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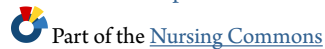
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Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial

Karen Taylor

The University of Notre Dame Australia

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

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This thesis is submitted for the degree of Doctor of Philosophy

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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)

- Taylor, K., Chan, R.J. & Monterosso, L. (2015). Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. *Supportive Care in Cancer*, 23(5), 1447–1458
 - This publication was peer-reviewed by two reviewers and underwent revision prior to publication

- Taylor, K., & Monterosso, L. (2015). Survivorship care plans and treatment summaries in adult patients with hematologic cancer: An integrative literature review. *Oncology Nursing Forum*, 42(3), 283–291
 - This publication was peer-reviewed by three reviewers and underwent revision prior to publication

- Taylor, K., & Monterosso, L. (2016). Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *The Australian Journal of Cancer Nursing*, 17(1), 6–12
 - This publication was peer-reviewed by two reviewers and underwent revision prior to publication

- 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(e010817), 1–10
 - This publication was peer-reviewed by three reviewers and underwent revision prior to publication

- Taylor, K., Bulsara, M., & Monterosso, L. (2018). Test–retest of the Short-Form Survivor Unmet Needs Survey. *Asia-Pacific Journal of Oncology Nursing*, 5(2), 165–171
 - This publication was peer-reviewed by two reviewers and underwent revision prior to publication

- Taylor, K., Monterosso, L., & Bulsara, C. (2018). Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *European Journal of Oncology Nursing*, 35, 9–14
 - 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)

- 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. *European Journal of Oncology Nursing, 28*, 62–68
- Monterosso, L., Taylor, K., Platt, V., Lobb, E., Musiello, T., Bulsara, C., Stratton, K., & Krishnasamy, M. (2017). Living with multiple myeloma: A focus group study of unmet needs and preferences for survivorship care. *Journal of Patient Experience, 1–10*

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Invited Non-Peer Reviewed Papers and Presentations

- Taylor, K. "Cancer survivorship" *Health Matters*, Winter Edition Volume 3. Consumers Council of WA, August 2016.
 - Article
- Taylor, K. "Survivorship" *Cancer Matters*, February 2015 Edition. Cancer Council of Australia.
 - Article
- Taylor, K. "Survivorship case studies" Haematology X conference, Crown Towers, Melbourne, 29 July 2017.
 - Oral presentation
- Taylor, K. "After cancer treatment ends" Cancer Council WA/Health Consumers' Council/Carers WA. Perth, 24 August 2016.
 - 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
- Taylor, K. Supervisory/student relationships. InSpire Conference, University of Notre Dame Australia, 30 June 2015.
 - Oral presentation

Conference Presentations

- Taylor, K., & Monterosso, L. "Integrative review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors." HAA2014: Annual Scientific Meetings of the HAA (Haematology Society of Australia and New Zealand, Australian & New Zealand Society of Blood Transfusion and Australasian Society of Thrombosis and Haemostasis). Perth Convention and Exhibition Centre, 19–22 October 2014.
 - 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.
 - 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.
 - Oral presentation

- Taylor, K., & Monterosso, L. "Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors." Inaugural Science on the Swan research conference, Perth Convention and Exhibition Centre, 21–23 April 2015.
 - Poster presentation

- Taylor, K., & Monterosso, L. "Survivorship care plans and treatment summaries in adult patient with haematological cancer: An integrative review." 18th Winter Congress, Cancer Nursing Society of Australia (CNSA), Perth Convention and Exhibition Centre, 14–16 June 2015.
 - 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.
 - Oral presentation

- Taylor, K., & Monterosso, L. "Development of a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care: Care After Lymphoma (CALy) Trial." And "Development of a survivorship care plan and treatment summary for lymphoma survivors." Multinational Association of Supportive Care in Cancer (MASCC) International Annual Meeting, Adelaide Convention Centre, South Australia, 23–25 June 2016.
 - 2 Poster presentations

- Taylor, K., & Monterosso, L. "Development of a pilot randomised controlled trial: lymphoma nurse-led model of survivorship care." And "Development of a survivorship care plan and treatment summary for lymphoma survivors." International Conference on Cancer Nursing (ICCN 2016), Hong Kong, 4–7 September 2016.
 - 2 Oral presentations given on my behalf by L. Monterosso

- Taylor, K. "Development of a lymphoma survivorship care plan and treatment summary." 8th International Congress on Innovations in Nursing (ICIN) Conference, Perth, WA, 23–24 November 2016.
 - Oral presentation

- Taylor, K. "Effect of a nurse-led lymphoma survivorship clinic: A pilot randomised controlled trial." Institute of Health Research Symposium, University of Notre Dame, Fremantle, 8 December 2016.
 - Oral presentation

- Taylor, K., Joske, D., Oldham, D., & Monterosso, L. "Development of a survivorship care plan and treatment summary for lymphoma survivors." COSA Survivorship Conference—Adelaide Convention Centre, 2–3 February 2017.
 - Poster presentation

- Taylor, K., & Monterosso, L. "Development of a pilot randomised controlled trial: lymphoma nurse-led model of survivorship care." Nursing and Midwifery Leadership Conference, Perth, 30 November–1 December 2017.
 - Oral Presentation

- 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." St John of God Nursing and Midwifery Research Symposium, Perth, 20 August 2018.
 - Oral Presentation

- 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.” 45th Annual Scientific Meeting, COSA, Perth, 13-15 November 2018.
 - 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)



Professor Leanne Monterosso

(Principal Supervisor)

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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.