

# Survivorship Programs and Care Planning

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Formal cancer survivorship care is a growing focus internationally. This article provides a broad overview of the national strategies currently in progress for the development of survivorship programs and care plans within the United States and across Europe. The different approaches taken in their implementation, staffing, and clinical focus are highlighted, with an emphasis on how they are incorporated into various models of care. The considerable variation in making survivorship a formal period of care across countries and health care systems is discussed, including the factors influencing these differences. A review of research focused on the evaluation of definitions and outcomes is provided along with a discussion of important areas requiring future research. *Cancer* 2013;119(11 suppl):2179-86. © 2013 American Cancer Society.

**KEYWORDS:** survivorship; survivorship programs; care plans; rehabilitation; models of care.

## INTRODUCTION

Survivorship programs and care plans are frequently identified as core components in survivorship strategies after the completion of successful cancer treatment. The term “survivorship program” is used to describe a range of planned interventions to promote and support a patient’s participation in maximizing their recovery and the adoption of a healthy lifestyle for the future.<sup>1</sup>

The objectives include monitoring by clinicians and patients for possible symptoms of cancer recurrence and late effects, support to optimize quality of life and physical and psychological well-being, and a successful return to employment and other social functions.<sup>1,2</sup> The individual is encouraged to take a more active role in managing their own health care, with particular attention to prevention and screening behaviors.<sup>3,4</sup> A survivor care plan (SCP) refers to an individualized plan of care that is constructed through a holistic assessment and implemented at the conclusion of cancer treatment.<sup>5,6</sup> Although discussions and treatment choices that relate to long-term consequences should be part of the earlier pathway after diagnosis, the SCP is usually based on the end-of-treatment summary. It will also include both immediate and longer-term goals: from recovery and rehabilitation to future monitoring for potential late consequences of treatment or second cancers.<sup>7</sup> The SCP should be provided to the cancer survivor and shared with the primary care provider and other professionals who provide ongoing care, as well as others who may care for the individual in subsequent years.<sup>1</sup>

This article provides an overview of the concepts and ways in which survivorship programs and SCPs are being implemented within the United States and across Europe. The different approaches taken in their development and formulation are explored as is the context in which they are being applied to models of survivorship care. This article also illustrates the considerable variation in the extent to which cancer survivorship is a clearly defined period of care or even acknowledged within health care systems, the different factors that influence models of care, and the extent that these models have been formally tested.

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European-American Dialogues on Cancer Survivorship: Current Perspectives and Emerging Issues

This supplement was guest edited by Vittorio Mattioli, MD (NCRC, Bari, Italy) and Kevin Stein, PhD (American Cancer Society, Atlanta, Georgia) and was produced with the authoritative contribution of 58 authors from the European Union and the United States. The primary aims are to highlight the potential differences between European and American approaches to cancer survivors’ issues, increase coordination among oncologists and other primary care providers, and aid the development of a shared care model that can improve the quality of cancer care.

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### ***Influence of National Strategies and Policy Initiatives on the Development of Survivorship Programs***

The current literature reflects international heterogeneity with regard to the extent to which cancer follow-up care is considered a priority requiring a strategic approach in health care with an acknowledgment that there are survivors within the population who will require various degrees of support long after the completion of treatment.

In the United States, cancer survivorship as a formal period of care gained national recognition via 2 key publications in 2004 and 2005. *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was published in 2004 by the Centers for Disease Control and Prevention in collaboration with the LIVESTRONG Foundation.<sup>8</sup> This was followed by the influential Institute of Medicine (IOM) report entitled, *From Cancer Patient to Cancer Survivor: Lost in Transition*,<sup>1</sup> which offered a strong challenge and comprehensive guidance to the broad community of clinicians caring for cancer survivors. The broad set of Institute of Medicine recommendations established a survivorship roadmap for clinical care, research, communication, professional training, and education. It also included a strong recommendation for SCPs for all survivors.

In recent years, all 50 states in the United States have established cancer control plans and 88% of these plans include a focus on survivorship services with the intention of proposing ways to coordinate and communicate cancer efforts. These plans are intended to be a catalyst for community action, engaging health care providers, public health officials, and patient groups. This effort was further enhanced in 2005 with the identification and funding by LIVESTRONG Foundation of a Survivorship Centers of Excellence Network that included a group of National Cancer Institute-designated cancer centers.<sup>9</sup> The goal of this ongoing initiative was to "... provide a mechanism to bring together these 8 cancer centers and their community partners to address the most pressing issues of cancer survivorship. -the Network sought to harness the expertise, experience, creativity and productivity of leading cancer centers to accelerate progress in survivorship, research care and services."<sup>10</sup> In 2011, LIVESTRONG expanded their scope of activity by publishing a brief on the Essential Elements of Survivorship Care that are relevant to all oncology care settings in the United States.<sup>11</sup>

Across Europe, there is considerable variation both in the recognition of cancer survivorship and how organizations are responding to these identified needs. In 2008, 16 European countries had defined national cancer plans,<sup>12</sup>

although to our knowledge very few currently have survivorship services within these plans. European Commission recommendations to reduce the burden of cancer endorse the inclusion of an integrated approach to care across the cancer trajectory.<sup>13</sup> In contrast to the United States, there are no single pan-European templates for care planning and survivor programs. Consequently, some countries are further ahead than others, but the growing number of cancer survivors in the European population will require discussions about the implications of this growth and the resulting expenditure of health care resources.<sup>14</sup> In Scandinavia, where there is a public tax-financed health care system with resources allocated to specific areas including cancer aftercare and rehabilitation, survivorship programs are further developed. Norway has undertaken population surveys through cancer registries to inform the design of rehabilitation programs for survivors.<sup>14,15</sup> Sweden is evaluating the government-funded development of an integrated approach for all cancer survivors.<sup>16</sup> Italy also has free access to medical care and social services; however, a survey in 2003 established that there was variable access to rehabilitation after cancer treatment, although referrals could be made by oncologists or primary care physicians. In response, a research-based approach has been initiated using provider-reported outcomes to demonstrate the benefits of support services to cancer survivors and to the health economy as well.<sup>17</sup> However, even when there is free access to rehabilitation, there is a poor uptake of these services,<sup>18</sup> suggesting that other psychological and social factors to improve implementation are needed for the population to fully benefit from such recovery models.<sup>19</sup>

In the United Kingdom, the landmark development in cancer survivorship was the creation in 2008 of the National Cancer Survivorship Initiative, which is a partnership between the Department of Health (England and Wales) and a major UK charity, Macmillan Cancer Support. The publication of a national strategy, the so-called "National Cancer Survivorship Vision," followed in January 2010.<sup>20</sup> Similar to the IOM recommendations in the United States, this report made the case for identifying the priority developments for survivorship cancer services and research. The document was informed by a health and well-being survey undertaken by Macmillan in 2008, which provided evidence of chronic health care needs among cancer survivors.<sup>21</sup> The following year, the UK government's Cancer Reform Strategy included reference to survivorship for the first time and included specific outcome measures for cancer survivors.<sup>20</sup>

The Health Council of the Netherlands has also promoted a national approach, including the use of SCPs and cancer rehabilitation as a strategic objective<sup>22</sup> with the

inclusion of a detailed quality-of-life assessment of cancer survivors linked to the cancer registry. This approach may be aspirational for other parts of Europe. For example, in Hungary, which has the highest cancer incidence and mortality rates in central Europe, Csikai et al<sup>23</sup> described the challenges for the existing health care system with few health care professionals who are equipped to address the psychological consequences of cancer treatment support and rehabilitation for survivors. This is not just an issue for Eastern Europe; workforce capacity is a contributing factor to the engagement of health care professionals in many countries worldwide in survivorship care.<sup>24,25</sup>

The promotion and development of cancer survivorship care is increasingly influenced by professional societies and organizations in both the United States and Europe. The American Society of Clinical Oncology, the American Cancer Society, the Oncology Nursing Society, and the National Comprehensive Cancer Network all have made survivorship a strategic priority and have launched important initiatives to develop clinical guidance for the identification and management of survivorship issues that occur as a result of the cancer and its treatment. The Organization of European Cancer Institutes is a platform that fosters pan-European collaboration for cancer care, education, and research and includes those issues relating to survivorship. The European Oncology Nursing Society and the European CanCER Organization endeavor to share learning and enhance survivorship models. In parallel, there is a growing patient voice. The European Cancer Patient Coalition, which represents over 300 patient cancer groups across Europe, has identified survivorship care as one of their priorities. Such developments will influence all aspects of cancer service development, including survivorship.

### ***Design of Survivor Programs***

In the United States to date, formal survivorship planning is structured around the types of providers and types of facilities in which patients and their families seek cancer treatment and care, and this diversity has resulted in several care models.<sup>25-29</sup> With so much of US medical care currently focused on the specialist rather than the primary care provider, the key provider in these survivorship models has been the cancer specialty team and not the primary care physician, although increasingly a shared care model with the primary care physician is being adopted and is driven by the development of Accountable Care Organizations under the Patient Protection and Affordable Care Act.<sup>30</sup> Although the initial models began in academic cancer centers, they currently are being implemented and adapted in community oncology practices and hospitals.<sup>31</sup> This is an

important advancement in survivorship care in the United States because the majority of cancer patients are treated and receive follow-up care in the community.<sup>26,27</sup>

In both the United States and many countries within Europe, nurses have developed the skills to care for cancer survivors and play an increasingly important role in providing follow-up care with particular attention paid to a holistic assessment of the patient; a focus on lifestyle interventions and psychological adjustment; a sharing of follow-up monitoring with the oncologist; and, in addition, the management of patients with late-onset and chronic symptoms.<sup>28,32,33</sup> This expertise supports the construction and use of SCPs. In contrast, the role of the cancer nurse specialist is not well developed in several European countries, thereby limiting their ability to intervene in a patient's care after the completion of treatment.

In the United States, nurse practitioners and physician assistants may see patients either independently or in a collaborative visit with a physician for ongoing survivorship care planning and support. This may take place in cancer centers, hospitals, or community practices. Survivors may also be referred for a 1-time comprehensive survivorship visit although the ongoing care continues to be provided by the oncology team.<sup>28,34</sup> Both models of care include the provision of a treatment summary and care plan; a review of the recommended surveillance for long-term and late effects; and a discussion of health promotion and disease prevention activities, such as appropriate cancer screening, diet, exercise, and smoking cessation. For individual problems that may be identified, survivors are referred to medical subspecialists, physical rehabilitation, nutrition counseling, and psychological or psychiatric services. There is emphasis on establishing primary care-based support for the survivor with the expectation that communication between the oncology team and primary care provider will continue.<sup>35</sup> Evaluation of this type of follow-up is currently being conducted both within the United States<sup>36</sup> and Europe.<sup>24,37</sup>

Thus in the United States, the components of the "survivor program" are customized to the individual, provided via targeted referral to specific services, and coordinated by the care planning process, rather than a formal course for a group of patients. To our knowledge to date, there has been limited evaluation of these models, but there is increasing emphasis on the need to do so.<sup>31,34,38</sup>

Another model of a survivor program used in both Europe and the United States and customized to the individual is that of a planned and brief course provided by several experts and accessed by groups of survivors. This approach can harness mutual encouragement and

support, enhance motivation to adopt better lifestyle choices, and promote self-care.<sup>39-41</sup> The group visit model of survivorship care is a means of encouraging survivors to actively participate in the development of their SCP. In Sweden, Grahn<sup>42</sup> developed the “Learning to Live With Cancer” program, which has been evaluated in several European countries.<sup>43-45</sup> Such a model is also often led by nurses and focuses on adaptation to chronic health issues as well as the development of the SCP.<sup>46</sup>

### Survivor Program Models Linked to Rehabilitation

The components of what are called survivorship programs in the United States are recognizable within the provision of rehabilitation by several European countries; indeed the term “rehabilitation” may be considered to be a surrogate for “survivorship program” because they have broadly similar aims. Although rehabilitation (physical and vocational) in the United States is most often a separate service used by individuals cared for in a survivorship program, the broad dissemination of these services into the community has been limited.<sup>4</sup> In contrast, rehabilitation is well established within Europe and the elements of survivorship programs can be identified within the context of rehabilitation after cancer treatment, including the promotion of psychological care and exercise.<sup>47,48</sup> Although there are examples of interventions and pathways<sup>49</sup> that relate to these survivorship models, the way in which rehabilitation is implemented as part of cancer survivorship will be shaped within the context of different health care systems, financial support, and cultures across Europe.

Provision of rehabilitation after any significant illness has been long established within the health care and social care systems in Germany and are now financed via the Social Insurance code system. The intention is to enhance recovery after acute illnesses through vocational rehabilitation that promotes a return to employment. The established model is a 3-week to 4-week residential course of intensive rehabilitation training (requiring that individuals remain at the facility) at the conclusion of cancer treatment.<sup>50</sup> Patients apply for funding for this training, which is provided at a rehabilitation hospital or specialist cancer institutions. However, although access to rehabilitation is a legal right, not all patients access these services. For example, Rick et al<sup>51</sup> highlighted that only a few patients used the rehabilitation services provided after resection for lung cancer or treatment of ovarian cancer.<sup>52</sup> Outpatient rehabilitation is currently the exception in Germany, although such services have been shown to be comparable and are more popular with patients.<sup>53</sup> This preference for outpatient services may influence the future

development of patient programs and in doing so widen access to those who cannot commit to the standard rehabilitation clinics because of personal circumstances.

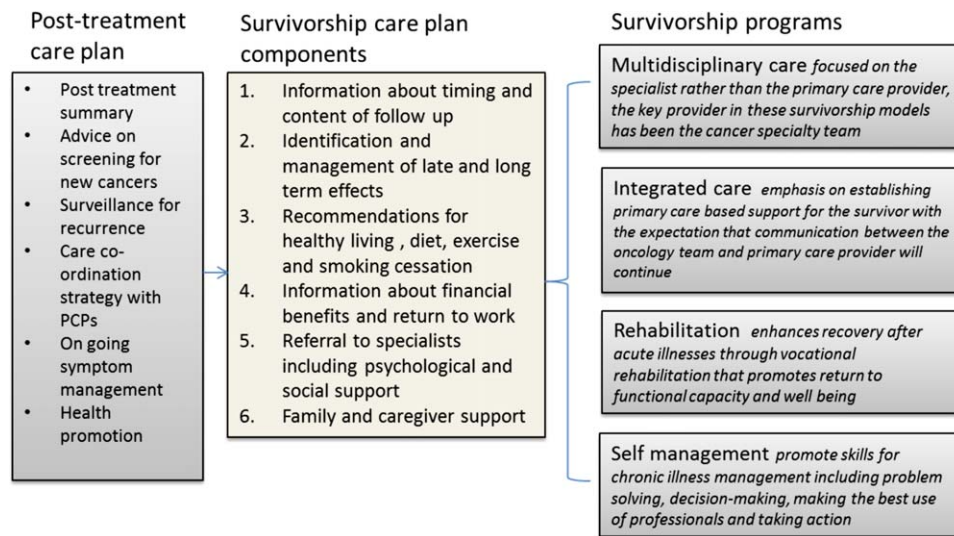
In Italy, rehabilitation centers are focused on diagnostic groups other than cancer and cancer rehabilitation protocols are generally not yet established, although there are reports of rehabilitation, particularly after surgery, with a recommendation for wider use in cancer services.<sup>54,55</sup> In the Netherlands, although cancer rehabilitation programs are not yet routinely available to all patients, models of nonresidential programs currently are being developed and evaluated.<sup>56-58</sup> Models of cancer rehabilitation have been well described across Scandinavian countries, but again there is no systematic provision of services and consequently access is variable.<sup>49</sup> The Danish Cancer Society highlighted the importance of rehabilitation in patients with cancer in 1993, after which there was growth noted with regard to residential cancer rehabilitation initiatives.<sup>59</sup> However, only between 5% and 50% of patients (depending on their diagnosis) were admitted to cancer rehabilitation programs.<sup>18,60</sup> Currently, physical and rehabilitation medicine is underdeveloped in relation to oncology in France.<sup>61</sup> In the United Kingdom, although the role of rehabilitation is identified for specific cancer pathways,<sup>62</sup> there has not been widespread implementation of rehabilitation services due to a lack of staff and reimbursement of aftercare.

Cancer survivorship services are therefore developed in parallel with rather than built on a rehabilitation model.<sup>63</sup> Although the focus of rehabilitation appears to be more on physical recovery, there is acknowledgment of the importance of screening survivors for physical, psychological, and social care needs.<sup>57,64</sup> Although rehabilitation has been tailored to the needs of individual patients, some researchers have demonstrated little change in psychological stress in the longer term, identifying the need for the inclusion of other aftercare approaches<sup>65-67</sup> within the rehabilitation model. Clearly there are many rehabilitation initiatives occurring across Europe; however, these are often occurring in selected patient groups and there is no consensus on best approaches or data on long-term effectiveness.

### Survivor Programs Adopted From Self-Management Approaches With Other Chronic Conditions

Self-management is an interactive process aimed at enhancing individual responses and behavior by managing the physical and psychosocial consequences of





**Figure 1.** Critical elements of survivorship care planning.

symptoms and treatment.<sup>68</sup> These are supported by a clinician, and often involve cognitive behavioral therapy approaches.<sup>39</sup> The promotion of patient confidence in self-management was launched by the UK Department of Health in 2002 through Expert Patient Programmes<sup>69</sup> and expanded across long-term health conditions. Self-management for cancer patients promotes skills for chronic illness management including problem solving, decision-making, making the best use of professionals, and taking action,<sup>39</sup> and draws on the chronic disease self-management model developed by Lorig et al and Barlow et al.<sup>70,71</sup> This concept has also been used successfully in the United States to promote lifestyle change and psychosocial health.<sup>72</sup> In Norway, a self-management program has been developed for women with breast cancer.<sup>73</sup> It includes a 1-week residential course designed to provide a holistic approach to enhance coping strategies, with an additional 4-day course taking place 2 months later, which was reported to reduce anxiety levels. Evidence from feasibility studies indicated that this targeted self-management approach can reduce long-term symptoms as a consequence of cancer treatment and improve the quality of life in patients with prostate cancer.<sup>74,75</sup> However, further research is needed to adequately power these self-management studies to determine the benefits, if any, for patients with cancer.

### **Evolution of the SCP**

The SCP should be developed at the conclusion of treatment by the principal providers who coordinated the patient's oncology care. In addition to providing a sum-

mary of treatment as a source of future reference, this document relates to the unique experience of each patient and should identify requirements for monitoring, encourage self-management, and be clear on when and how to access advice and support. Given the diversity in health care delivery systems and the uniqueness of the differing survivor populations, the lesson thus far is that no "one size fits all" approach can be taken. However, although care planning may differ in focus, organization, and type of provider, each of which has their own implementation challenges, there are commonly agreed on elements that are considered essential (Fig. 1).<sup>7</sup>

In the German studies evaluating rehabilitation programs, there was no reference to individual care plans, although it is evident that rehabilitation itself is based on a holistic assessment of individual function and need. Schnipper-Haasler and Gonschewski<sup>76</sup> describe individualized "discharge papers" directed toward the family physician who is responsible for the patient's future care. The letters generated by the oncologist signaling the completion of treatment and plans for follow-up should also provide information regarding possible long-term problems. It is considered best practice for the patient to hold a copy of such a letter, although not all patients are asked about this or indeed wish to obtain a copy. In the United Kingdom, the National Cancer Survivorship Initiative provides and promotes templates for end-of-treatment summaries, which are accessible via the Web site ([ncsi.org.uk](http://ncsi.org.uk)). These can form the basis of an SCP but the challenge lies in its adoption into mainstream practice among oncologists for all patients.<sup>77</sup>

Although there is broad support for formal survivorship care planning throughout the United States, 7 years after the publication of the IOM report, the use of SCPs and evaluation of those that are used is limited.<sup>78-81</sup> A recent review by Salz et al<sup>82</sup> reported that although SCPs are accepted in comprehensive cancer centers, only 43% of such centers provided them to survivors of colorectal cancer. Even when used, there appears to be no consistent approach to what should be included.<sup>83</sup> Variations in the content may be due to the broad range of topics to be included, or the clinical team may be unclear about how best to impart this information.<sup>30</sup> There may be a lack of clarity regarding which items in the plan are the responsibility of the oncology team and which are the responsibility of the primary care physician.

Barriers to implementation also exist. For example, putting this information together for a survivor in a busy clinic may be too time-consuming to be practical, the lack of an electronic medical record may make it difficult to pull all the needed information together, and the lack of financial reimbursement for the time it takes to prepare the document is a disincentive.<sup>5</sup> In a recent survey of US oncologists, the majority reported that the SCP should take no more than 20 minutes per patient to complete.<sup>79</sup> Despite all these real challenges, there are several tools that are being used, revised, and evaluated in the United States. The American Society of Clinical Oncology has several SCP templates that can be completed online (asco.org). There are plans to revise and condense these in the near future because of their length and complexity. Another example, called "Journey Forward," includes a simple treatment summary along with modules with recommendations for future care.<sup>6</sup> This tool was developed as a collaboration between the National Coalition for Cancer Survivorship, the UCLA-Cancer Survivorship Center, WellPoint Inc, and Genentech. The **LIVESTRONG** Care Plan is another option that has been developed as an online, patient-oriented tool and can be completed by patients, family members, and providers. It has undergone numerous revisions and has a high satisfaction rating from users.

However, if the generation of individual SCPs is viewed as a hallmark of good practice and required as part of the future accreditation of cancer programs, there is a growing expectation that SCPs will become part of standard oncology practice. Nevertheless, broad adaptation will also require the education and training of practitioners along with evaluation of the usefulness of the various components.<sup>83</sup> As a first step, the American College of Surgeons Commission on Cancer is requiring that the provision of SCPs be phased in as part of accreditation in 2015.<sup>84</sup>

## Conclusions

International attention is increasingly focused on the unique care needs of cancer survivors, resulting in the implementation of SCPs and programs. In turn, these will enable new and more flexible models of care to meet the needs of the increasing numbers of cancer survivors. Survivorship is a growing area of research, resulting in a rapid increase in knowledge both across Europe and in the United States, as evidenced in this article. Despite this increase in publications, to the best of our knowledge, evidence remains limited concerning the value of SCP use and whether new models of survivorship care delivery improve health outcomes for survivors. It is now incumbent on the research community to develop an evidence base for the components of survivorship care planning, vigorously evaluate the information and communication value of SCPs, and test models of care for efficiency and quality in the various health care systems in which survivorship programs are operationalized. Few survivorship studies are conducted within the context of controlled trials, and therefore the evidence base is largely descriptive with preintervention and postintervention evaluations. To the best of our knowledge, studies evaluating survivorship programs have rarely defined the theoretical basis for the interventional approach or the components that comprise the program and therefore it is difficult to compare studies across Europe and the United States. In addition, there may be benefits to instituting survivorship programs that begin during treatment with the opportunity to engage patients when they may be strongly motivated and enable them to take charge of their adjustment and recovery, both during treatment and into survivorship.

To better inform survivorship care planning, there are several important questions to be addressed, including understanding the specific relationships between comorbidity and functional ability and how these are manifested in long-term health problems, quality of life, and health service usage. An additional important area that has to our knowledge received little attention to date is research focused on the unique needs of specific at-risk populations that may not necessarily be represented in studies conducted with the general population of cancer survivors. Such individuals often lack the ability to navigate health care systems, confront social and economic barriers to accessing needed services, and are often reluctant to seek assistance. It will be important to demonstrate that future SCPs and survivorship programs can be effective for these survivors as well as for those who are informed, articulate, and self-motivated.

Although the current article provides a valuable source of shared learning, it is important to recognize the

distinct nature of the respective health care systems that shape the approaches to survivorship care internationally. Even as research builds a clinical evidence base, we can expect to see these differences influence the way in which these interventions and services are adopted across health care settings.

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## REFERENCES

- Hewitt M, Greenfield S, Stovall E, eds. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: National Academies Press; 2005.
- Ganz PA. Survivorship: adult cancer survivors. *Prim Care*. 2009;36:721-741.
- Institute of Medicine. Implementing Cancer Survivorship Care Planning: Workshop Summary. Washington, DC: The National Academies Press; 2006.
- Alfano CM, Ganz PA, Rowland JH, Hahn EE. Cancer survivorship and cancer rehabilitation: revitalizing the link. *J Clin Oncol*. 2012;30:904-906.
- Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol*. 2006;24:5112-5116.
- Hausman J, Ganz PA, Sellers TP, Rosenquist J. Journey forward: the new face of cancer survivorship care. *J Oncol Pract*. 2011;7(suppl 3):e50s-e56s.
- Earle CC, Ganz PA. Cancer survivorship care: don't let the perfect be the enemy of the good. *J Clin Oncol*. 2012;30:3764-3768.
- Centers for Disease Control and Prevention. A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. Atlanta, GA: Centers for Disease Control and Prevention, Lance Armstrong Foundation; 2004.
- Rechis R, Eargle E, Dutchover Y, et al. Defining Survivorship Care: Lessons Learned From the LIVESTRONG Survivorship Centers of Excellence Network. Austin, TX: Lance Armstrong Foundation; 2011.
- Campbell M, Tessaro I, Gellin M, et al. Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. *J Cancer Surviv*. 2011;5:271-282.
- Rechis R, Beckjord E. The Essential Elements of Survivorship Care: A LIVESTRONG Brief. Austin, TX: Lance Armstrong Foundation (LIVESTRONG); 2011.
- Bastos J, Peleteiro B, Gouveia J, Coleman MP, Lunet N. The state of the art of cancer control in 30 European countries in 2008. *Int J Cancer*. 2010;126:2700-2715.
- Gouveia J, Coleman M, Haward R, et al. Improving cancer control in the European Union: conclusions from the Lisbon round-table under the Portuguese EU Presidency, 2007. *Eur J Cancer*. 2007;44:1457-1462.
- Simonelli C, Annunziata MA, Chimenti E, Berretta M, Tirelli U. Cancer survivorship: a challenge for the European oncologists. *Ann Oncol*. 2008;19:1216-1217.
- Gjerset G, Fossa S, Courneya K, Skovlund E, Jacobsen AB, Thorsen L. Interest and preferences for exercise counselling and programming among Norwegian cancer survivors. *Eur J Cancer Care (Engl)*. 2011;20:96-105.
- Goransson P. Developing and integrating a cancer rehabilitation process in order to achieve a patient focused and coherent cancer care at hallnds hospital Halmstead: a pilot project. *Psychooncology*. 2011;20(Suppl S1):154.
- Mattioli V, Montanaro R, Romito F. The Italian response to cancer survivorship research and practice: developing an evidence base for reform. *J Cancer Surviv*. 2010;4:284-289.
- Rix B. A national strategy for cancer rehabilitation and palliative care in Denmark. *Psychooncology*. 2011;20(Suppl S1):236.
- Stein K, Syrjala K, Andrykowski M. Physical and psychological long-term and late effects of cancer. *Cancer*. 2008;112(suppl 11):2577-2592.
- Department of Health, Macmillan Cancer Support, NHS Improvement: National Cancer Survivorship Vision, 2010. [http://www.dh.gov.uk/en/publications and statistics\\_DH123371](http://www.dh.gov.uk/en/publications and statistics_DH123371).
- Elliott J, Fallows A, Staetsky L, et al. The health and well-being of cancer survivors in the UK: findings from a population survey. *Br J Cancer*. 2011;105(suppl 1):S11-S20.
- van de Poll-Franse L, Horevoorts N, van Eenbergen M, et al; Profiles Registry Group. The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer*. 2011;47:2188-2194.
- Csikai E, Walsh K, Allen F, et al. Best practices and challenges in psychosocial oncology in Hungary: outcomes of a professional exchange summit. *Psychooncology*. 2009;18(Suppl 2):S253-254.
- Heins M, Schellevis F, Rijken M, van der Hoek L, Korevaar J. Determinants of increased primary health care use in cancer survivors. *J Clin Oncol*. 2012;30:4155-4160.
- Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists: challenges to assuring access to oncology services. *J Oncol Pract*. 2007;3:79-86.
- McCabe M, Baker S, Huffman C, et al. Optimizing survivorship care: academic and community clinic models. In: Feurstein M, Ganz P, eds. Health Services for Cancer Survivors. New York: Springer; 2011:223-238.
- Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. 2006;24:5117-5124.
- McCabe MS, Jacobs LA. Clinical update: survivorship care-models and programs. *Semin Oncol Nurs*. 2012;28:e1-e8.
- Mao JJ, Bowman MA, Stricker CT, et al. Delivery of survivorship care by primary care physicians: the perspective of breast cancer patients. *J Clin Oncol*. 2009;27:933-938.
- McClellan M, McKethan AN, Lewis JL, Roski J, Fisher ES. A national strategy to put accountable care into practice. *Health Aff (Millwood)*. 2010;29:982-990.
- Chubak J, Tuzzio L, Hsu C, et al. Providing care for cancer survivors in integrated health care delivery systems: practices, challenges, and research opportunities. *J Oncol Pract*. 2012;8:184-189.
- Cox K, Wilson E, Heath L, Collier J, Jones L, Johnston I. Preferences for follow-up after treatment for lung cancer: assessing the nurse-led option. *Cancer Nurs*. 2006;29:176-187.
- Beaver K, Campbell M, Williamson S, et al. An exploratory randomized controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer. *Colorectal Dis*. 2012;14:1201-1209.
- Gage EA, Paillet M, Zevon MA, et al. Structuring survivorship care: discipline-specific clinician perspectives. *J Cancer Surviv*. 2011;5:217-225.
- Mayer DK, Gerstel A, Leak AN, Smith AK. Patient and provider preferences for survivorship care plans. *J Oncol Pract*. 2012;8:e80-e86.
- Mayer EL, Gropper AB, Neville BA, et al. Breast cancer survivors' perceptions of survivorship care options. *J Clin Oncol*. 2012;30:158-163.



37. Khan NF, Mant D, Rose PW. Quality of care for chronic diseases in a British cohort of long-term cancer survivors. *Ann Fam Med*. 2010;8:418-424.
38. Gilbert SM, Miller DC, Hollenbeck BK, Montie JE, Wei JT. Cancer survivorship: challenges and changing paradigms. *J Urol*. 2008;179:431-438.
39. Cockle-Hearne J, Faithfull S. Self-management for men surviving prostate cancer: a review of behavioural and psychosocial interventions to understand what strategies can work, for whom and in what circumstances. *Psychooncology*. 2010;19:909-922.
40. Berglund G, Petersson LM, Eriksson KC, et al. "Between Men": a psychosocial rehabilitation programme for men with prostate cancer. *Acta Oncol*. 2007;46:83-89.
41. May AM, Korstjens I, van Weert E, et al. Long-term effects on cancer survivors' quality of life of physical training versus physical training combined with cognitive-behavioral therapy: results from a randomized trial. *Support Care Cancer*. 2009;17:653-663.
42. Grahm C. Coping with the cancer experience. Developing an education and support programme for cancer patients and their significant others. *Eur J Cancer Care*. 1996;5:176-181.
43. Berat S, Djurdjevic A, Neskovic-Konstant Z, Vuckovic-Dekic Lj. Implementation of the European educational programme "Learning to live with cancer": how participants evaluate the seminars "Education of educators." *J BUON*. 2008;13:291-293.
44. Grahm G, Danielson M, Ulander K. Learning to live with cancer in European countries. *Cancer Nurs*. 1999;22:79-84.
45. van der Molen B, Hutchison G. Learning to live with cancer: the UK experience of a European patient education and support programme. *Eur J Cancer Care (Engl)*. 1999;8:170-173.
46. Trotter K, Schneider SM. Evaluation of a breast cancer survivorship clinic that uses a group medical appointment model: patient program evaluation and financial analysis. *ASCO Meeting Abstracts*. 2012;30:90.
47. EUROCHIP. Work Package-6 Indicators on Cancer Rehabilitation. Milan, Italy: Fondazione IRCCS "Istituto Nazionale dei Tumori"; 2012.
48. Department of Health: Living With and Beyond Cancer, Cancer Rehabilitation. London, UK: Department of Health; 2011.
49. Hellbom M, Bergelt C, Bergenmar M, et al. Cancer rehabilitation: a Nordic and European perspective. *Acta Oncol*. 2011;50:179-186.
50. Johansen C. Rehabilitation of cancer patients-research perspectives. *Acta Oncol*. 2007;46:441-445.
51. Rick O, Seifart U, Faber G, et al. Lung resection tumour patients and rehabilitation. *Onkologie*. 2011;17:933-939.
52. Schrock R. Rehabilitation of patients with ovarian cancer. *Onkologie*. 2006;12:444-450.
53. Bergelt C, Lehmann C, Beierlein V, et al. Patients assessment of inpatient and outpatient cancer rehabilitation. *Psychooncology*. 2009;18(Suppl 2):S48.
54. Di Fabio F, Koller M, Nascimbeni R, Talarico C, Salerni B. Long-term outcome after colorectal cancer resection. Patients' self-reported quality of life, sexual dysfunction and surgeons' awareness of patients' needs. *Tumori*. 2008;94:30-35.
55. Magrone G, Bozzone A, Romanelli A, et al. Rehabilitation and quality of life in patients undergoing surgery for esophageal cancer. *Rays*. 2006;31:13-16.
56. van de Poll-Franse LV, Nicolaije KA, Vos MC, et al. The impact of a cancer Survivorship Care Plan on gynecological cancer patient and health care provider reported outcomes (ROGY Care): study protocol for a pragmatic cluster randomized controlled trial. *Trials*. 2011;12:256.
57. Dergent T, Troch E, Vandebroek A, et al. Finding a new balance: a cancer rehabilitation program. *Psychooncology*. 2009;18(Suppl 2):S120.
58. Korstjens I, Mesters I, Van Der Peet E, Gijzen B, van den Borne B. Quality of life of cancer survivors after physical and psychosocial rehabilitation. *Eur J Cancer Prev*. 2006;15:541-547.
59. Hansen H, Tjornhoj-Thomsen T. Cancer rehabilitation in Denmark: the growth of a new narrative. *Med Anthropol Q*. 2008;22:360-380.
60. Hansen H, Tjornhoj-Thomsen T, Johansen C. Rehabilitation interventions for cancer survivors: the influence of context. *Acta Oncol*. 2011;50:259-264.
61. Genty M, Ribinik P, Frenay C, et al. Physical medicine and functional rehabilitation and cancer: state of the art and literature review. *Phys Rehab Med*. 2011;54:1877.
62. Robb K. Addressing consequences of treatment-the role of rehabilitation. *Eur J Cancer*. 2011;47:S61-S62.
63. Stubblefield M, O'Dell M. Cancer Rehabilitation: Principles and Practice. New York: Demos Medical Publishing; 2009.
64. Cheville AL, Kornblith AB, Basford JR. An examination of the causes for the underutilization of rehabilitation services among people with advanced cancer. *Am J Phys Med Rehabil*. 2011;90(5 suppl 1):S27-S37.
65. Fors E, Bertheussen G, Thune I, et al. Psychosocial interventions as part of breast cancer rehabilitation programs? Results from a systematic review. *Psychooncology*. 2011;20:909-918.
66. Mehnert A, Koch U. Distress among cancer patients during cancer rehabilitation: a prospective study using the German version of the NCCN distress thermometer. *Psychooncology*. 2011;20(Suppl 2):243.
67. Holzner B, Kemmler G, Kopp M, et al. Quality of life in breast cancer patients-not enough attention for long-term survivors? *Psychosomatics*. 2001;42:117-123.
68. Foster C, Fenlon D. Recovery and self-management support following primary cancer treatment. *Br J Cancer*. 2011;105(suppl 1):S21-S28.
69. Department of Health. The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century. London, UK: Her Majesty's Stationery Office; 2001.
70. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. *Eff Clin Pract*. 2001;4:256-262.
71. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns*. 2002;48:177-187.
72. Trotter K, Frazier A, Hendricks CK, Scarsella H. Innovation in survivor care: group visits. *Clin J Oncol Nurs*. 2011;15:E24-E33.
73. Granstam B, Lindemalm C, Ojutkangas M, et al. Support group intervention after breast cancer treatment: first results of a prospective randomized study. *Eur J Cancer*. 2010;8:80-81.
74. Faithfull S, Cockle-Hearne J, Khoo V. Self-management after prostate cancer treatment: evaluating the feasibility of providing a cognitive and behavioural programme for lower urinary tract symptoms. *BJU Int*. 2011;107:783-790.
75. Penedo FJ, Dahn JR, Molton I, et al. Cognitive-behavioral stress management improves stress-management skills and quality of life in men recovering from treatment of prostate carcinoma. *Cancer*. 2004;100:192-200.
76. Schnipper-Hassler U, Gonschewski R. Therapy of secondary effects in medical rehabilitation. *Gynakologe*. 2008;41:269-274.
77. Maher J, McConnell H. New pathways of care for cancer survivors: adding the numbers. *Br J Cancer*. 2011;105(suppl 1):S5-S10.
78. Stricker CT, Jacobs LA, Risendal B, et al. Survivorship care planning after the institute of medicine recommendations: how are we faring? *J Cancer Surviv*. 2011;5:358-370.
79. Hewitt M, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol*. 2007;25:2270-2273.
80. Jacobs LA, Palmer SC, Schwartz LA, et al. Adult cancer survivorship: evolution, research, and planning care. *CA Cancer J Clin*. 2009;59:391-410.
81. Faul LA, Shibata D, Townsend I, Jacobsen PB. Improving survivorship care for patients with colorectal cancer. *Cancer Control*. 2010;17:35-43.
82. Salz T, Oeffinger KC, McCabe MS, Layne TM, Bach PB. Survivorship care plans in research and practice. *CA Cancer J Clin*. 2012;62:101-117.
83. Merport A, Lemon SC, Nyambose J, Prout MN. The use of cancer treatment summaries and care plans among Massachusetts physicians. *Supportive Care Cancer*. 2012;20:1579-1583.
84. American College of Surgeons. Cancer Program Standards 2012, Version 1.1: Ensuring Patient-Centered Care. Chicago, IL: American College of Surgeons; 2012.