

Worldwide Use of Internet-based Survivorship Care Plans

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Abstract

Over the past decade, the world has demonstrated an increased interest in and awareness of the unique needs of cancer survivors. Survivorship care plans are a communication tool intended to provide guidelines for the healthcare of survivors as they complete active cancer care, and for the duration of their lives. The Internet represents a unique way to communicate with cancer survivors, and data from several groups indicate that increasing numbers of survivors both desire information about their care and seek this information on the Internet. A handful of US-based groups have developed Internet-based tools for the creation of survivorship care plans. The first of these, the LIVESTRONG Care Plan (www.livestrongcareplan.org), is available via the *OncoLink* cancer information website based at the University of Pennsylvania. Data from the first three years since the launch of this tool demonstrate increasing use by survivors from nearly every continent, with international users accounting for 16% of total users. Data from these users also demonstrate wide variability with regard to receipt of previous survivorship information and treatment summaries based on location of residence. This variation emphasises the vital role that Internet-based survivorship care plans may continue to play in the care of survivors worldwide.

Keywords

Survivorship care plan, cancer survivor, Internet, cancer-associated late effects, long-term effects, treatment summary, survivor

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International Recognition of the Unique Needs of Cancer Survivors

Over the past five years, the important role of survivorship care plans for all cancer survivors has been formally recognised. In the US, recommendations from the Institute of Medicine in 2005 that all patients completing active cancer care be provided with a survivorship care plan were a major part of this impetus.¹ Particularly since that time, the available literature has expanded dramatically with regard to recognition of unmet needs of cancer survivors.²⁻¹¹ Cancer survivors remain at risk of recognised late effects of treatment related to surgeries, chemotherapies and radiation; in addition, several groups have demonstrated that cancer survivors may not receive appropriate surveillance for recurrent disease and/or age-appropriate screening for other illnesses,⁵⁻⁷ and others have found survivors to be at increased risk of infertility,¹¹ unemployment²⁻⁴ and anxiety/depression.^{1,9} Cancer survivors in the US report rarely receiving survivorship information to address these issues.¹² Although the modern era of cancer care is accompanied by increasing recognition of needs during the survivorship phase of a cancer diagnosis,¹³ the healthcare community is faced with great obstacles to providing this care.

First, the majority of cancer survivors living in the US and worldwide are over 60 years of age.¹⁴ Simply as a result of the healthcare risks associated with normal ageing, cancer survivors often have or are at risk of serious co-morbidities and require complex care. Most of them do not appear to ultimately receive routine follow-up care from both

oncologists and primary care providers,¹² and the onus for providing comprehensive care – including cancer follow-up care and care for general health – often falls on one provider. Second, providers may not be fully aware of which or how many healthcare providers a given patient receives care from; this may result in aspects of care being neglected because one provider assumes the other will attend to them, and vice versa. Although different healthcare systems worldwide are faced with varied limitations and obstacles, a universal factor appears to be a need for increased communication among healthcare providers and between healthcare providers and survivors.

The Essential Role of Survivorship Care Plans

A survivorship care plan is primarily a tool for improved communication. Ideally, survivors should be provided with care plans at the time of completion of active cancer therapy, or during active therapy if this course is protracted or indefinite. Survivorship care plans should be individualised, and should be based on as many factors as possible that may affect an individual's future health; these may include, but are not limited to, cancer diagnosis, age, health behaviours, demographic features and cancer treatments received. Survivorship care plans should then address as many long-term risks and healthcare concerns as possible, while also providing guidelines for surveillance for cancer recurrence, screening and care for age-related illness and resources for care for infertility and psychosocial concerns.¹ This information may serve both to facilitate communication and to empower survivors to ensure that they receive complete care. Data accrued and published by

several groups over the past two decades have demonstrated that more and more cancer survivors desire as much information as possible about their disease and treatment, and that many are ready and willing to take an active role in managing their care.¹⁵⁻¹⁷ Certain demographic groups of cancer survivors appear to seek information more frequently than others, namely those who are younger (<65 years of age), females, those on higher incomes and those who receive regular healthcare from the same provider(s).¹⁸ Although desire for information and autonomy has been demonstrated to vary with such demographic features as well as with cultural norms, giving survivors worldwide the option to have further information seems universally indicated.

The Internet as a Tool for Cancer and Survivorship Information

Although healthcare providers appear to appreciate the potential benefit of providing survivorship care plans,¹⁹ creating them is certainly a resource-intensive activity that may be expensive and time-consuming. In response to this, a small number of co-operative and survivorship-orientated US-based groups have initiated efforts to provide care plans via the Internet. The Internet represents a rapidly growing source for transmission of health information worldwide. Recent work has shown that over 50% of a US sample of cancer patients used the Internet to seek cancer-related information, with many citing the reason for Internet use being to help them make informed decisions regarding treatment and side effect management.²⁰ Although cancer survivors appear to continue to prefer interpersonal communication with healthcare providers over all other sources of information, many appear to augment information provided with that from other sources, often the Internet,²¹ and a recently surveyed group of US survivors reported that they would turn to the Internet for cancer-related information second only to their healthcare provider.¹⁸

Although data regarding Internet use by non-US survivors are more limited, use of the Internet for cancer-related information appears to be increasing worldwide. Carlsson recently documented a rise in Swedish Internet use in the past decade, with 6% of cancer patients seeking Internet-based information in 1998 versus 59% in 2008.²² A recent survey of Australian women demonstrated that 62% of women presenting to a breast screening programme accessed the Internet for health-related information, and 70% related that they would access the Internet for breast cancer information if incurring such a diagnosis.²³ Similarly, Newnham and colleagues demonstrated that 77% of ambulatory Australian oncology patients report seeking cancer information on the Internet.¹⁷ Certainly, in many parts of the world the availability of non-English-language information may be an obstacle to those seeking cancer information on the Internet, as has been documented by Chinese²⁴ and French groups;^{25,26} however, the Internet appears to be a tool whose role in providing information is increasing worldwide at a rapid pace.

International Use of Internet-based Survivorship Care Plans, Including the LIVESTRONG Care Plan

Currently, a handful of Internet-based tools for creation of survivorship care plans are available. The first of these, the LIVESTRONG Care Plan, was first made available via *OncoLink*, a cancer information website based at the University of Pennsylvania, in May 2007. *OncoLink* (www.oncolink.org) is a website dedicated to the general needs of cancer patients and survivors, as well as their family members and caregivers, and serves over 3.9 million pages monthly to 385,000 unique

Figure 1: Distribution of Non-US Users of the LIVESTRONG Care Plan, an Internet Tool for the Creation of Cancer Survivorship Care Plans

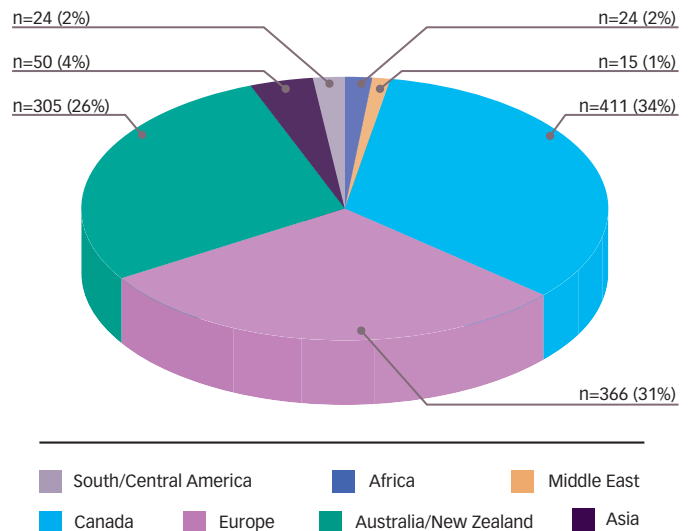
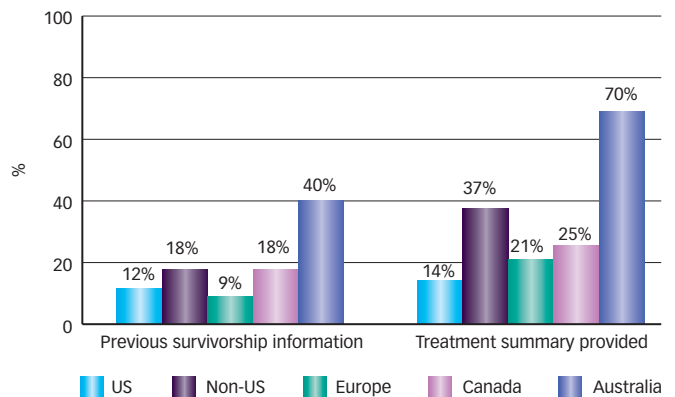


Figure 2: Reported Receipt of Previous Survivorship Information and Treatment Summaries by Users of the LIVESTRONG Care Plan According to Country/Region



internet protocol (IP) addresses. The care plan tool, first launched with the name *OncoLife*, was developed by a small team of oncology nurses and physicians. After being piloted to test groups of survivors, the tool was made publically available via the *OncoLink* website. Detailed design and implementation procedures have been described previously.¹² The care plan tool is designed to allow users to enter information regarding demographics, diagnosis and treatments received. Once this information has been entered, users receive customised, individualised survivorship care plans that may be printed or stored electronically in portable document format (PDF). Over the nearly three years since the tool was made available, it has evolved over six iterations. With each iteration, further information has been added and user queries have become more detailed to allow improved customisation of information provided. From the time of launch, the care plan has been available in both English and Spanish.

With the second care plan iteration, queries regarding location of residence were added. As of March 2010, 10,405 care plans had been created, with data regarding location of residence available for 8,969 users. After the first 18 months of availability, with a total of 1,872 users with residency data available, 91% of users reported being from the US,

6% from Canada and only 3% from other countries.¹² Further data have been presented in abstract form,²⁷ and are updated here. Use by non-US individuals has continued to increase, with 14% of users now reporting living outside the US. In addition, the group of non-US survivors using this tool has become increasingly diverse, with 34% being from Canada, 31% Europe (most commonly Great Britain) and 26% Australia/New Zealand (see *Figure 1*). Small percentages of users now represent Asia (4%), South/Central America (2%), Africa (2%) and the Middle East (1%). Both US and non-US users were equally likely to have utilised the Spanish version of the care plan tool (<2% in both groups). Breast cancer was the most common diagnosis in both groups (46 and 36%, respectively), and the groups remain similar demographically: median diagnosis and current age are 49 and 53 years, respectively, in the US group, versus 47 and 50, respectively, in the non-US group.

Users completing care plans appear to be somewhat more likely to be survivors themselves (62%) than family members/friends (10%) or healthcare providers (27%) among US users compared with non-US users, 54% of whom identified themselves as survivors (13% family members/friends and 31% healthcare providers). Healthcare providers who created plans for survivors identified themselves as physicians more often in non-US (15%) than US (9%) countries.

Interestingly, non-US users were more likely to report having received previous survivorship information (18%) than were US users (12%) ($p < 0.001$). Non-US users were also much more likely to report having received a written treatment summary (37%) than were US survivors (14%) (see *Figure 2*). These trends varied significantly across regions of the world: Australian users reported receiving a treatment summary in 70% of cases and survivorship information in 40%. This compares with only 21% of European survivors receiving treatment summaries and <10% receiving survivorship information, and Canadian survivors receiving treatment summaries in 25% of cases and survivorship information in 18%. These data are very interesting in that they demonstrate that potentially more attention is paid to survivorship issues in countries other than the US. Physicians in other parts of the world appear more likely to use a tool such as the LIVESTRONG Care Plan for their patients, and survivors appear more likely to have received treatment summaries and survivorship information from other sources. This appears to vary considerably, as would be expected, based on region, with Australian survivors having a much higher likelihood of receiving this information than US and European survivors, and Canadian survivors having an intermediate likelihood.

Certainly, these data do not provide enough information to draw conclusions regarding the reasons behind such discrepancies, which are in all likelihood multifactorial and may include differences in healthcare systems, physician–patient ratios and expenditure of resources. Interestingly, however, US and European survivors appear to be among the least likely to receive this information. Hopefully, this trend will begin to change over time, as attention to survivorship issues outside of a few specialised centres within the US is a relatively modern concept. Certainly, these issues have come to the forefront over the past decade,²⁸ and the few groups who have implemented Internet-based, accessible tools for survivorship care plans are testament to this. Aside from the LIVESTRONG Care Plan, other US-based tools are available through the American Society of Clinical Oncology (www.asco.org) and the Journey Forward Program (www.JourneyForward.org). Other individual US institutions also report

developing and implementing Internet-based tools for creation of survivorship care plans, including the Fred Hutchinson Cancer Research Center, the Dana Farber Cancer Institute and the University of Colorado Cancer Center.²⁸ The fact that most such Internet-based tools, to this author's knowledge, are US-based, may signify that US providers are aware of a true deficit in survivorship care in this country, which may be worse than exists in some other parts of the world.

Current and Future Roles of Internet-based Survivorship Care Plans in the International Setting

Just as provision of survivorship information is in its early phases of development in many parts of the world, research regarding the best way to provide this information is as well. Several groups have studied the ways in which survivorship care plans may be best provided, and have found that, overall, the healthcare community appears receptive to the care plan concept.¹⁹ Survivors appear willing to use Internet-based tools for creation of care plans;^{12,29} over 90% of users of the LIVESTRONG Care Plan report 'good' to 'excellent' levels of satisfaction with it, and over 80% report that they will share the generated plans with the healthcare team.¹² Recent data from other groups demonstrate that a balance between providing high-quantity, high-quality information and avoiding being overly technical and requiring excessive time is important in the design of Internet-based care plan tools.³⁰

The huge field of cancer survivorship research and understanding remains quite young at this point. Early data demonstrate that Internet-based tools for the creation of survivorship care plans may be useful, and may result in wide use and high levels of satisfaction worldwide. Based on data from use of one such tool, discrepancies in attention to survivorship issues appear to exist across the globe. Publicly available Internet-based survivorship care plans are one tool to reduce these discrepancies and to provide essential information to all cancer survivors worldwide. ■

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1. Hewitt M, Greenfield S, Stoval E, *From Cancer Patient to Cancer Survivor – Lost in Transition*, Washington, DC: National Academies Press, 2005.
2. de Boer AG, Taskila T, Ojajarvi A, et al., Cancer survivors and unemployment: a meta-analysis and meta-regression, *JAMA*, 2009;301:753–62.
3. Stanton AL, Psychosocial concerns and interventions for cancer survivors, *J Clin Oncol*, 2006;24:5132–7.
4. Short PF, Vargo MM, Responding to employment concerns of cancer survivors, *J Clin Oncol*, 2006;24:5138–41.
5. Earle CC, Neville BA, Under use of necessary care among cancer survivors, *Cancer*, 2004;101:1712–9.
6. Keating NL, Landrum MB, Guadagnoli E, et al., Surveillance testing among survivors of early-stage breast cancer, *J Clin Oncol*, 2007;25:1074–81.
7. Snyder CF, Earle CC, Herbert RJ, et al., Preventive care for colorectal cancer survivors: a 5-year longitudinal study, *J Clin Oncol*, 2008;26:1073–9.
8. Earle CC, Chretien Y, Morris C, et al., Employment among survivors of lung cancer and colorectal cancer, *J Clin Oncol*, 2010;28:1700–5.
9. Greenfield DM, Walters SJ, Coleman RE, et al., Quality of life, self-esteem, fatigue, and sexual function in young men after cancer: a controlled cross-sectional study, *Cancer*, 2010;116(6):1592–1601.
10. Shin DW, Ahn E, Kim H, et al., Non-cancer mortality among long-term survivors of adult cancer in Korea: national cancer registry study, *Cancer Causes Control*, 2010;21(6):919–29.
11. Menesis K, McNeess P, Azuero A, Jukkala A, Development of the Fertility and Cancer Project: an Internet approach to help young cancer survivors, *Oncol Nurs Forum*, 2010;37(2):191–7.
12. Hill-Kayser CE, Vachani C, Hampshire MK, et al., An Internet tool for creation of cancer survivorship care plans for survivors and health care providers: design, implementation, use and user satisfaction, *J Med Internet Res*, 2009;11(3):e39.
13. Simonelli C, Annuziata MA, Chimienti E, et al., Cancer survivorship: a challenge for the European oncologists, *Ann Oncol*, 2008;19(7):1216–17.
14. Centers for Disease Control and Prevention (CDC), Cancer survivorship – United States, 1971–2001, *MMWR Morb Mortal Wkly Rep*, 2004;53(24):526–9.
15. Cassileth BR, Zupkis RV, Sutton-Smith K, March V, Information and participation preferences among cancer patients, *Ann Intern Med*, 1980;92:832–6.
16. James C, James N, Davies D, et al., Preferences for different sources of information about cancer, *Patient Educ Couns*, 1999;37:273–82.
17. Newnham GM, Burns WI, Snyder RD, Information from the Internet: attitudes of Australian oncology patients, *Intern Med J*, 2006;36(11):718–23.
18. Mayer DK, Terrin NC, Kreps GL, et al., Cancer survivors information seeking behaviors: a comparison of survivors who do and do not seek information about cancer, *Patient Educ Couns*, 2007;65(3):342–50.
19. Hewitt ME, Bamundo A, Day R, Harvey C, Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians, *J Clin Oncol*, 2007;25(16):2270–73.
20. Nagler RH, Romantan A, Kelly BJ, et al., How do cancer patients navigate the public information environment? Understanding patterns and motivations for movement among information sources, *J Cancer Educ*, 2010 (Epub ahead of print).
21. Basch EM, Thaler HT, Shi W, et al., Use of information resources by patients with cancer and their companions, *Cancer*, 2004;100(11):2476–83.
22. Carlsson ME, Cancer patients seeking information from sources outside the health care system: change over a decade, *Eur J Onc Nurs*, 2009;13(4):304–5.
23. Dey A, Reid B, Godding R, Campbell A, Perceptions and behavior of access of the Internet: a study of women attending a breast screening service in Sydney, Australia, *Int J Med Inform*, 2008;77(1):24–32.
24. Lau L, Hargrave DR, Bartels U, et al., Childhood brain tumour information on the Internet in the Chinese language, *Childs Nerv Syst*, 2006;22(4):346–51.
25. Leveque M, Dimitriu D, Gustin T, et al., Evaluation of neuro-oncology information for French speaking patients on the Internet, *Neurochirurgie*, 2007;53(5):343–55.
26. Evrad AS, Guertin L, Remacle M, et al., Internet information of head & neck oncology in French, *Ann Otolaryngol Chir Cervicofac*, 2009;126(3):99–111.
27. Metz JM, Hill-Kayser CE, Hampshire MK, et al., Worldwide and European use of Internet survivorship care plans (Abstract), Presented at the Multinational Association of Supportive Care in Cancer 2009 International Symposium, Rome, Italy, June 25–27, 2009.
28. Jacobs LA, Palmer SC, Schwartz LA, et al., Adult cancer survivorship: evolution, research, and planning care, *CA Cancer J Clin*, 2009;59:391–410.
29. Hill-Kayser CE, Vachani C, Hampshire MK, et al., Utilization of survivorship care plans by lung cancer survivors, *Clin Lung Cancer*, 2009;10(5):347–52.
30. Burg MA, Lopez EDS, Dailey A, et al., The potential of survivorship care plans in primary care follow-up of minority breast cancer patients, *J Gen Intern Med*, 2009;24(Suppl. 2):467–71.