

Transforming Cancer Survivorship Care: An Australian Experience

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The number of cancer survivors is increasing, worldwide. In Australia, the number of people with a personal history of cancer now exceeds one million (over 4% of the country’s population). Survivorship challenges are similar internationally: growing numbers of survivors, broad range of issues that survivors may experience, and limited health workforce. Current models of care do not adequately identify and respond to survivors’ concerns, nor are they an efficient use of limited resources. Numerous international reports have called for greater attention to the posttreatment phase and have recognized the need to redesign care.

The Australian Cancer Survivorship Centre, A Richard Pratt Legacy (ACSC), is based at Peter MacCallum Cancer Centre (Peter Mac) in Melbourne, Australia. It receives funding from The Pratt Foundation, the Victorian Department of Health and Human Services (DHHS), and Peter Mac. ACSC aims to improve outcomes for people affected by cancer. We work with clinical providers (medical, nursing, and allied health) as well as

patients, survivors, and carers to facilitate improved care for survivors, their families, and carers. Our vision is “to optimize the health and well-being of cancer survivors and their carers.” ACSC considers a person to be a “cancer survivor” from the time of diagnosis, through the balance of their life. We focus our work primarily on the posttreatment phase of cancer survivorship.

In this summary article, based on an instructional session, “Transforming Cancer Survivorship Care – An Australian Experience,” presented during the International Conference on Cancer Nursing held in Hong Kong in September 2016, we report on lessons learned from various approaches to support improved survivorship care, highlighting approaches that are transferable to other settings and relevant to a global workforce.

Table 1 contains a list of web links to access resources that have been developed to support nurses and other health-care professionals (HCPs) to implement survivorship initiatives.

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Table 1: Resources to support improved survivorship care

<p>Victorian Cancer Survivorship Program</p> <p>Phase 1 Report</p> <p>https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-survivorship-program</p> <p>Victorian Cancer Survivorship Program</p> <p>https://www.petermac.org/services/support-services/australian-cancer-survivorship-centre/health-professionals/victorian-survivorship-care-plans</p> <p>Survivorship care plans</p> <p>Survivorship care plans – fact sheet health professionals</p> <p>https://www.petermac.org/sites/default/files/media-uploads/Survivorship%20care%20plans.pdf</p> <p>Survivorship care plan toolkit</p> <p>https://www.petermac.org/sites/default/files/media-uploads/ACSC_Survivorship_Care_Plan_toolkit_Jan_2016.pdf</p> <p>Survivorship care plan literature review</p> <p>https://www.petermac.org/sites/default/files/media-uploads/ACSC_Care_Plan_literature_review_Jan_2016_2_.pdf</p> <p>Survivor Resources</p> <p>Fact sheets</p> <p>https://www.petermac.org/services/cancer-information-resources/survivorship-life-after-treatment</p> <p>Just take it day to day video series</p> <p>https://www.youtube.com/watch?v=AscXQaiUMH8&feature=youtu.be</p> <p>General practice and cancer survivorship video</p> <p>https://www.youtube.com/watch?v=6mzU4-dwNU0&feature=youtu.be</p> <p>Wellness and life after cancer</p> <p>https://www.petermac.org/services/support-services/australian-cancer-survivorship-centre/acsc-news-and-events</p> <p>Information for diverse survivors groups</p> <p>On the road to recovery - Arabic</p> <p>https://www.petermac.org/sites/default/files/On_the_road_to_recovery_Arabic_2016.pdf</p> <p>On the road to recovery - Cantonese</p> <p>https://www.petermac.org/sites/default/files/OnTheRoadToRecoveryCantonese%20Booklet.pdf</p> <p>On the road to recovery Greek</p> <p>https://www.petermac.org/sites/default/files/OnTheRoadToRecoveryGreek%20Booklet.pdf</p> <p>On the road to recovery - Italian</p> <p>https://www.petermac.org/sites/default/files/page/downloads/On_the_road_to_recovery_Italian_2016.PDF</p> <p>On the road to recovery - Mandarin</p> <p>https://www.petermac.org/sites/default/files/OnTheRoadToRecoveryMandarin%20Booklet.pdf</p> <p>On the road to recovery - Vietnamese</p> <p>https://www.petermac.org/sites/default/files/On_the_road_to_recovery_Vietnamese2016.pdf</p> <p>GP placement projects</p> <p>General Practice and Survivorship Video – project overview</p> <p>https://www.petermac.org/research/clinical-research-trials/clinical-research/australian-cancer-survivorship-centre-research-3</p> <p>General practice clinical placements, first phase – final report</p> <p>https://www.petermac.org/sites/default/files/media-uploads/ACSC_GPCPPP_Final_report_080116.pdf</p> <p>General practice (primary care) and cancer survivorship - videos</p> <p>Hospital based health professionals - long version (8 minutes)</p> <p>https://www.youtube.com/watch?v=OukMSVy-XQ4&feature=youtu.be</p> <p>Hospital based health professionals - short version (4 minutes)</p> <p>https://youtu.be/RqTLlavXrKkv</p> <p>General practice – long version (8 minutes)</p> <p>https://youtu.be/6mzU4-dwNU0</p> <p>General practice - short version (4 minutes)</p> <p>https://youtu.be/afKRSszdYSI</p> <p>Consumer version (8 minutes)</p> <p>https://youtu.be/sED-ZIVNDlw</p> <p>Health care professional education</p> <p>Cancer survivorship – online learning modules</p> <p>http://cancerlearning.gov.au/topics/survivorship</p> <p>Delivering Innovative Cancer Survivorship Care</p> <p>https://www.petermac.org/education/survivorship-education</p> <p>Resources to support practice</p> <p>Toolkits, literature reviews and fact sheets for health care professionals</p> <p>https://www.petermac.org/services/support-services/australian-cancer-survivorship-centre/health-professionals/resources</p>

Developing New Models of Care

In 2011, in recognition of the need to explore new models of care for survivors, the Victorian state government funded six projects examining different models of posttreatment survivorship care through the Victorian Cancer Survivorship Program (VCSP). Key aims were to pilot and evaluate models of posttreatment care in diverse settings and using a variety of approaches. ACSC provided advice regarding development of the models of care, supported workforce development, and established a community of practice, which created a forum for sharing and collaboration.

ACSC also supported evaluation of the first phase (2011–2014) of the VCSP program. Survivors reported interventions to be acceptable, appropriate, and effective. We defined a set of recommendations that are relevant to a multidisciplinary workforce, locally and globally.^[1] Partnerships with community organizations and primary care facilitated successful transition to shared care. Establishing strong links between health services and community-based organizations improved access to services and supports for survivors and facilitated survivor self-management in some projects. The projects developed a range of resources including survivorship care plan (SCP) templates, apps, and information resources that are still in use. By supporting diverse projects, the VCSP generated a better understanding of the needs of different populations. ACSC has subsequently developed evidence summaries and practical guidance regarding key elements of survivorship care, including needs assessment and SCP (www.petermac.org/cancersurvivorship). A second phase of VCSP was funded in 2016.

Sustainable Approaches to Survivorship Care Plans

SCPs are internationally endorsed as a key communication tool. They are strongly supported by survivors; however, uptake remains a challenge. SCP development and delivery are resource intensive. Supported by additional funding from The Pratt Foundation, ACSC has supported SCP implementation at Peter Mac. The project included a literature review, development of SCP templates tailored to clinical services, workforce education, and development of resources. We have reviewed the implementation of SCPs.^[2] Patients and healthcare professionals support the use of SCPs and nurses are instrumental to SCP implementation. Consistent with published literature, we found that key enablers are: organizational and clinical leadership, multidisciplinary engagement, and adequate resourcing. Challenges include lack of infrastructure to implement SCPs and inadequate communication and engagement with the SCP program.

In recent work, ACSC investigated the preferences of cancer survivors regarding SCPs, to inform development of sustainable models of delivery (article in press in *Acta Oncologica*). Survivors report a range of information needs. To meet these needs, a range of existing evidence-based resources may be used. Needs assessment tools can be used to identify and prioritize groups of survivors to receive other aspects of survivorship care. Nurses can provide these initiatives face-to-face as well as by telephone or email.

Information for Diverse Survivor Groups

About a quarter of the resident Australian population are migrants. About a quarter speaks a language other than English at home. A large number speak English poorly or not at all. Migrants with cancer report inferior quality of life and have greater levels of unmet need compared to Australian-born people with cancer. Many people desire information in their own language. With funding from Cancer Australia, we have completed two projects developing new written resources for people who speak Cantonese, Mandarin, Greek, Arabic, Italian, or Vietnamese. We developed these resources with members of the relevant communities. We undertook focus group work and have published regarding this.^[3] Some survivorship issues are shared between English-speaking Australian-born survivors and culturally diverse groups; however, we identified unique needs of particular culturally diverse groups. It is anticipated that these resources may be transferable and can assist HCPs when supporting diverse survivor groups in global settings. We are extending this work and also developing low literacy and audio resources.

Facilitating Primary Care Engagement Posttreatment

There is growing recognition of the importance of primary care in the management of patients during and after cancer treatment. With additional funding from the DHHS, we undertook a pilot placement program for general practitioners (GPs, primary care physicians) and primary care nurses at Peter Mac in 2015.^[4] The pilot aimed to bring together generalists and specialists to encourage engagement, bidirectional learning and to reduce barriers to shared management. The placement reinforced the role of GPs in posttreatment care and enabled knowledge and skills transfer. It raised awareness of chronic disease management protocols that might support posttreatment survivorship care. Specialists identified greater understanding of general practice and the role of chronic disease management. DHHS provided further funding in 2016 for a second

program, extending to three other public hospital oncology sites. Educational videos and a toolkit were developed to support implementation.

Evaluation is underway to determine the feasibility and impact of delivering the placement programs at these sites. Initial results indicate that program participation enhances generalists' knowledge and confidence regarding the care of cancer survivors and is highly regarded by both generalists and specialists.

The video series include videos for patients and survivors, for GPs, and for cancer specialists. They describe the valuable role of GPs in the care of survivors. The value of chronic disease management in cancer survivors is emphasized and the value and benefits of shared care are highlighted. The videos have been well received.

Workforce Development

The need to further educate and train the health workforce is a key recommendation to enable improved survivorship care. Nurses play an important role in survivorship care. ACSC collaborated with a number of partners to develop a free online learning resource for nurses, specific to cancer survivorship. We have described the development and evaluation of this educational resource.^[5] Enablers to accessing the online education site included a desire to strengthen survivorship knowledge; content being relevant to practice; an engaging interface design and convenience. On the whole, participants reported the resource to be relevant to practice and also useful in developing SCPs. This experience suggests that online platforms are a useful mechanism to deliver evidence-based education about survivorship care.

ACSC has also developed face-to-face training for HCPs. The workshops aim to provide education, information, and resources to enable allied health and nursing staff to better implement survivorship care. Evaluation of the workshops suggests that participation provides ideas and inspiration to promote and implement survivorship care in the workplace. Participants would promote attendance to others and generally endorse that the workshop met their learning objectives. Based on feedback, we have refined the workshops. Major changes have been to develop "beginner" and "intermediate" courses, responsive to experience, and learning needs. ACSC provides ongoing advice, support, and networking opportunities for HCPs developing survivorship initiatives.

The impact of the face-to-face training and the community of practice has been a strengthened survivorship capability in the health system. Programs such as these could be applied elsewhere.

Conclusion

The Australian experience of implementing innovative survivorship programs has contributed to improved care of cancer survivors. We have developed materials and programs responsive to survivors' experiences, concerns, needs, and preferences. Substantial work has been undertaken to identify enablers and barriers and to embed enhanced care. Nurses are positioned to provide leadership in survivorship care and promote health care change. Adopting an iterative process of pilot, evaluation, and refinement has been instrumental in facilitating nursing contributions and successful implementation of survivorship initiatives.

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Conflicts of interest

There are no conflicts of interest.

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