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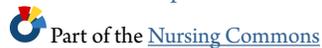
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Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial

Karen Taylor

The University of Notre Dame Australia

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Chapter Eight — Conclusion

“But to know that look, don’t worry, after treatment you are going to see a nurse, that would have been very calming for me” F_64yo_HL

8.0 Implications and Recommendations

Implications

Provision of evidence-based cancer survivorship care must be a common goal throughout the healthcare system, as cancer diagnoses and survival rates continue to increase. The impact of cancer does not end with active treatment as cancer survivors continue to have numerous diverse and varied needs at different time points along the survivorship trajectory. Efficient targeting and provision of clinical services is key to meeting and improving the care of cancer patients at all stages.

This study was based on the assumption that the current model of lymphoma follow-up, which is haematologist-led, has been unable to comprehensively provide the supportive care required to transition patients from the treatment phase into the survivorship phase. Consequently, a nurse-led lymphoma survivorship model of care was conceptualised, successfully developed and tested within this research.

Sixty lymphoma patients from one haematology department in Perth, Western Australia were recruited and randomised. While not the aim of a pilot study, many findings were not statistically significant, likely due to the small number of participants. The intervention participants did demonstrate less unmet informational and practical needs, less depression, anxiety and stress while demonstrating higher levels of coping and empowerment compared with the control (usual care) group. As intended, the study did produce data that can be used to power larger randomised trial studies for future competitive funding applications.

Psychological concerns among patients are often not addressed by clinicians in follow-up due to a number of limitations on their time and the availability of routine screening mechanisms. Clinicians will often assess for signs of depression, which is common following a cancer diagnosis (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013) without addressing the levels of anxiety and stress which can be a major concern for cancer survivors (Marker, 2015; Mitchell et al., 2011). Findings from this study suggest anxiety and stress can remain elevated over time and was notable in the control group where scores were higher in comparison with the intervention group who had an opportunity to discuss concerns and issues. Therefore, future interventions may need to consider anxiety-related issues such as fear of recurrence, thereby normalising the need for psychosocial support when developing cancer survivorship support and resources.

Participants in the 30–59-year-old age group across both the control and intervention groups exhibited higher levels of unmet practical concerns and less empowerment, a finding that corresponds to this life stage where patients are often juggling family, employment and financial issues. This study has confirmed the need that lymphoma patients require support and resources that are targeted to their life stage, and which can support them to re-establish their lives post-treatment. A finding supported by the qualitative interviews which revealed patients appreciated the individualised aspect of the nurse-led lymphoma survivorship model of care, valued the opportunity to discuss their concerns and issues and had a plan for monitoring potential late effects in the future, regardless of their age and life circumstances.

Lack of resources and support for survivors was evident in Phase Two of this study when a resource pack was developed. It would be difficult in the limited time survivors have in their haematologist appointments to provide

and discuss all the information and support an individual lymphoma survivor might need at that time. Therefore nurse-led survivorship models of care may provide the time and space to assist with this issue.

Recommendations

The results of this cancer nursing thesis have provided phase II evidence of the need for future research on nurse-led survivorship models of care in unique and rarer cancer groups such as lymphoma. The research highlighted the need for nurses to consider the whole cancer trajectory, not just the diagnosis and treatment phases of cancer care. The wider implications of the long-term and late effects of diagnosis and treatment for cancer survivors are equally imperative. Delivering cancer survivorship care that is evidence-based, holistic, cost-effective and adaptable to different health care settings is a continual challenge. Regardless of this, the provision of quality care and improvement in overall quality of life should be a greater focus in effective healthcare initiatives than just successful medical treatment. The following recommendations could enhance research in the area of cancer survivorship.

Clinical Nursing

- Experienced and senior cancer nurses should provide training and education on the use of assessment measures in survivorship to all nurses working in cancer care.
- Cancer nurses should be encouraged to identify and refer patients to appropriate health care providers for psychological and emotional support.
- Cancer nurses should be encouraged to undertake research and professional development to address the gaps in information and

resources provided to patients during their treatment and survivorship phases.

- Experienced cancer nurses should be provided with additional time to provide holistic follow-up on survivorship needs post-treatment.
- Cancer nurses should be offering educational forums to survivors to enhance post-treatment coping skills, healthy lifestyle behaviour choices and normalisation of treatment effects.
- Cancer nurses should be encouraged to provide input into the development and delivery of SCPTS for all cancer survivors.
- Cancer nurses should find opportunities to communicate with GPs to ensure survivorship needs will be addressed in the future.

Research

- Further research should be undertaken to promote and support the development, testing and evaluation of survivorship models of care.
- Further research on nurse-led survivorship models of care should be undertaken with survivors of:
 - Other haematological cancers
 - Other cancers.
- Further research should include the recruitment of cancer patients from rural/regional areas and evaluate the provision of localised support.
- Exploring options for providing targeted support to carers during cancer treatment and post-treatment requires further investigation.
- Further examination of debriefing mechanisms during and after treatment for patients is required.
- Research that encourages advocacy and peer support among survivors is required:
 - Investigation of the types of peer support mechanisms currently available

- Development of peer support for patients of all stages of the cancer trajectory.
- Longitudinal studies are required to determine:
 - If participants follow through recommendations with their GP when haematologist follow-up is completed
 - If this impacts earlier diagnosis and management of late effects
 - If healthy lifestyle choices were maintained and how motivation to continue was sustained.
- Future studies in the primary care arena to deliver nurse-led survivorship models of care would be valuable.
- Larger phase III multi-centre studies are required to explore nurse-led survivorship models of care that deliver patient-centred options for frequency and type of contact, such as face-to-face or telephone support.
- Further studies in the development and examination of psychometrically sound measures that capture the unique needs of survivors of less common cancers, such as lymphoma are essential.

Education

- Findings from this study could be used to increase public awareness of resources that can normalise and provide support for the issues and concerns that occur post-treatment.
- Findings from this study could be used in hospitals to provide greater awareness of community-based support organisations
 - Carer support mechanisms.
- An awareness of and provision of multi-cultural support and information requires further development and testing.

- Further education is necessary to provide relevant information and support resources to regional and rural Australia to enable improved referral pathways and communication between health care providers.
- Further research and education is required to increase support for employees and employers where identified employment concerns may arise
 - Provide access to information on support services and employee entitlements
 - Identify barriers that inhibit employers from implementing supportive policies in the workplace
 - Provide better mechanisms for transitioning back into the workforce or retraining.
- Increased flexibility in accessing financial government funding and effective utilisation.
- Promotion of the re-evaluation of funding allocation for rarer cancers is required by cancer agencies and professional health organisations to ensure equity of research and services.