Nurse-led survivorship care

Priscilla Gates[1] and Meinir Krishnasamy[2]
1. Nurse Consultant – Late Effects, Peter MacCallum Cancer Centre, Victoria.
2. Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre, Victoria.
Email: meinir.krishnasamy@petermac.org

Abstract

The goal of post treatment survivorship care is primarily to promote the health of an individual. This goal has clear resonance with theories and practice of nursing, where the essence of specialised nursing knowledge is directed towards helping individuals regain health, at a time when they are unable to, or lack an appreciation of the importance of doing so. With impressive improvements in survival rates, survivors of Hodgkin's Lymphoma constitute a large cohort of survivors who are at risk of developing long-term and late effects related to treatment. Late effects include secondary malignancies, cardiac dysfunction, endocrine dysfunction, infertility, functional decline and psychosocial morbidity. Many late effects are avoidable or amenable to amelioration by early detection or risk modification.This paper describes the development of an innovative model of nurse-led care, delivered within the context of a multi-disciplinary, haematology, late effects clinic.

The provision of follow-up care to cancer survivors is an essential component of excellent cancer care.[1] Essential features of high quality models of survivorship care include comprehensiveness, a coordinated approach and individualised care provision.[1] Models differ based on the needs or risk-determinants of specific cancer patients, however their intent is the same – the delivery of multi-disciplinary follow-up care to optimise survivor wellbeing and improve treatment outcomes.

As role boundaries between health professionals become increasingly blurred in response to a changing and diminishing workforce, an increase in numbers of cancer patients and survivors,[2] and a desire to deliver patient centred care,[3] new models of care delivery are becoming increasingly prevalent. However, the potential contribution of any new model of care must be considered according to its capacity to optimise patient outcomes during treatment and survivorship. For patients with cancer, life beyond treatment is affected by physical, psychological, social and spiritual needs.[4,5] Fatigue, sterility, loss of sexual function,[2] anxiety, uncertainty, social isolation,[6,7] financial hardship and search for meaning in life,[6,8] can all impact survivorship. This plethora of needs indicates the importance of providing effective survivorship care across a range of domains and reinforces the importance of multidisciplinary care provision. Furthermore, this complexity of need highlights the difficulty of designing and implementing models of follow-up that are both responsive to the needs of cancer survivors, but are also feasible and achievable in practice. Nurse-led services have been proposed as one means to help address some of these challenges.[3,9]

Nurse-led services

Nurse-led services are characterised by the delivery of evidence based, patient-centred care, focused on patient-centred outcomes and delivered by advanced practice nurses.[10] Patient centred care is defined as the provision of information by a health care provider in a manner that: educates patients; is inclusive of family and friends; meets a person's emotional and physical needs; is respectful of individuals' preferences; and is delivered in a coordinated and cohesive manner.[11] These characteristics have strong resonance with recommendations for survivorship care articulated in the Institute of Medicine's report, *From Cancer Patient to Survivor: Lost in Transition.*[9] They also resonate with an evolving paradigm of cancer survivorship in which the traditional focus on disease orientation and physical dysfunction is replaced by a multi-disciplinary, rehabilitative approach to the promotion of healthy living.[5] Patient centred outcomes include health related quality of life, functional status, emotional wellbeing, optimism and motivation to engage in health promoting activities.[12]

Nurse-led clinics

One of the ways in which nursing is attempting to respond to the drive for new models of care is through the development of nurse-led clinics. Current treatment review appointments are generally a very brief focus on the detection of cancer recurrence and physical side-effects, but do not adequately deal with patients' needs, nor do they realise the opportunity for health promotion.[13] To date there have been no robust, empirical studies that report the potential of nurse-led, cancer survivorship clinics to enhance long-term survivor outcomes. There is however, a steady growth in literature that claims a positive impact from nurse-led, follow-up care on patient outcomes in the period immediately after treatment completion. Studies published over the past decade indicate that nurse-led follow-up results in:

- a greater number of referrals and liaison with other support services than traditional models of follow-up[14,15]
- increased satisfaction with provision of follow-up, including organisation of care, information and advice, reassurance and overall rating of support[16,17,18]

- greater capacity to respond to individual need through more flexible models of follow-up, for example, by telephone or patient driven needs initiated follow-up[19]
- capacity to maximise opportunities for behavioural change through targeting interventions to a "teachable moment"[20]
- provision of individualised, tailored self-care information, linked to a reduction in patient-reported physical problems.[16]

Crucially, nurse-led clinics have been shown to be safe, with no difference found between nurse-led and medical follow-up of patients with early stage breast cancer in terms of disease outcomes, such as overall survival or time to detection of recurrence.[3,14,19] In a randomised, equivalence trial of study to compare hospital versus nurse-led telephone follow-up for women with breast cancer (n=374), telephone follow-up was well received by women in the intervention arm, with no physical or psychological disadvantage.[19] Similarly, no statistically significant difference was reported for time to symptom detection in a sample of 400 men with prostate cancer randomised to hospital nurse-led follow-up (n=200) versus conventional follow-up (n=200),[21] and in a randomised control trial to compare hospital nurse-led follow-up (n=99) versus conventional follow-up (n=103) for patients with non-small cell lung cancer.[17] However, results from a recent systematic review of nurse-led versus conventional physician follow-up for patients with cancer concluded that the current evidence available was characterised by methodological limitations, including inadequate randomisation processes, lack of blinding, poorly reported statistical tests and underpowered studies.[22] Further research is needed to demonstrate benefits in terms of survival, patient wellbeing and cost-effectiveness.[22]

Quality nurse-led care

A review of theoretical and descriptive papers on the evolution of nurse-led services,[3,22,23] led to the identification of five essential characteristics of quality, nurse-led follow-up care.

1. Nursing expertise

Care planned and led by specialists with cancer site/disease specific expertise.

2. Nurse-led care coupled to a robust evaluation framework

Care that is focused on achieving specific results. There are clearly articulated, measurable outcomes.

3. Driven by a theoretical framework

The nature and choice of interventions offered, their dose, frequency, intensity, duration and proposed outcomes should be based on sound theoretical propositions.

4. Multidisciplinary collaboration

Patient eligibility criteria for the nurse-led clinic, care pathways and protocols for the clinic should be based on an agreed, service-wide model of care delivery.

5. Evidence-based care

The nurse-led clinic should function according to evidence based protocols/best available evidence and practice driven by best practice guidelines.

Below, we describe how these characteristics have been applied to the development of nurse-led care for patients who have completed treatment for Hodgkin's lymphoma at the Peter MacCallum Cancer Centre in Melbourne, Victoria.

Haematology late effects and nurse-led survivorship care

Long-term survivors of childhood, adolescent and adult Hodgkin's Lymphoma (HL) are an expanding patient group who encounter a wide range of survivorship issues. With advances in multimodality therapy, survival rates from HL now exceed 90%.[24] However, among patients who do not survive, approximately half die as a direct result of HL, 20% from new cancers and 14% from cardiovascular complications.[25] In addition to physical effects, evidence from a qualitative survey of 1024 cancer survivors of mixed diagnoses, indicated that the transition from treatment to long-term survivorship is marked by significant emotional and psychosocial concerns.[26] One hundred and twenty two respondents (12%) were diagnosed up to one year, 42% between two to five years and 45% over five years. Almost half, (49%), reported emotional concerns, 60% relationship problems and a third (338) having trouble coping with emotional concerns. Over half of the study sample, (53%) reported their emotional needs harder to cope with than their physical needs.[26]

Data from a recent study of 1040 cancer survivors, two to five years after completing treatment, (39% of whom were survivors of haematological malignancies), demonstrated a lack of awareness of heightened health risks following treatment completion and inadequate information provision to enable people to manage future health needs.[8] Information needs were prevalent among the total study sample, with unmet information needs reported in relation to: follow-up care and surveillance (71%); health promotion (68%); late effects of treatment (63%); psychosocial issues (54%) and sexual function and fertility (31%). Similar findings were reported from a study of 266 cancer survivors regarding their knowledge of increased vulnerability to health problems following treatment completion.[27] The authors concluded that the knowledge deficits identified limited survivor awareness of their health risks and the importance of adopting healthy lifestyle behaviours. As the numbers of HL survivors grow, it is imperative that they are able to adopt healthy behaviours in order to maximise quality of life and longevity.[4] Nurse-led care has the capacity to improve survivors' outcomes by recognising and dealing with psychosocial distress, ensuring survivors have adequate information and support and by promoting sustained behavioural change.[20]

Nurse-led care in the context of a multidisciplinary, haematology late effects clinic

The Late Effects Clinic at Peter MacCallum Cancer Centre was established in 2000 and is one of three known late effects units for adult survivors in Australia. Referrals come from all over Australia and include hospitals, advocacy groups, primary care physicians and survivors who may self-refer. Patients are accepted into the unit five years after completion of treatment. Despite an acknowledgement that survivors experience unmet informational and emotional needs during early stages of survivorship (for example, from time of diagnosis or during treatment),[28] the clinic was developed to address the needs of the growing population of longer term survivors, who experience increased risk from and impact of late effects at a time when the frequency and intensity of follow-up decreases.[5,29,30] Currently, there are 396 patients on the late effects unit database, of whom 36% are survivors of haematological malignancies. The team includes a haematologist, transplant physician, radiation oncologists, fellow and registrar, cardiologist, endocrinologist, primary care liaison officer, psychologist and a specialised late effects social worker. In 2008, a late effects nurse consultant was appointed to the team to work specifically with survivors of haematological malignancies. The position was motivated by recognition of the considerable health deficits experienced by survivors of heamatological malignancies.

Prior to each late effects clinic, all patients scheduled to attend are considered in detail by the multidisciplinary team in order to consider anticipated health risks, review relevant past disease and treatment issues and relevant or potential areas of risk. Any screening investigations required are identified in advance of the clinic appointment. This preparatory work is undertaken to maximise efficiency of the review appointment for the individual and multidisciplinary team. The model of care in the late effects clinic is strongly patient orientated, with outcomes directed at sustained or enhanced wellbeing of each attendee. All relevant practitioners meet with the patient on the same day. Patients remain in one location throughout the visits and are not required to move from room to room for consultations with the relevant practitioners.[31]

A model of nurse-led, late effects consultations

Referral for nurse-led consultation is a core element of the late effects model of care at Peter MacCallum Cancer Centre, based on evidence that nurse-led consultations may improve survivor outcomes. Nurse-led consultations aim to address patient needs through systematic assessment of supportive needs and identification of dominant patient concerns in order to deliver individualised, comprehensive, education packages to promote a healthy lifestyle.[32] The structure of the nurse-led service is based on quality components of nurse-led care as defined above. Care is planned and delivered by an expert haematology nurse with 13 years experience in the specialty. All consultation interactions, interventions and patient outcomes are recorded in a dedicated database to assess the impact of the late effects nurse consultant contribution to survivor outcomes. The choice of interventions offered are targeted at relevant, patient centred concerns and are amenable to nursing intervention (ie. there is adequate indication of the capacity of the intervention to improve patient reported outcomes). Patient eligibility criteria for nurse-led consultation, evidence based care pathways and protocols for the clinic have been developed in consultation with the multidisciplinary, late effects team.

Since the incidence of emotional distress is significant in cancer survivors,[5] screening for emotional distress is undertaken at every consultation, with timely referral for specialist support as needed. The late effects nurse consultant has undergone training in eliciting and responding to emotional cues and uses a locally developed supportive care needs screening tool in all her consultations.

The nursing consultation focuses on six key domains, informed by best available evidence, to indicate prominent health related needs for cancer survivors: physical activity; healthy eating; smoking status; alcohol consumption; self examination; and sun protection.[3,33,34,35] The information is presented to each individual within the context of an education package directed specifically at their concerns, problems or health risks. Concerns or risks are identified during completion of the screening tool and through data provided by patient self-report measures completed by each individual prior to attending the consultation. Measures include the General Health Index,[35] a 22 item self-report instrument that assesses perceptions of personal health and the Health Promoting Lifestyle Profile 11,[36] a 56 item self-report tool to assess frequency of engagement in health promoting activities. The purpose of the education package is to inform survivors about the importance of healthy lifestyle behaviors in a manner that motivates and promotes sustainable, behavioural change.[37] In response to evidence indicating lack of awareness of where to find additional supportive information, each individual is given details of recommended websites to access information when at home.[38]

As gender, age, primary diagnosis and treatment history all impact the nature of late effects experienced and risks associated with them, the ability to undertake screening and assessment is essential to the success of the nursing consultation.[37] Education provision is tailored to each person's social context, personal beliefs and health requirements. The interventions form part of a cohesive, multidisciplinary survivorship care package.[9]

Survivorship care plans are recognised as an important element of comprehensive survivorship care and as a means of raising survivors' awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care.[1,5] In response to evidence that indicates that as few as 30% of survivors know they are at risk of developing late effects and that as many as 15% of cancer survivors choose not to attend long-term follow-up clinics,[33] each survivor attending for nurse-led consultation receives an individualised care plan. This includes details of medical history, treatments received,

potential for late effects, requirements for follow-up appointments, tests and reasons for them. The care plan focuses on health promotion and highlights the need for and how to adopt healthy behaviours. It also addresses psychosocial issues, how to identify them and where to get help. A copy of the care plan is sent to each person's primary care physician to ensure they are kept up-to-date with information essential to monitoring the health of a cancer survivor and to provide the cancer survivor with a knowledgeable source of support and advice close to home.

Conclusion

This innovative nurse-led model of survivorship follow-up is in its infancy. Data is currently being gathered to evaluate its contribution to the outcomes of survivors of haematological malignancies and findings will be published in 2010. The interventions are informed by patient reported concerns and common concerns of this survivor group, are delivered by an advanced practice haematology nurse, have been based on best available evidence and endorsed by a multidisciplinary team of experts in the field. As such, the initiative demonstrates an evolution in the thinking around the development of nurse-led follow-up and may offer a useful model for the development of other nurse-led models of cancer survivorship care.

Acknowledgement

The Haematology Late-effects Nurse Consultant role is supported by funding from the Leukaemia Foundation of Australia.

References

1. Institute of Medicine (US). Committee on quality health care in America. Crossing the quality chasm: a new health system for the 21st century. Washington,D.C: The National Academy Press; 2001.
2. Eakin EG, Youlden DR, Baade PD, Lawler SP, Reeves MM, Heyworth JS, et al. Health status of long-term cancer survivors: results from an Australian population-based sample. Cancer Epidemiol Biomarkers Prev.2006;15:1969-76.
3. Corner J. The role of nurse-led care in cancer management. The Lancet. 2003;4:631-36.
4. Ness KK, Hudson MM, Ginsberg JP, Nagarajan R, Kaste SC, Marina N, et al. Physical performance limitations in the childhood cancer survivor study cohort. J Clin Oncol. 2009;27:2382-9.
5. Aziz NM. Cancer survivorship research: state of knowledge, challenges and opportunities. Acta Oncol. 2007;46:417-32.
6. Garofalo JP, Choppala S, Hamann HA, Gierde J. Uncertainty during the transition form cancer patient to survivor. Cancer Nurs. 2009;32:E8-E14.
7. Doyle N. Cancer survivorship: evolutionary concept analysis. J Adv Nurs. 2008;62:499-509.
8. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton As, Hesse BW. Health related information needs in large diverse sample of adult cancer survivors: implications for cancer care. J Ca Surviv. 2008;2:179-89.
9. Hewitt M, Weiner SL, Stovall E. From cancer patient to cancer Survivor: Lost in transition. Washington, DC: Institute of Medicine and National Research Council of the National Academies Press; 2006.
10. Hinds PS. Patient-reported outcomes: A desirable specialty standard for oncology or an incomplete measurement approach? Cancer Nurs. 2008;31:259.
11. Gerteis M, Picker/Commonwealth Program for Patient-Centered Care. Through the patient's eyes: understanding and promoting patient-centered care. San Francisco: Jossey-Bass; 1993.
12. Lipscomb J, Gotay CC, Snyder CF. Patient-reported outcomes in cancer. A review of recent research and policy initiatives. CA: Cancer J Clin. 2007;57:278-300.
13. Beaver K, Luker K. Follow-up in breast cancer clinics: Reassuring for patients rather then detecting recurrence. Psych-Oncol. 2004;14:94-101.
14. Faithfull S, Corner J, Leyer L, Huddart R, Dearnley D. Evaluation of nurse-led follow-up for patients undergoing pelvic radiotherapy. Br J Cancer. 2001;85:1853-64.
15. Howell D, Sussman J, Wiernikowski J, Pyette, Bainbride D, O'Brien M, et al. A mixed-method evaluation of nurse-led community-based supportive cancer care. Support Care Cancer. 2008;16:1343-52.
16. Beaver K, Twomey M, Witham G, Foy S, Luker KA. Meeting the information needs of women with breast cancer: piloting nurse-led intervention. Eur J Oncol Nurs. 2006;10:378-90.
17. Moors S, Corner J, Haviland J, Wells M, Salmon E, Normand C, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomized trial. BMJ. 2002;325:1145-47.
18. Brown L, Payne S, Royle G. Patient initiated follow up of breast cancer. Psycho-Oncol. 2002;11:346-55.
19. Beaver K, Tysver-Robinson D, Campbell M, Twomey M, Williamson S, Hindley A, et al. Comparing hospital and telephone follow-up after treatment for breast cancer: randomized equivalence trial. BMJ. 2009;338:a3147. doi10.1136/bmj.a3147.
20. Sharp L, Tishelman C. Smoking cessation for patients with head and neck cancer: a qualitative study of patients' and nurses' experiences in a nurse-led intervention. Cancer Nurs. 2005;28:226-35.
21. Helgesen VS, Cohen S. Social support and adjustment to cancer: reconciling descriptive, correlational and intervention research. Health Psychol. 1996;15:135-48.
22. Lewis R, Neal RD, Williams NH, France B, Wilkinson C, Hendry M, et al. Nurse-led vs. conventional physician-led follow-up for patients with cancer: systematic review. J Adv Nurs. 2009;65:706-23.
23. Dellagiacomo T. Eight essential factors for successful nurse-led services. Aust Nurs J. 2007;14:28-32.
24. Chow LML, Nathan PC, Hodgson DC, Jenkin D, Weitzman S, Grant RM, et al. Survival and Late Effects in children with Hodgkin's Lymphoma treated with MOPP/ABV and low-dose, extended field irradiation. J Clin Oncol. 2006;24:5735-37.
25. Donaldson SS, Hancock SL, Hoppe RT. Hodgkin's disease – finding the balance between cure and Late Effects. Cancer J Sci Am. 1999;5:325-33.
26. Wolff SN. The burden of cancer survivorship; a pandemic of treatment success. In: Feuerstein Med. Handbook of Cancer Survivorship. New York, NY: Springer; 2006.
27. Hudson MM, Tyc VL, Jayawardene DA, Quargnenti A, Greenwald C, Crom DB, et al. Feasibility of implementing health promotion interventions to improve health related quality of life. Int J Cancer .1999;12:139-42.
28. Bloom JR. Surviving and thriving? Psycho-Oncol. 2002;11:89-92.
29. Grunfeld E. Looking beyond survival: how are we looking at survivorship? J Clin Oncol. 2006; 24:5166-69.
30. Ganz PA. A teachable moment for oncologists: Cancer survivors, 10 million strong and growing! J Clin Oncol. 2005;23:5458-60.
31. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol. 2006;5:117-24.
32. Absolom K, Eiser C, Michel G, Hancock BW, Coleman RE, Snowden JA, et al. Follow-up care for cancer survivors: views of the younger adult. Br J Cancer. 2009;doi:10.1038/sj-bjc.6605213.
33. Klosky JL, Cash DK, Buscemi J, Lensing S, Garces-Webb DM, Zhao W, et al. Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. J Cancer Surviv. 2008;2:225-32.
34. Razzouk BI, Rose SR, Hongeng S, Wallace D, Smeltzer MP, Zacher M, et al. Obesity in survivors of childhood acute lymphoblastic leukemia and lymphoma. J Clin Oncol. 2007;25:1183-9.
35. Davies AR, Ware JE Jr. Measuring health perceptions in the health insurance experiment. (R-2711-HHS). Santa Monica, CA: Rand; 1981.
36. Walker SN, Sechrist KR, Pender NJ. The Health-Promotng Lifestyle Profile: Development and psychometric characteristics. Nurs Res. 1987;36:76-81.
37. Cox CL, Montgomery M, Oeffinger KC, Leisenring W, Zeltzer L, Whitton JA, et al. Promoting physical activity in childhood cancer survivors: results from the Childhood Cancer Survivor study. Cancer. 2006;115:642-54.
38. Mesters I, van der Borne B, deBoer M. Measuring information needs among cancer patients. Patient Educ Couns. 2001;43:255-64.