultation at 4 wk, 8 wk and 12 wk.[35,36] Personal health goals were developed collaboratively with the participant and participants were referred to sections of the evidence-based educational booklet

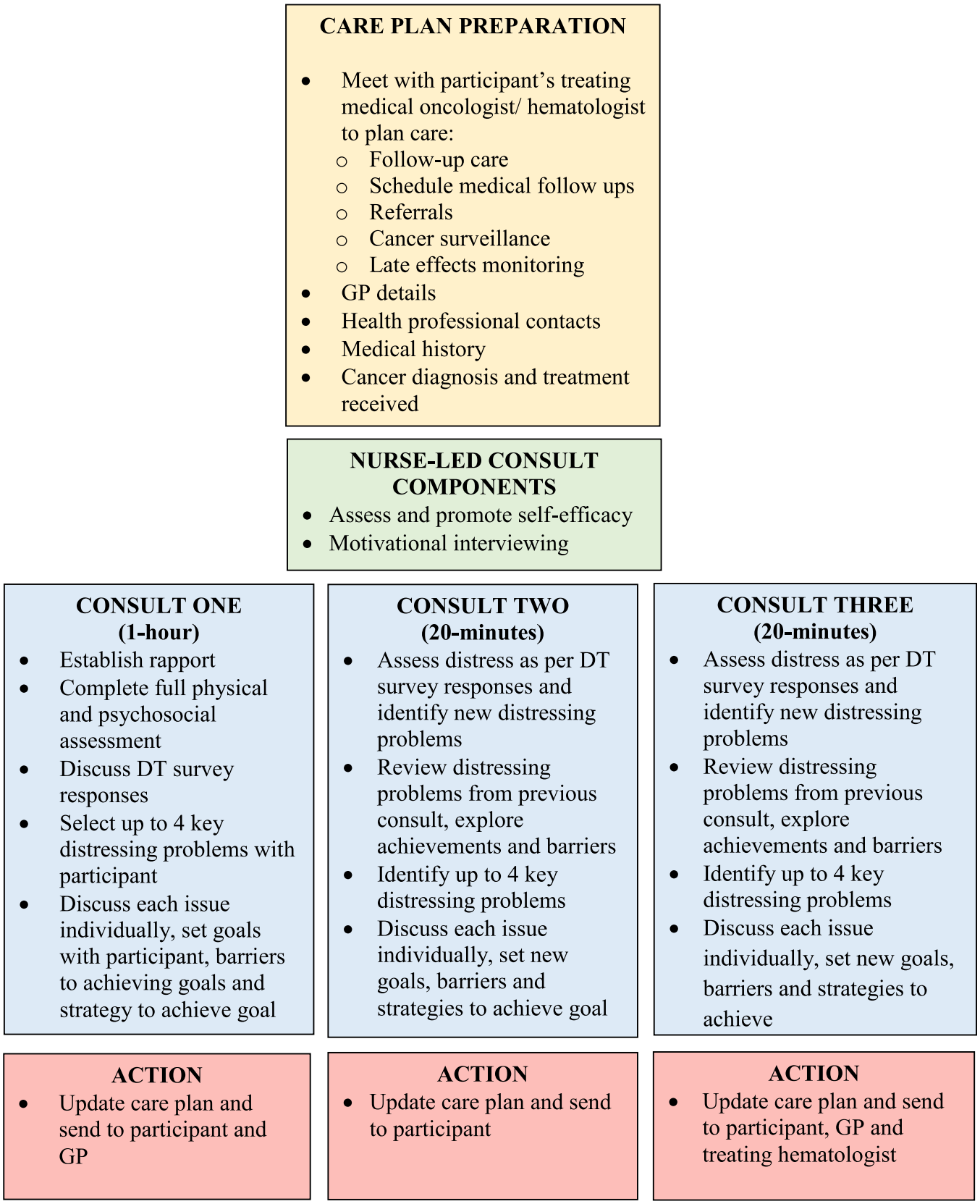

FIG 2. Nurse-led consultation and care plan development process. DT, distress thermometer; GP, general practitioner.

according to their identified goals. The evidence-based booklet was posted to the participant and a copy of the completed care plan was emailed or mailed to the GP immediately following the first consultation. Participants were encouraged to discuss the care plan with the GP during their follow-up appointments (Fig. 2).

After the initial consultation, the cancer nurse provided 2 additional 20-minute consultations per participant a month apart. During these consultations, the nurse evaluated progress in achieving the predetermined participant care plan goals and addressed any new unmet needs as nominated in the participant's updated DT measures (mailed to the participant prior to the follow-up). The nurse also re-endorsed the collaborative goals previously set using the same motivational interviewing and self-efficacy enhancement techniques in the first consultation (Fig. 2).

Data Collection

Following informed consent and prior to randomization, a research nurse collected baseline data from the participant and their electronic health record which included clinical and demographic characteristics. Outcome measures were collected at baseline by providing a hardcopy questionnaire to the participant prior to discharge from hospital with a replied paid envelope and at 12-wk from the electronic health record with hardcopy questionnaires, including a reply-paid envelope, posted to participants a week before the final timepoint to minimize dropout. The intervention group received a satisfaction survey at the end of 12 weeks.

Feasibility, Process, and Acceptability Outcomes

Feasibility was measured through:

(i) recruitment rate (numbers of people screened and participants consented),
(ii) retention rate (completed 3 consults as per the intervention),
(iii) fidelity to the intervention (completed as per the planned schedule),
(iv) preferred mode of contact (phone, videoconference, or face-to-face) and
(v) DT survey completion.

A structured care plan containing up to 4 priority unmet needs and self-managed goals were completed during each nurse-led consultation with the participant. All participants (including usual care, information only and information and ENGAGE intervention groups) completed the DT at baseline and 12-wk. The DT is a brief clinical tool that is reliable and valid and commonly used, with strong international utility.[36-39] The DT is responsive to change in cancer populations and includes a 0 (no distress) to 10 (extreme distress) point Likert scale to rate distress levels over the past week and a problem list for cancer survivors to identify practical, family, emotional, spiritual, religious, and physical problems they are experiencing.[35] The ENGAGE intervention arm completed additional DTs prior to 4-wk and 8-wk consultations to inform discussion content during the session.

Acceptability of the intervention was measured using a satisfaction of care survey at 12 wk that included 5 questions and an open-text question related to intervention delivery. A researcher external to the study contacted participants after the final consult to discuss the survey questions. Participants rated their overall satisfaction of care on an 11-point scale (0-10) and could also provide a comment on what aspects of post-treatment care the participants found useful, or not useful.

Sample Size

A sample of 10 to 15 cancer survivors per study arm (usual care, education booklet, ENGAGE intervention, n = 30-45) were deemed appropriate to assess feasibility and acceptability of the ENGAGE intervention. Aligning with the purpose of testing feasibility and acceptability, sample size calculation is irrelevant, and the proposed sample size was expected to provide useful insights to inform future research.[40]

Randomization

Following completion of baseline assessments, participants were randomized to 1 of the 3 arms using a computer-generated randomization sequence by an investigator with no involvement in participant care. To ensure even allocation across 3 study arms, participants were allocated according to a block randomization schedule held by the central registry (1:1:1 ratio).

Data Analysis

Descriptive statistics were performed for all measures including clinical and demographic information, frequency of problems identified in the DT problem checklist, and mode of consult delivery (telehealth or face-to-face).

Results

Participant Recruitment and Characteristics

Of the 152 people screened for eligibility, 43 (28%) were excluded as they either went on to receive additional treatment or the treating oncologist chose to continue monitoring the patient's response to the initial treatment before confirming whether treatment had finished (Fig. 3). Forty-four HL or NHL cancer survivors were approached over the 15-mo recruitment period to take part in the study, of which 77% (34/44) consented. Ten people declined (10/44; 23%) as they did not feel it was necessary or felt too unwell to participate. This resulted in 34 people with HL or NHL randomized to the trial: n = 11 the ENGAGE intervention; n = 11 to information only, and n = 12 to usual care (Fig. 3).

Participants were aged between 21 and 79 y (median 49). Half (n = 17, 50%) of the participants were female. Most participants were Caucasian (n = 30, 88%); had 1 or more comorbidities (n = 20, 59%); approximately half were overweight (n = 7, 21%) or obese (n = 11, 32%); had aggressive (n = 17, 50%) or indolent (n = 12, 35%) NHL; and had received chemotherapy (n = 34, 100%) to treat their cancer. Most people lived with a partner (n = 20, 59%), family or friend (n = 7, 21%) and had completed secondary or tertiary education (n = 65%) (Table 1).

Feasibility and Process Outcomes

Retention

Of the 34 participants, 27 (79%) completed all time points from baseline to 12 wk. Three participants in the ENGAGE intervention arm were lost to follow up (2/11, 18%) or withdrew (1/11, 9%), 1 participant in the information only group was lost to follow up (1/11, 9%) and 3 (3/12, 25%) participants in the usual care group were lost to follow up (Fig. 3).

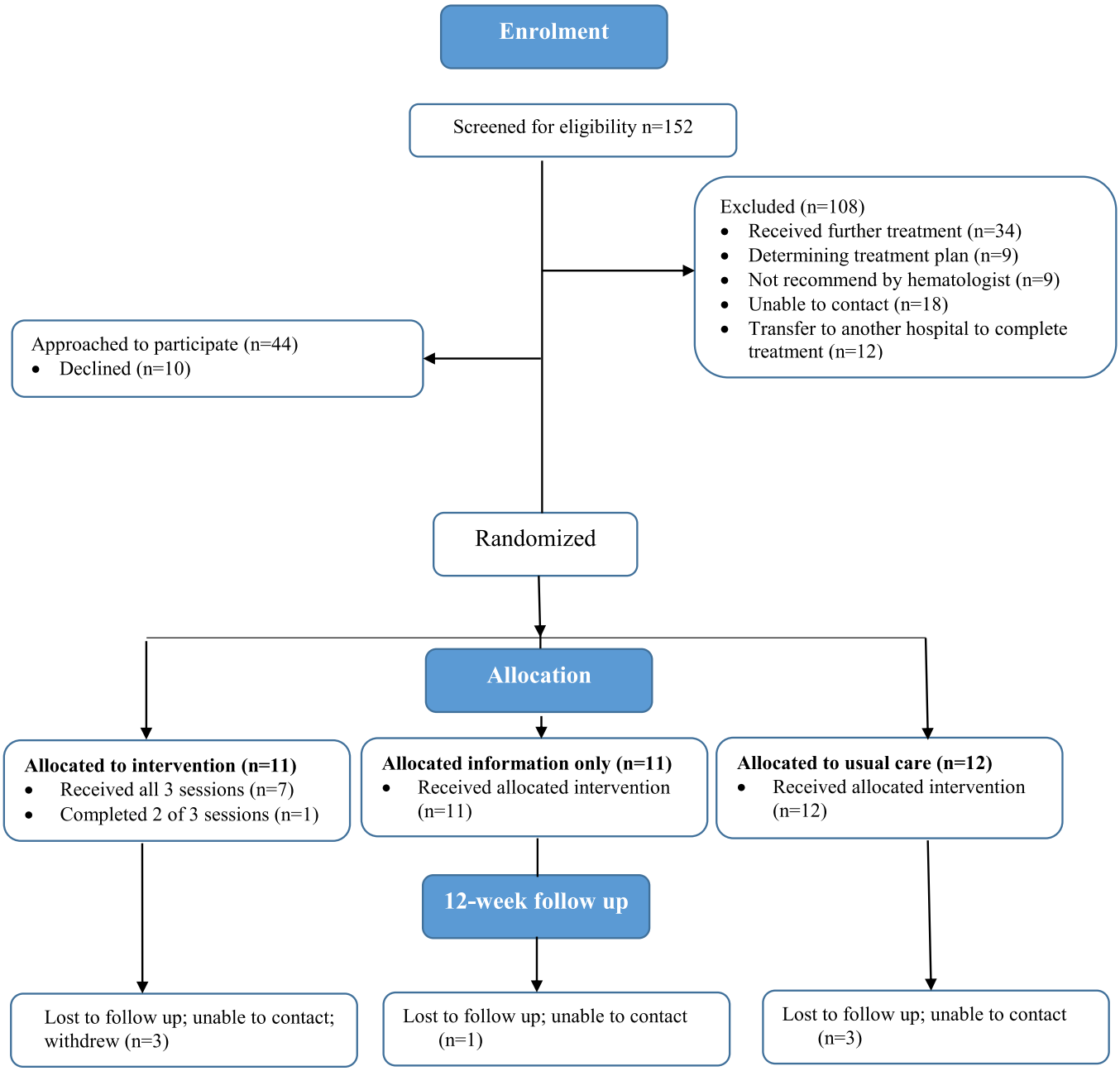

FIG 3. CONSORT diagram.

Fidelity to Number and Timing of Consultations

Of the 11 participants in the ENGAGE intervention arm, 7 (64%) completed all 3 consultations, 1 (9%) received 2 consultations, and 3 (27%) participants did not receive nurse-led consultations as they were either lost to follow up or withdrew (Fig. 3).

Care Plan and Shared Goals

In the intervention group, the median distress thermometer ratings were 2 (IQR 5, 0-8) at baseline, 0 (IQR 3, 0-5) at 4 wk, 2 (IQR 2.5, 0-6) at 8 wk and 1.5 (IQR 3, 0-7) at 12 wk. The highest number of issues (Median 8, IQR 7.5, 1-20) reported through the DT problem checklist occurred prior to commencing the first nurse-led consultation (baseline or 12 wk after completing treatment), and at the first consultation (4 wk following baseline, Median 0, IQR 7, 0-27) and collaborative healthcare goals were established for the proceeding 4 wk. At the second consultation for the intervention group (8 wk following baseline, Median 2, IQR 5, 0-15), goals from the first consultation were revisited and updated and either carried over for the following 4-wk period (3/8, 38%) or new priority issues (5/8, 63%) and healthcare goals were developed. At the third consultation for the intervention group (12 wks post baseline), a median of 1 (IQR 6, 0-13) issue was identified on the DT problem check list, 2 participants (2/8, 25%) had new issues to discuss with new healthcare goals developed while

TABLE 1
Demographic and Clinical Characteristics of Participants

	Total N (%) n = 34	Intervention N (%) n = 11	Information only N (%) n = 11	Usual care N (%) n = 12
Age	52.1 (SD 14.9) 49 (IQR = 22, 21-79)	56.55 (SD 17.0) 65 (IQR = 26, 25-79)	53.6 (SD 12.2) 47 (IQR = 20, 44-77)	46.8 (SD 15.4) 49 (IQR = 27, 21-74)
Gender				
Female	17 (50)	5 (45.5)	5 (45.5)	7 (58.3)
Ethnicity				
Caucasian	30 (88.2)	7 (63.6)	11 (100)	12 (100)
Other[a]	4 (11.8)	4 (36.4)	0	0
Current smoker				
Yes	4 (11.8)	2 (18.2)	1 (9.1)	1 (8.3)
BMI				
Normal weight	16 (47.1)	6 (54.5)	5 (45.5)	5 (41.7)
Overweight	7 (20.6)	3 (27.3)	2 (18.2)	2 (16.7)
Obese	11 (32.4)	2 (18.2)	4 (36.4)	5 (41.7)
Previous cancer diagnosis	12 (35.3)	3 (27.3)	4 (36.4)	5 (41.7)
Comorbidities				
None	14 (41.2)	2 (18.2)	6 (54.5)	5 (41.7)
1	7 (20.6)	3 (27.3)	0	4 (33.3)
2	8 (17.6)	2 (18.2)	3 (27.3)	2 (16.7)
≥ 3	5 (14.7)	4 (36.4)	2 (18.2)	1 (18.2)
Living arrangements				
With partner	20 (58.8)	5 (45.5)	6 (54.5)	9 (75)
With other family/friend	7 (20.6)	3 (27.3)	3 (27.3)	1 (8.3)
Alone	7 (20.6)	3 (27.3)	2 (18.2)	2 (16.7)
Income				
<$20,000	10 (29.5)	4 (36.4)	2 (18.2)	4 (33.3)
$20,000-$40,000	7 (20.5)	4 (36.4)	3 (27.3)	0
$40,000-$60,000	7 (20.5)	2 (18.2)	2 (18.2)	3 (25)
>$60,000	10 (29.5)	1 (9.1)	4 (36.4)	5 (41.7)
Marital status				
Married	16 (47.1)	6 (54.5)	4 (36.4)	6 (50)
Divorced	3 (8.8)	1 (9.1)	1 (9.1)	1 (8.3)
De facto	7 (20.6)	1 (9.1)	3 (27.3)	3 (25)
Widowed	3 (8.8)	1 (9.1)	1 (9.1)	1 (8.3)
Single	5 (14.7)	2 (18.2)	2 (18.2)	1 (8.3)
Education level				
7-12 years	8 (23.5)	2 (18.2)	3 (27.3)	3 (25)
Completed high school	4 (11.8)	2 (18.2)	1 (9.1)	1 (8.3)
Postsecondary	7 (20.6)	3 (27.3)	2 (18.2)	2 (16.7)
Tertiary education	15 (44.1)	4 (36.4)	5 (45.5)	6 (50)
Disease type				
Aggressive NHL	17 (50)	8 (72.7)	3 (27.3)	6 (50)
Indolent NHL	12 (35.3)	2 (18.2)	6 (54.5)	4 (33.3)
HL	5 (14.7)	1 (9.1)	2 (18.2)	2 (16.7)
Treatments received				
Chemotherapy	34 (100)	11 (100)	10 (90.9)	9 (81.8)
Radiation	10 (29.4)	5 (45.5)	3 (27.3)	2 (18.2)
Stem cell transplant	8 (23.5)	2 (18.2)	3 (27.3)	3 (27.3)
Surgery	5 (14.7)	0	4 (36.4)	1 (9.1)

HL, Hodgkin's lymphoma; NHL, non-Hodgkin's lymphoma.
[a] Ethnicity – Other includes Asian, Aboriginal and Torres Strait Islander and Polish.

TABLE 2
Top 10 Issues Identified in the Problem Checklist at Baseline and 12-Wk

Distress thermometer problem checklist	Intervention N (%) (n = 11)		Information only N (%) (n = 11)		Usual care N (%) (n = 12)	
	Baseline	12 wk	Baseline	12 wk	Baseline	12 wk
Fatigue	6 (54.5)	3 (27.3)	9 (81.8)	7 (63.6)	9 (75)	6 (50)
Sleep	7 (63.6)	1 (9.1)	9 (81.8)	6 (54.5)	7 (58.3)	4 (33.3)
Nausea	3 (27.3)	3 (27.3)	8 (72.7)	2 (18.2)	7 (58.3)	0
Eating	6 (54.5)	2 (16.7)	4 (36.4)	3 (27.3)	5 (41.7)	2 (16.7)
Memory/concentration	5 (45.5)	2 (18.2)	5 (45.5)	2 (18.2)	5 (41.7)	5 (41.7)
Nose dry/congested	2 (18.2)	1 (9.1)	5 (45.5)	2 (18.2)	8 (66.7)	1 (8.3)
Tingling in hands/feet	6 (54.5)	5 (45.5)	5 (45.5)	4 (36.4)	3 (25)	1 (8.3)
Skin dry/itchy	4 (36.4)	3 (27.3)	4 (36.4)	4 (36.4)	5 (41.7)	3 (25)
Worry	4 (36.4)	2 (18.2)	4 (36.4)	5 (45.5)	4 (33.3)	4 (33.3)
Sadness	3 (27.3)	1 (9.2)	2 (18.2)	3 (45.5)	6 (50)	4 (33.3)

TABLE 3
Mode of Contact During Consultations with the Cancer Nurse

Participant number	Consult 1	Consult 2	Consult 3
1	Videoconferencing	Videoconferencing	Videoconferencing
2	Videoconferencing	Videoconferencing	Videoconferencing
3	Face-to-face	Face-to-face	Face-to-face
4	Videoconferencing	Videoconferencing	Videoconferencing
5	Videoconferencing	Videoconferencing	Phone
6	Phone	Phone	Phone
7	Face-to-face	Phone	Unable to contact
8	Videoconferencing	Videoconferencing	Videoconferencing

Note: Two participants were lost to follow up and 1 participant withdrew.

5 (5/8, 63%) participants continued working on their previous healthcare goals (Table 4).

Mode of Intervention Delivery

Intervention group participants (n = 11) completed 23 consultations in total, using various modes to communicate with the nurse. Most consultations were conducted using telehealth via videoconference (13/23, 57%), followed by telehealth via phone (5/23, 22%) or face-to-face consultations (4/23, 17%). Most intervention group participants (5/8, 63%) chose to receive the same mode of contact for all consultations while others (3/8, 37%) utilized up to 2 different modes of contact (eg, phone and face-to-face consultations) to receive consultations (Table 3).

Problems Identified

The most prevalent issues identified in the problem checklist at baseline across the 3 groups were fatigue (ENGAGE intervention arm: 6/11, 55%; Information Only arm: 9/11, 82%; and Usual Care arm: 9/12, 75%) and trouble sleeping (ENGAGE intervention arm: 7/11, 64%; Information Only arm: n = 9/11, 82%; and Usual Care arm: n = 7/12, 58%). At 12 wk, while fatigue remained high amongst study groups, other issues became prevalent in varying levels across groups such as tingling in the hands/feet and memory/concentration deficits indicating that issues change over time (Table 2).

Participant Satisfaction with Nurse-Led Consultations

Overall, participants who received the ENGAGE intervention (8/11; 73%) were very satisfied with the nurse-led intervention (average score = 9/10). Participants who received telehealth using videoconferencing described it as a suitable way to remain connected with their specialist care team and were satisfied and relaxed using it. One intervention group participant found the timing difficult with having to get organized and wait for the videoconferencing call. Aspects of the nurse-led interventions that participants found useful included: regular and ongoing connection and contact; information, advice and ideas provided; and referrals. One participant commented that they are independent and did not need much assistance. Other positive feedback from the intervention included: *"awareness, professional and helpful care," "it was beneficial to be able to talk to someone generalist about a lot of stuff, not just someone who only knows about their topic (i.e., dietitian)", "all amazing, useful, I feel like I was given the best care and attention that I deserved", "very satisfied, the quality and communication was excellent and very sympathetic."* One participant mentioned they would like to be able to contact a health professional via phone or videoconferencing if they are concerned, and for urgent needs, rather than waiting for the next consultation.

Discussion

While completion of treatment and transition into survivorship is a significant milestone for cancer survivors, they express feelings of abandonment as they deal with the late effects of treatment with significantly reduced access to resources and support from the healthcare team.[41] Like previous studies,[6,14,42,43] our research showed that HL and NHL survivors have several healthcare needs in the initial stages following treatment which change and evolve over time warranting a need for follow up care. Our study findings indicate that the ENGAGE intervention is feasible and acceptable, and also provides insights into the timing of survivorship care initiation and how healthcare professionals can support people surviving HL and NHL.

This pilot trial provides valuable understanding of the recruitment and retention of participants receiving the ENGAGE intervention. Due to the natural clinical course of lymphoma and need to carefully observe disease response, challenges were encountered when determining treatment completion, which was seen with 152 HL and NHL potential survivors screened and only 44 survivors considered eligible for recruitment. Unlike other cancers, hematological cancer trajectories may change, posing challenges with determining when treatment is judged to have finished, and when to initiate survivorship care.[44] Enhancing ongoing communications between a hematologist acting as a champion and updating on health status in real time may help resolve some of these challenges to an extent. For instance, factors such as the proliferation and stage of the cancer and response to treatment will influence whether cancers are treated intensively, monitored with or without non-invasive chemotherapy, or managed supportively requiring palliative care rather than survivorship care.[45] Flexibility is required when offering survivorship interventions for people with lymphoma who experience different treatment regimens for the various types of disease, and unexpected complications post-treatment.

Interestingly, 10 people with HL or NHL who were eligible for the study declined consent as some survivors were keen to move on and forget their cancer experience, and saw no benefit with follow-up care, while others felt uncomfortable by one-on-one sessions with a nurse via telehealth despite other modes of consultation delivery being available. Three participants randomized to the ENGAGE intervention arm withdrew or were not contactable prior to commencing nurse-led consultations. Individuals completing treatment will have varying levels of readiness for survivorship care, which needs to be recognized to successfully engage people in these types of interventions.[14] While previous work has shown that motivational interviewing around health behaviors when introduced early can ensure uptake of initiatives occurs synergistically with treatment thereby improving uptake of survivorship care post-treatment, our findings suggest that some cancer survivors would benefit from the initiation of survivorship more than 12 wk following treatment completion. As a person moves through their illness trajectory, nurses are in a unique position to be able to assess and coordinate the timing of the introduction of survivorship care following treatment completion due to their ongoing contact with people and coordination role they play in the outpatient setting.

Consistent with previous research, our findings identified that hematological cancer survivors experience many late effects following treatment.[6] The most prevalent issues were fatigue and trouble

TABLE 4
Issues and Shared-Care Goals Discussed During 3 Consultations with a Cancer Care Nurse

No	Consult One			Consult Two				Consult Three			
	No. DT items	Issues	Goals	No. DT items	Goals revisited	New issues	New goals	No. DT items	Goals revisited	New issues	New goals
1	2	Fatigue Anxiety Overweight	Energy Be informed Diet control	2	Energy Be informed Diet control	High blood sugar Memory loss Tingling and numbness	Diet control Information recall Comfortable	1	Energy be informed Diet control Information recall Comfort	N/I	N/A
2	0	Sedentary Overweight	Exercise Balanced diet	N/C	Exercise Balanced diet	N/I	N/A	0	Exercise Balanced diet	N/I	N/A
3	N/C	Sedentary Overweight Fatigue	Mobility Weight gain Return to work	4	Mobility Weight gain Fatigue	Concentration	Brain exercises	6	Mobility Weight gain Fatigue	Nausea Pain	Medical review Medication plan
4	27	Finance Worry/fear Lifestyle	Return to work Reduce fears Diet control and exercise	6	Finance Reduce fears Diet control and exercise	N/I	N/A	6	Finance Reduce fears Diet control and exercise	Numbness and pain	Comfort
5	11	Overweight Fatigue Loss of interest	Weight gain More energy Resume hobbies	7	Weight gain More energy Resume hobbies	Anxiety Insomnia	Feel calm Feel rested	8	Weight gain More energy Resume hobbies Feel calm	N/I	N/A
6	4	Leg swelling Disc protrusions Back pain	Ride motorbike Ride motorbike Ride motorbike	3	Ride motorbike	Housing/ finance	Sell house and business	2	Ride motorbike Sell house and business	N/I	N/A
7	10	Anxiety Fatigue Memory Concentration	Feel calmer More energy Remember appts More focussed	15	Feel calmer	Family issues	Support network	13	N/C	N/C	N/C
8	0	Poor diet Sedentary Insomnia	Diet control Exercise 8hrs sleep/ night	1	Diet control Exercise 8hrs sleep/ night	N/I	N/A	0	Diet control Exercise 8hrs sleep/ night	N/I	N/A

N/A, Not applicable; N/C, Not completed; N/I, None identified.

sleeping. A study of hematology cancer survivors in the United Kingdom found pain or discomfort and performing usual activities to be the highest rated unmet need following treatment leading to long term impairments hindering efforts to return to work and quality of life.[46–48] In the ENGAGE intervention arm, healthcare problems and priorities changed over time, with the most frequent issues occurring immediately after and up to 16 wk following treatment completion, requiring the establishment of defined healthcare goals. Early implementation of survivorship care is warranted in this cancer survivor cohort and has the potential to reduce long term distress and avoid increased need for healthcare use long term. Overall, cancer survivors who received the ENGAGE intervention found it to be beneficial and indicated long-term follow up was needed.

Nurse-led consultations were offered to HL or NHL cancer survivors via telehealth (videoconferencing or phone), enabling them to attend sessions from home, thus avoiding hospital visits or incurring travel and parking expenses. Most participants (75%, 18/23) chose to receive nurse-led consultations via telehealth. Since the COVID-19 pandemic, there has been significant advances in the uptake of telehealth by clinicians and cancer survivors.[49] Without the need for physical assessment, telehealth shows great potential for the provision for cancer survivorship.[49] Despite the advantages and potential for telehealth some cancer survivors chose to meet face-to-face for nurse-led sessions. Some cancer survivors received nurse-led consultations using several modes of communication (videoconferencing, telephone, and face-to-face) indicating that preferences can differ over time and demonstrating flexibility with modes of contact when conducting consultations may improve attendance rates, which was demonstrated in this study with only 1 consultation missed of the participants that received the intervention.[50] It is important that future trials offer sufficient flexibility in terms of the mode of care.

This is a pilot with a small sample size, thus comparisons of outcomes including satisfaction between study arms were not planned and could not be performed. Furthermore, the pilot was conducted at a single site, thus the results may not be generalized to other hospitals or centers that treat people with HL and NHL. Despite these limitations, this research provides valuable information to inform future studies and indicates that nurse-led consultations in this cancer survivor cohort is acceptable and feasible. Based on this pilot, we suggest a Type I hybrid effectiveness and implementation trial to test the effectiveness of the ENGAGE intervention for lymphoma survivors.

Conclusions

This pilot RCT indicates that the nurse-led, ENGAGE intervention is feasible and acceptable in people surviving HL and NHL. The ENGAGE intervention was able to identify several clinical problems experienced by lymphoma survivors over 3 time points, with the intervention nurse responding to them in collaboration with the survivor. These findings can be used to further develop a Phase III trial testing this unique nurse-led model of care for HL and NHL survivors which considers the variability in treatment plans and survivor readiness to commence survivorship care.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Professor Raymond Chan reports financial support was provided by The Royal Brisbane and Women's Hospital Foundation. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Amy J. Spooner: Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Investigation, Formal analysis, Data curation. **Jane Turner:** Writing – review & editing, Writing – original draft, Supervision, Resources, Methodology, Investigation, Funding acquisition, Conceptualization. **Elise Button:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Patsy Yates:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Funding acquisition, Data curation, Conceptualization. **Glen Kennedy:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Jason Butler:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Funding acquisition, Conceptualization. **Natalie Bradford:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Funding acquisition, Conceptualization. **Alexandre Chan:** Writing – review & editing, Writing – original draft, Visualization, Methodology, Conceptualization. **Nicolas H. Hart:** Writing – review & editing, Writing – original draft, Supervision. **Raymond J. Chan:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Funding

This study was supported by the Royal Brisbane and Women's Hospital foundation, Brisbane, Queensland.

Acknowledgments

We acknowledge Mary-Ellen, Natasha Booth, Justine Leach, Kiara Mason who are research assistants supporting the conduct of this study.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.soncn.2024.151592.

References

1. Australian Institute of Health and Welfare. *Cancer in Australia*. Canberra: AIHW; 2021.
2. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2021;71(3):209–249.
3. Pallister C, Watson M. *Haematology*. 2nd ed. Branbury: Scion Publishing Limited; 2011.
4. National Institute for Clinical Excellence. *Guidance on Cancer Services, Improving Outcomes in Haematological Cancers. The Manual*. London: NICE; 2016.
5. Zhang N, Wu J, Wang Q, et al. Global burden of hematologic malignancies and evolution patterns over the past 30 years. *Blood Cancer J*. 2023;13(1):82.
6. Esser P, Kuba K, Mehnert A, et al. Quality of life in survivors of hematological malignancies stratified by cancer type, time since diagnosis and stem cell transplantation. *Eur J Haematol*. 2018;101(3):340–348.
7. Allart-Vorelli P, Porro B, Baguet F, Michel A, Cousson-Gelie F. Haematological cancer and quality of life: a systematic literature review. *Blood Cancer J*. 2015;5(4):e305.
8. Swash B, Hulbert-Williams N, Bramwell R. Unmet psychosocial needs in haematological cancer: a systematic review. *Support Care Cancer*. 2014;22(4):1131–1141.
9. Chan RJ, Crawford-Williams F, Crichton M, et al. Effectiveness and implementation of models of cancer survivorship care: an overview of systematic reviews. *J Cancer Surviv*. 2023;17(1):197–221.
10. Hart NH, Crawford-Williams F, Crichton M, et al. Unmet supportive care needs of people with advanced cancer and their caregivers: a systematic scoping review. *Crit Rev Oncol Hematol*. 2022;176: 103728.

11. Chan RJ, Teleni L, McDonald S, et al. Breast cancer nursing interventions and clinical effectiveness: a systematic review. *BMJ Support Palliat Care*. 2020;10(3):276–286.
12. Monterosso L, Platt V, Bulsara M, Berg M. Systematic review and meta-analysis of patient reported outcomes for nurse-led models of survivorship care for adult cancer patients. *Cancer Treat Rev*. 2019;73:62–72.
13. Sara SAM, Chambers SK, Briggs R, Heneka N, Dunn J. A vanguard approach to the design and delivery of nurse-led survivorship care. *Semin Oncol Nurs*. 2023;39(1): 151366.
14. Taylor K, Chivers P, Bulsara C, Joske D, Bulsara M, Monterosso L. Care after lymphoma (CALy) trial: a phase II pilot pragmatic randomised controlled trial of a nurse-led model of survivorship care. *Eur J Oncol Nurs*. 2019;40:53–62.
15. Taylor K, Monterosso L, Bulsara C. Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *Eur J Oncol Nurs*. 2018;35:9–14.
16. Ouchveridze E, Banerjee R, Desai A, et al. Financial toxicity in hematological malignancies: a systematic review. *Blood Cancer J*. 2022;12(4):74.
17. Chan RJ, Crichton M, Crawford-Williams F, et al. The efficacy, challenges, and facilitators of telemedicine in post-treatment cancer survivorship care: an overview of systematic reviews. *Ann Oncol*. 2021;32(12):1552–1570.
18. Patel KB, Turner K, Alishahi Tabriz A, et al. Estimated indirect cost savings of using telehealth among nonelderly patients with cancer. *JAMA Netw Open*. 2023;6(1): e2250211.
19. Suleman A, Vijenthira A, Berlin A, Prica A, Rodin D. The use of virtual care in patients with hematologic malignancies: a scoping review. *Curr Oncol*. 2022;29 (2):892–900.
20. Schulz KF, Altman DG, Moher D, Group C. CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. *BMJ*. 2010;340:c332.
21. Turner J, Yates P, Kenny L, et al. The ENHANCES study—enhancing head and neck cancer patients' experiences of survivorship: study protocol for a randomized controlled trial. *Trials*. 2014;15:191.
22. National Health and Medical Research Council. *Levels of Evidence and Recommendation Grading*. Melbourne: Commonwealth of Australia; 2009.
23. Sullivan K, O'Conor F. A readability analysis of Australian stroke information. *Top Stroke Rehabil*. 2001;7(4):52–60.
24. Weih M, Reinhold A, Richter-Schmidinger T, Sulimma AK, Klein H, Kornhuber J. Unsuitable readability levels of patient information pertaining to dementia and related diseases: a comparative analysis. *Int Psychogeriatr*. 2008;20(6):1116–1123.
25. Button E, Chan RJ, Turner J. *Living Well After Treatment: A Guide for Patients and Families*. Brisbane: Leukemia Foundation; 2017.
26. Bandura A, Adams NE, Beyer J. Cognitive processes mediating behavioral change. *J Pers Soc Psychol*. 1977;35(3):125–139.
27. Bandura A, Health NIoM. *Social Foundations of Thought and Action: A Social Cognitive Theory*. Washington: Prentice-Hall, Inc; 1986.
28. Lawn S, Battersby M. Capabilities for Supporting Prevention and Chronic Condition Self-Management: A Resource for Educators of Primary Health Care Professionals. In: Australian Government Department of Health and Ageing, ed. Adelaide: Flinders University; 2009.
29. Chan R, Yates P, McCarthy AL. Fatigue self-management behaviors in patients with advanced cancer: a prospective longitudinal survey. *Oncol Nurs Forum*. 2016;43 (6):762–771.
30. Spencer JC, Wheeler SB. A systematic review of motivational interviewing interventions in cancer patients and survivors. *Patient Educ Couns*. 2016;99(7):1099–1105.
31. White LL, Cohen MZ, Berger AM, Kupzyk KA, Bierman PJ. Self-efficacy for management of symptoms and symptom distress in adults with cancer: an integrative review. *Oncol Nurs Forum*. 2019;46(1):113–128.
32. Lundahl B, Moleni T, Burke BL, et al. Motivational interviewing in medical care settings: a systematic review and meta-analysis of randomized controlled trials. *Patient Educ Couns*. 2013;93(2):157–168.
33. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev*. 1977;84(2):191–215.
34. Bandura A. *Self-Efficacy: The Exercise of Control*. Washington: American Psychological Association; 1997.
35. Gessler S, Low J, Daniells E, et al. Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psychooncology*. 2008;17(6):538–547.
36. Jacobsen PB, Donovan KA, Trask PC, et al. Screening for psychologic distress in ambulatory cancer patients. *Cancer*. 2005;103(7):1494–1502.
37. Alosaimi FD, Abdel-Aziz N, Alsaleh K, AlSheikh R, AlSheikh R, Abdel-Warith A. Validity and feasibility of the Arabic version of distress thermometer for Saudi cancer patients. *PLoS One*. 2018;13(11): e0207364.
38. Cutillo A, O'Hea E, Person S, Lessard D, Harralson T, Boudreaux E. The distress thermometer: cutoff points and clinical use. *Oncol Nurs Forum*. 2017;44(3):329–336.
39. Tang LL, Zhang YN, Pang Y, Zhang HW, Song LL. Validation and reliability of distress thermometer in Chinese cancer patients. *Chin J Cancer Res*. 2011;23(1):54–58.
40. Hoffman AJ, Brintnall RA, Brown JK, et al. Too sick not to exercise: using a 6-week, home-based exercise intervention for cancer-related fatigue self-management for postsurgical non-small cell lung cancer patients. *Cancer Nurs*. 2013;36 (3):175–188.
41. Heveran L, Andrewes T. Nursing measures to support the needs of haematological cancer survivors post-treatment: a literature review. *Br J Nurs*. 2020;29(3):S18–S24.
42. Berkley A. Support for adult survivors of lymphoma: a literature review. *Br J Nurs*. 2022;31(17):S12–S16.
43. Troy JD, Locke SC, Samsa GP, Feliciano J, Richhariya A, LeBlanc TW. Patient-reported distress in Hodgkin lymphoma across the survivorship continuum. *Support Care Cancer*. 2019;27(7):2453–2462.
44. Bugos KG. Issues in adult blood cancer survivorship care. *Semin Oncol Nurs*. 2015;31(1):60–66.
45. Langbecker D, Ekberg S, Yates P, Chan A, Chan RJ. What are the barriers of quality survivorship care for haematology cancer patients? Qualitative insights from cancer nurses. *J Cancer Surviv*. 2016;10(1):122–130.
46. Immanuel A, Hunt J, McCarthy H, van Teijlingen E, Sheppard ZA. Quality of life in survivors of adult haematological malignancy. *Eur J Cancer Care (Engl)*. 2019;28(4): e13067.
47. Kreissl S, Muller H, Goergen H, et al. Health-related quality of life in patients with Hodgkin lymphoma: a longitudinal analysis of the German Hodgkin Study Group. *J Clin Oncol*. 2020;38(25):2839–2848.
48. van der Poel MW, Oerlemans S, Schouten HC, et al. Quality of life more impaired in younger than in older diffuse large B cell lymphoma survivors compared to a normative population: a study from the population-based PROFILES registry. *Ann Hematol*. 2014;93(5):811–819.
49. Chan A, Ashbury F, Fitch MI, Koczwara B, Chan RJ, Group MSS. Cancer survivorship care during COVID-19-perspectives and recommendations from the MASCC survivorship study group. *Support Care Cancer*. 2020;28(8):3485–3488.
50. Snoswell CL, Comans TA. Does the choice between a telehealth and an in-person appointment change patient attendance? *Telemed J E Health*. 2021;27(7):733–738.