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

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Effect of a Nurse-led Lymphoma Survivorship Model of Care: A Pragmatic Phase II Pilot Randomised Controlled Trial

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Abstract

Background
Cancer survivorship is recognised as an integral component of the cancer continuum. Robust evidence on how best to deliver tailored survivorship care is limited, particularly for individuals affected by rarer cancers such as lymphoma, a potentially curable haematological cancer. These survivors may face long-term and late effects affecting quality of life due to the aggressiveness of the disease and treatment that may not be adequately addressed in current follow-up models of care.

Aim
To develop and pilot test a nurse-led model of survivorship care intervention that utilises an individualised survivorship care plan and treatment summary (SCPTS), motivational interviewing, tailored support and resources with lymphoma patients who have completed active treatment.

Method
A four-phase prospective study was undertaken: Phase One consisted of integrative/systematic reviews; Phase Two focused on development of the survivorship model of care; Phase Three comprised a pragmatic randomised controlled trial (RCT) to test the intervention; and Phase Four elicited qualitative feedback from intervention participants and their general practitioners’ (GP). A published pilot pragmatic RCT protocol was implemented and participants were randomised to a control group (n=30) or intervention group (n=30). Four patient reported outcome measures were administered to both groups at three time points; baseline (Time 1), 3 months (Time 2) and six months (Time 3).
Data Analysis

Descriptive, univariate and multivariate statistical techniques were applied to quantitative data. Content analysis was performed on qualitative interview data and GP evaluations.

Results

Three comprehensive integrative/systematic reviews were undertaken, published (survivorship models of care, SCPTS, survivorship needs assessment measures) and informed the development of a unique and concise evidence-based SCPTS and other model of care (intervention) components. The intervention comprised three face-to-face appointments over six months to deliver the lymphoma survivorship model of care. Intervention participants reported increased self-empowerment and less unmet needs. Test–retest reliability analysis was performed and published for the Short-Form Survivor Unmet Needs Survey (n=40). Ten intervention participants interviewed at completion of the RCT reported a positive experience of the model of care. Feedback from 18/28 (64%) GPs confirmed the SCPTS was a useful tool for patient consultations.

Conclusion

Findings add to a limited body of knowledge in lymphoma survivorship care and nurse-led models of care. They highlight the importance and perceived value of providing individualised, tailored support to lymphoma survivors from treatment completion. The evidence produced from this study provides baseline data to support future rigorous testing of nurse-led models of lymphoma survivorship care with larger samples.
List of Publications

(The complete PDF published versions of these papers are presented in Appendix A)

  o This publication was peer-reviewed by two reviewers and underwent revision prior to publication

  o This publication was peer-reviewed by three reviewers and underwent revision prior to publication

  o This publication was peer-reviewed by two reviewers and underwent revision prior to publication

  o This publication was peer-reviewed by three reviewers and underwent revision prior to publication
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Other Survivorship Research Published Journal Articles

(The complete PDF versions of these papers are presented in Appendix B)


Copyright permission has been obtained from publishers where necessary, and details are included in Appendix B with each paper.
Invited Non-Peer Reviewed Papers and Presentations

  - Article

  - Article

  - Oral presentation

  - Oral presentation

- Taylor, K. “Survivorship issues in Western Australia” Genesis Care Perth, 18 May 2016.
  - Oral presentation

- Taylor, K. “Nurse-led survivorship intervention and survivorship issues in Western Australia”. Oncology Nurses and Pharmacists Conference, Perth, 30 August 2015.
  - Oral presentation

  - Oral presentation


Conference Presentations

  o Poster presentation

- Taylor, K., & Monterosso, L. “Integrative review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors.” 41st Annual Scientific Meeting, Clinical Oncology Society of Australia (COSA), Melbourne Convention Centre, Victoria, 2–4 December 2014.
  o Poster presentation

- Taylor, K., & Monterosso, L. “Integrative review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors” UIC World Cancer Congress, Melbourne Convention Centre, Victoria, 4–6 December 2014.
  o Oral presentation

  o Poster presentation
  o Poster presentation

• Taylor, K. “Effect of a nurse-led lymphoma survivorship clinic: A pilot randomised controlled trial.” School of Nursing and Midwifery Research Symposium, University of Notre Dame, Fremantle, 3 June 2016.
  o Oral presentation

  o 2 Poster presentations

  o 2 Oral presentations given on my behalf by L. Monterosso
  o Oral presentation

  o Oral presentation

  o Poster presentation

  o Oral Presentation

  o Oral Presentation
  o Poster Presentation

Awards and Recognition

• December 2014, I was awarded the IPSEN-COSA Travel grant that enabled me to attend COSA and the World Cancer Congress conferences in Melbourne, Australia. This was only one of two grants awarded and I was the only nurse recipient.

• June 2016, I was awarded: Best Oral Presentation; and Best Presenter, for my PhD proposal presentation at the School of Nursing and Midwifery Research Symposium, University of Notre Dame, Fremantle.
Statement of Contribution by Others

The author of this thesis, under the guidance of the principal supervisor Professor Leanne Monterosso and co-supervisors Associate Professor Caroline Bulsara and Professor Max Bulsara, undertook the planning, research development, literature reviews, data collection, data checking, statistical analysis, interpretation of results, discussions and conclusions included in this thesis. The candidate was 100% responsible for the drafting of this thesis. The candidate is 90% responsible for the published articles associated with the thesis. The articles have been peer-reviewed, and co-authors have contributed to the corrections and recommendations that have made each article relevant and clear.

All supervisors reviewed drafts of this thesis and the manuscripts. All co-authors granted permission to include publications arising from this research in this thesis (Appendix C)

This thesis is the work of Karen Margaret Taylor alone and has not been submitted previously, in whole or in part, in respect of any other academic award at this or any other university.

Signed:

Karen M Taylor

(PhD Candidate)

[Signature]

Professor Leanne Monterosso

(Principal Supervisor)
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Thank you to Dr David Joske for your professional and personal support with this research at Sir Charles Gairdner Hospital (SCGH). Thank you to all the other Haematologists at SCGH, for supporting the research and trusting me to transition your patients after they had finished treatment.

Thank you to all the members of the Haematology Survivorship Research Advisory Committee. Professionals and consumers who were committed to
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Thank you to the University of Notre Dame Australia, Fremantle who have supported me as a PhD candidate. I would like to acknowledge the support of the Australian Government’s Collaborative Research Networks (CRN) program through the University of Notre Dame Australia (Fremantle) and an Australian Government Research Training Program Scholarship that enabled me to undertake my PhD.

Finally, I particularly want to thank everyone who participated in the research. It is not easy to say yes to a randomised controlled trial.

In January 2017, I was diagnosed with cancer and underwent treatment. My 25 + years of cancer nursing may have given me some insight, however being a cancer patient is something very different. It did strengthen my belief that supporting survivors is important.