



Published in final edited form as:

*Lancet Oncol.* 2017 January ; 18(1): e39–e50. doi:10.1016/S1470-2045(16)30659-3.

## Provision of integrated psychosocial services for cancer survivors post-treatment

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### Abstract

Meeting the psychosocial needs of patients with cancer has been recognised as a priority within oncology care for several decades. Many approaches that address these needs have been developed and described; however, until recently much of this work had focused on patients during treatment and end-of-life care. With continued improvement in therapies, the population of cancer survivors who can expect to live for 5 or more years after cancer diagnosis has increased dramatically, as have associated concerns about how to meet their medical, psychosocial, and health behaviour needs after treatment. Guidelines and models for general survivorship care routinely address psychosocial needs, and similar guidelines for psychosocial care of patients with cancer are being extended to address the needs of survivors. In this Series paper, we summarise the existing recommendations for the provision of routine psychosocial care to survivors, as well as the challenges present in providing this care. We make specific recommendations for the integration of psychosocial services into survivorship care.

### Introduction

Survivorship is recognised as a specialty in oncology, within the continuum of care from prevention, through diagnosis and treatment to survivorship or end of life.<sup>1–6</sup> In the USA, 5-year relative survival after a diagnosis of invasive cancer now exceeds 67% for patients diagnosed between 2002–12.<sup>6</sup> As a result of this progress in the treatment of cancer, survivors will spend a large portion of their lives managing the consequences of their disease and its treatment on their health and wellbeing. Systematic reviews, meta-analyses, and large population-based reports have defined the needs of these survivors, and all recognise that a significant number (15–20%) of long-term survivors have clinically significant anxiety, depression, or post-traumatic stress disorder for 10 years after diagnosis, which remain higher than the general population.<sup>7–9</sup> However, at least 40% of cancer survivors have diverse, often subclinical or focal psychosocial and lifestyle needs, such as fear of

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#### Contributors

CJR did the literature search. Both authors had the concept, prepared the tables, and wrote the report.

#### Declaration of interests

We declare no competing interests.

recurrence, post-traumatic stress symptoms, or distress related to life changes such as persisting symptoms, altered body image, existential distress, social isolation or lack of support, or employment, insurance and other financial concerns. Simultaneously, they are also in need of interventions to ensure healthy behaviours including physical activity, sleep quality, alcohol limitation, smoking cessation, nutrition, and weight control.<sup>7–10</sup>

Despite progress in understanding the needs of survivors, models for survivorship care and practical applications with evident success in improving psychosocial outcomes for cancer survivors<sup>11</sup> are still needed. Although all guidelines for survivorship care recommend screening cancer survivors for psychosocial needs, few clinicians or researchers have grappled with how best to meet their complex psychosocial vulnerabilities, and even fewer provide a model for integrated services that directly meet their needs. In part, this gap is a result of insufficient clinical trials from which to build evidence-based interventions that target long-term survivors. Even guidelines that take on the challenges of integrated survivorship care often emphasise screening or other components of care rather than expressly defining models that could meet survivors' diverse psychosocial needs.<sup>3,4,12,13</sup>

In this Series paper, we focus on off-treatment cancer survivors, and summarise the progress achieved to understand and address their psychosocial needs. We also outline the work yet to be done to establish evidence-based models of integrated psychosocial care. After we address the scope of psychosocial needs common in post-treatment survivors, we summarise the published work on provision of behavioural health care, before addressing gaps in research and practice, the challenges in providing psychosocial health care, and recommendations for integrated survivorship care. To structure this paper, we focus on consensus reports and clinical practice guidelines that have been highly influential among clinicians and researchers (table 1), and publications specifically focused on how psychosocial care should be integrated into survivorship care (table 2). In reviewing and synthesising these publications, we acknowledge both the range of terms used to describe so-called psychosocial needs and the diversity of professionals who provide care to address them. The term psychosocial is often used broadly in the oncology context, and might include behavioural, psychological, psychiatric, emotional, and mental health functioning, as well as social and vocational function and lifestyle factors or health behaviours. According to convention from oncology and other areas of medical care, we refer to these terms as either psychosocial or behavioural health needs. Similarly, services to address these needs are provided by diverse disciplines. We use the terms psychosocial provider and behavioural health provider to refer to professionals who focus primarily on non-oncology care (eg, psychologists, psychiatrists, social workers, and chaplains); however, we recognise that advanced practice nurses, oncologists, primary care providers (PCPs), and other medical professionals also address psychosocial concerns.

## Psychosocial needs

A broad consensus exists that most cancer survivors adapt well after completing their cancer treatment.<sup>1,7,8,15,18,23,26,27</sup> Depending on the population, the timepoints at which patients are assessed, and the types and severity of problems evaluated, the proportion of survivors who have substantial psychosocial needs vary. However, most sources agree that somewhere

between 15% and 40% of survivors have prominent psychosocial needs.<sup>9,10,19,21</sup> The needs most commonly affecting these survivors can be conceptualised as falling into five broad areas.

### Psychological symptoms

Psychological issues most commonly identified as important for survivors include fear of recurrence,<sup>1,5,7,9,12,18–20,,22,23,26</sup> psychological distress, especially symptoms of anxiety and depression,<sup>1,4,5,7–10,12,18–23,26</sup> and post-traumatic stress.<sup>7,9,19–21,23,26</sup> Less commonly noted psychological issues include survivor guilt<sup>9,19</sup> and spiritual or existential concerns.<sup>1,5,19,23</sup> The severity of these psychological symptoms varies widely. Most cancer survivors presenting with psychological problems in oncology settings will not have major mental illnesses (eg, major depression or schizophrenia), but are more likely to have less severe diagnoses (eg, adjustment reaction, minor depression, or dysthymia) or to have symptoms that do not meet the threshold for psychiatric diagnoses.<sup>23,27–29</sup>

### Social and vocational adjustment

During cancer treatment, many patients experience limitations in their ability to fulfil their usual social, familial, and vocational commitments,<sup>30–32</sup> and after treatment these limitations might continue or new challenges might arise as the patients reintegrate socially or at work. Difficulty returning to work is widely recognised as a major problem for cancer survivors,<sup>1,5,7,9,10,12,15,18–23,26</sup> especially as reintegration can have serious financial implications.<sup>5,7,20</sup> Young survivors (ie, from childhood through young adulthood) are in phases of life when they would normally be acquiring many new skills and abilities, making them especially vulnerable to disruptions in normative development, including any cognitive changes associated with treatment.<sup>3,6,15</sup> Young patients with cancer often need to rely on parents and family support during treatment. When treatment is over, these patients might find it difficult to catch up with peers, who have taken on new social roles and become more financially and socially independent.<sup>26,33</sup> This difficulty can be particularly true if disruptions in education or early work opportunities have also occurred, since these can affect both a sense of independence and achievement and can have a lasting effect on survivors' careers, their financial earning potential, and their ability to form long-term relationships.<sup>3,6,15</sup>

### Lifestyle changes

Cancer survivors might be motivated by their cancer experiences, or by the recommendations from health providers, to make lifestyle changes to improve or maintain their health. The literature on cancer survivorship widely notes the need to support change in physical activity, nutrition, and weight management,<sup>1,4,5,7,10,12,17,20,22,26</sup> along with smoking cessation.<sup>1,5,10,12,22</sup> Other health behaviours, such as moderating sun protection<sup>5</sup> or monitoring alcohol use,<sup>5,22</sup> are discussed less frequently, and the issue of substance misuse is notably absent, although some reports suggest these risks warrant further investigation.<sup>34,35</sup> Although helping individuals to make and maintain long-term behavioural change is challenging,<sup>36</sup> several interventions for cancer survivors in this area have reported promising results.<sup>37,38</sup> Psychosocial practice, however, needs to continue to include support for survivors in helping them to make lifestyle changes.

### Stress caused by off-treatment transitions

The end of active cancer treatment is very stressful for many patients, who often experience anxiety about recurrence, concerns about lingering physical symptoms, uncertainty about their future, and worry about managing their health needs with less support and medical supervision.<sup>5,7,16,18,20,21,26</sup> Issues that survivors put on hold during treatment (eg, financial problems, education, career decisions, and marital discord) might re-emerge, and new issues such as disclosure of cancer history might arise. As Holland and Reznik<sup>19</sup> note, patients with cancer who are temporarily relieved of their usual role demands during active treatment, can be re-exposed to these expectations as soon as treatment ends and others view them as 'cured'. Cancer survivors can feel overwhelmed at the thought of immediately resuming work or family duties, especially if they are experiencing residual treatment-related symptoms. Alternatively, some survivors can feel ready to return to these roles but find other people hesitant or overly protective toward them.<sup>19</sup> These mismatches between survivor readiness and role expectations can contribute to family and social adjustment problems confronting survivors.<sup>9,12,18-22</sup> Although the transition from active treatment to the early off-treatment phase of care has received the most attention, other common life transitions can be associated with re-emergence of cancer-related concerns including change in medical providers, employment, or relationships.<sup>5,23</sup>

### Coping with late effects of medical treatment

The oncology community has widely accepted the importance of addressing late effects of medical treatment. With this acknowledgement, investigators have recognised the close connection between physical and mental wellbeing, as evidenced in the study of several conditions such as cancer-related fatigue, sexual dysfunction, pain, infertility, cognitive dysfunction, and disrupted body image.<sup>1,4,5,7,9,10,12,18-23,26</sup> Surprisingly, although insomnia and other sleep problems are prevalent in cancer survivors,<sup>39</sup> only a few guidelines highlight treatments for them.<sup>4</sup> Cancer survivors generally anticipate that after treatment is complete, they will feel better. Any continuation of some symptoms or emergence of new ones, therefore, can be a source of substantial stress, especially if the conditions are likely to be chronic. Survivors burdened by the late effects of medical treatment often report feeling that "it is not over when it is over"<sup>20</sup>, which reflects a disappointing irony that cure from cancer does not guarantee good health. When survivors are informed of their increased risks for subsequent cancers, as well as late effects of medical treatments (such as cardiomyopathy and lymphoedema), uncertainty and an increased sense of vulnerability might be added to their fear of cancer recurrence. Psychosocial clinicians need to be familiar with these late effects of medical treatments and appreciate their potential consequences because many affected cancer survivors will benefit from behavioural therapy. For example, studies have shown how survivors with fatigue,<sup>40,41</sup> insomnia,<sup>42</sup> and sexual dysfunction<sup>43</sup> can benefit from behavioural treatments. Although empirical support for behavioural intervention is less clear for survivors with other ongoing medical conditions, they are likely to benefit from behavioural interventions to more effectively manage their health needs and cope with any illness-related stress.

Although presented in this report as distinct types of challenges, these common psychosocial concerns are most often linked to each other and to physical functioning in notable ways.

For example, any serious physical problems can have a prominent negative effect on survivors' employment, finances, mood, or physical activity—and each of these can increase their sense of loss and isolation.<sup>10,19,20,26</sup>

## Provision of psychosocial care

The published work on the integration of psychosocial care into routine survivorship care has focused on defining essential services that can address the broad range of issues survivors can face, and to a lesser extent, addresses the need for models of integrated behavioural health services within survivorship care.

## Psychosocial assessment and screening

Because most cancer survivors are not expected to have prominent behavioural or psychosocial needs, identification of those individuals who do have these needs is crucially important. Some kind of case identification is widely recognised as an essential function of behavioural health providers working with survivors.<sup>4,5,7,9,12–14,17–20,22,26,44</sup> Identification of psychological symptoms or psychiatric diagnoses (in contrast to social, vocational, or lifestyle needs) has been the main focus in this area, with particular attention to symptoms of depression, anxiety, post-traumatic stress, or distress. Guidelines for survivorship care advocate for the assessment of psychological adjustment as part of routine care, but some offer little information about domains that should be assessed and questions that should be asked,<sup>1,3</sup> whereas others offer examples of several different assessment approaches with little guidance on how to select an appropriate assessment tool.<sup>12,13</sup> Guidelines for psychosocial care during active treatment, conversely, have highlighted the potential use of specific self-reported checklist measures, with the National Comprehensive Cancer Network Distress Management guidelines<sup>14</sup> having been influential in promoting use of the single item Distress Thermometer for patients with cancer. On the basis of these guidelines, many of these methods have been used for survivors, although some studies indicate that these instruments might not function as they do in patients on active treatment, and therefore their validity cannot be guaranteed for this population.<sup>45,46</sup> As part of survivorship care planning, experts have endorsed a broad behavioural assessment that includes survivors' psychological, symptom, financial, social, vocational, and health behaviour needs.<sup>1–4,16,24</sup>

## Survivorship care plans

A survivorship care plan that includes psychosocial issues is widely viewed as crucial in ensuring the provision of high-quality survivor care.<sup>1,4,5,12,13,17–22,26,44</sup> The care plan is intended to serve as a so-called road map for post-treatment health care and consists of a treatment summary, an assessment of current needs, and recommended follow-up.<sup>1</sup> Since survivorship care can involve PCPs as well as oncologists and other specialists, the care plan is seen as a crucial tool for sharing medical information between health-care providers, and as a means of educating survivors directly about their medical and psychosocial needs. By informing survivors about common concerns after treatment completion and their follow-up surveillance schedules, and providing information about survivorship resources, the care plan itself can provide a meaningful intervention. Additionally, because care planning typically occurs at the end of cancer therapy, it might provide a timely opportunity to

address concerns in the early off-treatment transition. In particular, Jacobsen<sup>22</sup> describes the survivorship care plan as an organisational feature of psychosocial care for survivors, with the process of care planning providing anticipatory guidance and education, as well as assessment and referral to recommended interventions or supportive resources.

### Referral to appropriate resources

As part of survivorship care planning, providers are expected to make referrals for health care, including mental health treatment, support groups, and lifestyle interventions (eg, smoking cessation and participation in physical activity programmes).<sup>1,2,12,16</sup> Although a few survivors with acute needs will benefit most from intensive professionally led interventions, most survivors will benefit from self-help programmes, advocacy groups, educational programmes, activity-based programmes, stress management or mindfulness programmes, and support groups.<sup>9,15,17,22,23</sup> In addition to referring survivors to services in accordance with their present needs, support also exists for routinely referring survivors to advocacy and support resources independent of any identified needs.<sup>2,5,7,12,17,18,22,23,47</sup> Provision of information about community-based programmes, especially those available online and by phone, is widely recommended<sup>1,5,7,10,22,23</sup> to ensure access for those limited by finances or who live far from cancer centres.<sup>2,7,23</sup> Cancer survivors who receive treatment in community settings typically do not have access to the same services offered at major cancer centres, and even survivors treated at large cancer centres can find it difficult to access services once they resume their normal daily activities. Moreover, since most patients with cancer will live at least 5 years after diagnosis, with many living for much longer, they can expect to face new health challenges over time. Consequently, resources that provide access to education and advocacy programmes can help survivors with identified needs to normalise the experience of post-treatment challenges, and prepare survivors for issues that might emerge later in their survivorship.

### Integration of psychosocial care into survivorship care

Almost all discussions about improving the behavioural health care for cancer survivors acknowledge the need for the integration of behavioural health into routine survivorship care.<sup>1,2,16,17,19,21,22</sup> On a practical level, this integration is a means to ensure that these needs are not overlooked, and for the improvement of survivorship care overall. Incorporation of behavioural assessments as a routine medical follow-up helps to ensure that they are completed regularly and become part of the medical record (table 3). Because survivorship care plans are shared by several health-care providers, as well as with survivors themselves, incorporation of behavioural considerations into this plan is an essential element to promote coordination of care.<sup>2,15,17,22,24,25,48,49</sup>

Promotion of patient-provider communication about behavioural concerns is essential for the delivery of integrated care.<sup>1,2,16,17,49</sup> Most oncologists and PCPs consider addressing behavioural issues as an important part of the care that they provide to survivors.<sup>24,25</sup> Behavioural health providers should support and augment medical providers' behavioural care by integrating behavioural assessments into existing patient completed history forms, coaching providers on methods for inquiring on behavioural topics, promoting use of validated assessment methods, defining referral pathways, and providing education and



consultation to providers and patients.<sup>17,23,33,48–51</sup> Co-location of behavioural health providers with medical providers in the survivorship setting can decrease stigma and remove barriers to care (eg, scheduling and transportation)<sup>2,23,49</sup> and can also increase informal communication and trust between providers from different disciplines.<sup>2,52</sup> Conversely, joint meetings and conferences<sup>2,51</sup> and shared medical records<sup>2,17,45,49</sup> should improve formal communication. Additionally, case management and navigation services<sup>49</sup> have been recommended to further integrate behavioural and medical care for survivors, and to increase the likelihood that survivors will follow up on recommended care<sup>2</sup> (table 3 provides additional details on steps to promote integration). Several existing programmes indicate how these steps can be applied in clinical settings.<sup>2,23,51</sup> For example, the 2008 Institute of Medicine Report<sup>2</sup> described three clinics implementing different approaches to providing psychosocial care for patients with cancer, including one highly integrated model. Similarly, Coscarelli and colleagues<sup>23</sup> described two clinics with different approaches for integrating psychosocial care into a survivorship programme. Together, these programmes offer practical examples of how these methods can be used to support the integration of behavioural health into routine survivorship care.

## Challenges and future directions

Psychosocial needs are recognised as crucial components of all phases of cancer care,<sup>2</sup> yet substantial challenges still persist in the integration of psychosocial care with other elements of survivorship care. To some extent, these integration efforts face many of the well documented systemic impediments to integrated health care in general.<sup>52–54</sup> Limited reimbursement or complex billing requirements can restrict the availability of behavioural health providers, as well as hinder integration efforts such as co-location.<sup>25</sup> However, the Oncology Care Model, an innovative payment model initiated in 2016 to improve care for Medicaid recipients receiving chemotherapy,<sup>55</sup> specifically promotes integrated care, including psychosocial services. If proven to be effective and extended to include post-treatment care, this model could greatly benefit survivors. The fact that oncologists, nurses, and PCPs view attending to behavioural issues as part of their role bodes well for integration, but limited time and staffing can impede their ability to attend to behavioural needs.<sup>18,23,48</sup> The ageing population in the USA<sup>56</sup> will further challenge the oncology and primary care workforce to care for both on-treatment and off-treatment patients. Additionally, oncologists and PCPs vary widely in their preparation for attending to these needs, with studies suggesting that many lack confidence in responding to mental health or sexual health problems.<sup>24,57,58</sup> Stigma and discomfort in discussing mental health issues continue to be a barrier,<sup>49,53,59</sup> since both survivors and providers might prefer to focus on physical concerns, especially in a brief medical appointment. Finally, to ask medical or behavioural providers to make changes in workflow, scheduling, and physical location raises a number of so-called turf issues that can impede integration efforts, especially if these changes diminish providers' prestige or financial rewards.<sup>16,25,53</sup>

In addition to systemic impediments, the unique needs of cancer survivors can themselves be challenges to integrated care. For example, as reviewed in this Series paper, psychosocial needs can be very broad, creating a substantial challenge for individual providers and care systems that need to be prepared to deal with a wide range of behavioural health needs and

at different levels of acuity. Survivors' needs are also dynamic and likely to change over the course of the survivorship period, necessitating ongoing assessments. Unlike patients receiving active treatment, survivors are seen less frequently for medical appointments and are more mobile in the medical system, with many receiving their care outside of oncology settings, which creates substantial challenges with regard to how, when, and where they should be assessed and treated.<sup>4,10,19,21,22,48</sup>

Simultaneously, provision of psychosocial care is thinly stretched in many oncology settings, and such care tends to be focused on patients during cancer treatment. Since survivors' psychosocial needs are not the same as those receiving active treatment,<sup>22</sup> even psychosocial providers who are experienced in caring for patients during treatment might not be fully prepared to address their survivorship needs. Some survivors will have complex biopsychosocial needs that require an appreciation of both the physical and emotional challenges of cancer and recovery,<sup>10,19</sup> which can make it difficult for them to find appropriate treatment in mental health settings. Rehabilitation services, which are needed by some survivors, are often separate from oncology care, which introduces another potential barrier to access and integrated care. To address these workforce issues, psychosocial providers need to be integrated into oncology settings, and more education about the needs of cancer survivors will be needed for mental health providers, oncologists, PCPs, and nurses. Innovative educational programmes for physicians, nurses, and psychosocial providers have been developed as part of training curricula<sup>60–62</sup> and continuing professional education<sup>63,64</sup> to address this requirement, but their quality and accessibility need to be ensured to educate the workforce at large.

A broader scope of research is essential to understand and address the psychosocial needs of all cancer survivors. In particular, research needs to be expanded to include survivors from a broad range of diagnoses and cultural backgrounds.<sup>10,22,26,48</sup> Adolescent and young adult survivors (commonly defined as age 15–39 years) are an important group to study because their psychosocial burden is often high.<sup>6,19,26,48</sup> The elderly survivor population, particularly those older than 65 years, is increasing rapidly and has unique psychosocial needs, making them another high-priority group to study.<sup>10,26,56</sup>

To better guide the implementation of services for survivors, intervention research should focus on survivors with needs that are clearly demonstrated. Compared with studies that accept all survivors regardless of clinical indication or need, those that target survivors with specific problems have shown larger treatment effects<sup>10,20,22,26,48</sup> and are likely to make better use of finite resources. Low-intensity interventions, including group interventions, home-based and web-based interventions, self-help programmes, and telehealth interventions might be best suited to meeting the needs of many survivors.<sup>2,7,10</sup> Stepped-care models, using low-intensity interventions as a first-level intervention and reserving more intensive interventions for non-responders,<sup>10,16,49</sup> might be especially important to develop and study. Although eHealth and mobile health treatment approaches could be particularly successful at increasing access to care, more research is needed to carefully investigate their effectiveness and the extent to which survivors engage with and adhere to them.<sup>2,26,65,66</sup>



Additionally, the research agenda should be broadened beyond specific interventions to include pathways of psychosocial care that more closely resemble care delivered in clinical settings.<sup>10,22,24,49</sup> For example, investigations of care for survivors with depression should examine the effectiveness of an integrated pathway that includes all relevant components (ie, screening, treatment planning, referral, intervention, relapse prevention, and follow-up). Because the effectiveness of each component for the treatment of depression depends on the others (eg, referral procedures improve outcomes only if assessment is accurate and treatment is effective), this process is the most meaningful way to evaluate clinical effectiveness. The importance of studying costs of psychosocial care for survivors is well recognised.<sup>10,22,49,67</sup> Despite the fact that survivor surveys report high levels of unmet psychosocial needs, behavioural interventions for survivors are often undersubscribed, leading to calls for more scrupulous study of barriers to care.<sup>10,20,49</sup> Low uptake is probably a complex phenomenon—which is indicative of problematic barriers to care needed in some survivors, and successful resumption of the demands of so-called normal life for others. Work, family obligations, or even leisure activities can compete with time for psychosocial interventions, especially if these are recommended by providers but not strongly desired by survivors. To understand this issue in full, and guide development of services with a substantial effect on survivors' adjustment, it will be beneficial to assess the severity of survivors' needs and their interest in getting help,<sup>68,69</sup> as well as the other competing needs they are working to meet.

Guidelines and consensus reports have been crucially important in promoting the integration of psychosocial care for survivors, but empirical assessment of the interventions they endorse remains very scarce.<sup>11,22</sup> For example, in response to guidelines, several different survivorship care plans are being used to guide psychosocial care, but there is little empirical evidence to support their effectiveness.<sup>22,48</sup> Similarly, psychological screening is being done with a range of screening approaches<sup>68</sup> that have not been validated against gold-standard psychiatric-structured interviews in cancer survivors.<sup>22,48,70–72</sup> Psychosocial services for cancer survivors cannot wait for these interventions to be fully evaluated, but it is important that they are critically appraised and tested, even as they are being adopted, to meet their immediate needs.<sup>11,73,74</sup> Ideally, survivorship programmes should be able to implement recommended care in ways that serve both the short-term goal of achieving compliance and the long-term goal of assessing which interventions are clinically effective. Unfortunately, once clinical practices become standard of care, or are mandated by payers or regulators, they are difficult to empirically study because patients and providers might be unwilling to accept the kind of no-treatment comparisons that are most useful for empirical testing. Additionally, after investing substantial time and resources to implement these new procedures, programmes might be inclined to celebrate their achievement and reluctant to critically assess their methods and results. For guidelines that are not evidence based, initial adoption in demonstration projects and clinical trials that aim to improve implementation methods and evaluate costs and benefits might be more prudent than full-scale universal adoption.

Efforts to provide integrated behavioural health care for cancer survivors are also challenged by the variability in models and approaches to survivorship medical care.<sup>2,52,75</sup> Models of psychosocial care for cancer survivors need to be general enough to apply to a wide range of

settings (eg, primary care, community oncology, comprehensive cancer centres); consequently, they might not include specific details about implementation. For example, the widely referenced psychosocial care model introduced by the Institute of Medicine in a 2008 report<sup>2</sup> highlights important activities such as “identifying strategies to address needs” or “providing emotional support” but does not specify how these goals should be accomplished, by what kinds of providers, and in what settings. Future guidelines will be most useful if they can help providers across settings identify specific practices that are best for meeting these needs; provide a framework for assessing, selecting, and evaluating practices and interventions; and support demonstration projects and clinical research to build evidence to guide care for survivors.

The broad consensus on common psychosocial needs and key strategies to address them should serve as a foundation for survivorship programmes to develop and test strategies for delivering integrated psychosocial care. Based on individual needs and resources, some survivors might need integrated psychosocial care in the survivorship setting, while others might not. Holland and Reznik,<sup>19</sup> for example, suggest that survivors with physical health problems that prominently contribute to adjustment issues will benefit from psychosocial care that is integrated with their medical care. Conversely, survivors with no substantial physical health problems might benefit from community-based care or specialty mental health care, depending on the severity of their psychological symptoms. Individual survivorship programmes will need to develop priorities based both on survivors’ needs and the availability of resources in the community, in primary care, and in specialty mental health programmes. Fear of recurrence, for example, is prevalent in the survivor population, and is unlikely to be adequately addressed in other settings, making it important for survivorship programmes to directly address this issue. By contrast, if cognitive behavioural therapy for panic disorders or exercise programmes are already available in other settings, and can be shown to be effective in survivors, these treatments might not be needed in survivorship programmes. For example, referral of survivors to smoking cessation programmes in the community or in primary care is probably more cost-effective and sustainable than attempting to develop new programmes specific for survivors. Individual survivorship programmes are best situated to decide what services to provide or to not provide in their setting, but guidelines set by professional or accrediting groups will be advantageous for ensuring provision of quality care for survivors. Programmes that assess survivors for psychosocial needs and refer out to local or remote treatment programmes and resources have been described;<sup>2,23</sup> if shown to be effective, these types of programmes will be useful in establishing minimum requirements for survivorship care.

New models for integrated psychosocial care will need to adapt to the ongoing evolution in survivorship medical care, but can benefit from existing psychosocial programmes<sup>2,23,51</sup> and the substantial integration work already done in other medical settings.<sup>28,48,49,76</sup> Of the many integrated care models developed for general medicine, several, including the chronic care model, rehabilitation model, the medical home, the illness self-management model, and collaborative care models, have been proposed as guides for survivorship behavioural health<sup>2,10,26,77,78</sup> (table 4). Although no model has shown broad applicability to psychosocial care for survivors, several have shown efficacy for patients with cancer during treatment,<sup>49,94,95</sup> and might be valuable for the development of similar interventions for

survivors. Behavioural health providers working in primary care face many of the challenges described in this Series paper, including having to anticipate a wide variety of patient needs, serving a population at risk for several medical co-morbidities, working in complex care settings, limited reimbursement, and other systemic challenges. In response, primary care behavioural health programmes have developed consultation models that aim not to reproduce specialty mental health care services, but to provide behavioural consultation to PCPs, and a selective number of highly accessible mental health services to patients in the primary care setting.<sup>28,48,49,76,96</sup> These models will be highly instructive for guiding future approaches to survivorship psychosocial care. In particular, the successful implementation of the Primary Care Behavioral Health Model<sup>76</sup> and the Primary Care–Mental Health Integration initiative<sup>97</sup> in several large health-care organisations<sup>76,96</sup> have produced a wealth of practice strategies and tools, including assessment measures, job descriptions, evidence-based interventions, clinical pathways, quality indicators, and scheduling and follow-up procedures. Rather than taking a so-called reinvent the wheel approach, adaptation and testing of these methods for survivorship settings should be a priority since they represent an important opportunity for rapidly improving clinical care for survivors, and developing an evidence base to guide future innovation.

## Conclusion

The psychosocial needs of cancer survivors are well defined, but are also complex, with numerous barriers to provision of care for these needs. Although psychosocial care is a top priority in every survivorship guideline, methods for integrating this care into oncology or other settings has not been well elaborated or tested. An integrated care model, building from models effective in primary care in chronic disease, holds promise for survivorship programmes and should be tested both in demonstration programmes and in clinical trial research.

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### Search strategy and selection criteria

We searched MEDLINE for published work that included three terms in their abstract or title: (1) “cancer survivors”; (2) “guidelines”, or “integrating”, or “integrated”, or “models of care”; and (3) “psychosocial”, or “mental health”, or “emotional”, or “distress”. The date of the last search was June 6, 2016. The reference lists from retrieved publications were hand searched, as were authors’ own files, to identify additional publications. Publications that reported mainly about health-care delivery outside the USA and those not in the English language were excluded.

**Table 1**

Reports and practice guidelines relevant to the psychosocial care of cancer survivors

	Article type	Population focus	Brief description
<b>1999</b>			
National Comprehensive Cancer Network. NCCN clinical practice guidelines in oncology: distress management <sup>14*</sup>	Clinical practice guideline	Adult patients with cancer	Guidelines for the assessment and management of the psychosocial needs of patients with cancer, as well as an overview of psychosocial needs of patients with cancer, available treatment methods and standards of care
<b>2003</b>			
Institute of Medicine. Childhood cancer survivorship — improving care and quality of life <sup>15</sup>	Consensus report	Survivors of childhood cancer throughout lifespan	Summary of medical and psychosocial effects of paediatric cancer, defines essential elements of quality care, reviews current research, and makes recommendations to improve care and outcomes for survivors
<b>2004</b>			
Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancer <sup>3†</sup>	Clinical practice guideline	Survivors of childhood cancer throughout lifespan	Provides recommendations for screening and management of medical and psychosocial late effects of children treated for cancer
President's Cancer Panel. Living beyond cancer: finding a new balance. President's Cancer Panel 2003–2004 annual report <sup>5</sup>	Consensus report based on stakeholder testimony	Cancer survivors throughout lifespan	Makes recommendations based on testimony from survivors, health-care professionals, caregivers, and advocates; describes common challenges encountered by survivors diagnosed at different ages; and makes recommendations for clinical care, research, and public policy
Institute of Medicine. Meeting psychosocial needs of women with breast cancer <sup>16</sup>	Consensus report	Female breast cancer survivors	Reviews the psychosocial effects of breast cancer, critically reviews available psychosocial services and related research, and makes recommendations to improve quality of care and quality of life outcomes
<b>2006</b>			
Institute of Medicine. From cancer patient to cancer survivor: lost in translation <sup>1</sup>	Consensus report	Survivors of adult cancers	Summary of medical and psychosocial consequences of cancer including definition of quality indicators for care following primary cancer treatment, and recommendations for improving care for survivors. Raises awareness of the medical, functional, and psychosocial consequences of cancer and its treatment
<b>2008</b>			
Institute of Medicine. Cancer care for the whole patient: meeting psychosocial health needs <sup>2</sup>	Consensus report	Adult patients with cancer during treatment	Describes availability and effectiveness of psychosocial care for patients with cancer, proposes a model for delivering psychosocial care, and makes recommendations for research, policy, and education to help improve the availability and quality of these services
<b>2011</b>			
Rechis et al. The essential elements of survivorship care: a LIVESTRONG brief <sup>17</sup>	Consensus report	Cancer survivors throughout lifespan	Summary of a meeting of more than 150 survivors, health-care providers, and other stakeholders, and their consensus statement

Article type	Population focus	Brief description
		about the essential elements of survivorship care delivery
<b>2013</b>		
National Comprehensive Cancer Network. NCCN guidelines in oncology: survivorship <sup>4,*</sup>	Clinical practice guideline	Cancer survivors
		Overview of survivorship care standards; provides recommendations for screening assessment and treatment for common medical and psychosocial late effects of cancer
<b>2014</b>		
Andersen et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology Guideline adaptation <sup>18</sup>	Clinical practice guideline	Adult patients with cancer and survivors
		Recommends routine assessment of anxiety and depression with standardised assessments, and follow-up care recommendations that are targeted to assessment results

\* Revision published in 2016.

<sup>†</sup> Revision published in 2013.

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**Table 2**

## Publications on provision of psychosocial care to cancer survivors

<b>Brief description</b>	
<b>2005</b>	
Holland and Reznik <sup>19</sup>	Proposes to extend the National Comprehensive Cancer Network guidelines <sup>16</sup> for distress management in cancer survivors
<b>2006</b>	
Alfano and Rowland <sup>20</sup>	Summarises common psychosocial challenges for survivors, offers a critique of current research, and makes recommendations for steps to improve care for survivors
<b>2008</b>	
Holland and Weiss <sup>21</sup>	Summarises recommendations for psychosocial care from the 2008 Institute of Medicine report, <sup>2</sup> and briefly notes how they can be used to support psychosocial care of survivors specifically
<b>2009</b>	
Jacobsen <sup>22</sup>	Reviews the concept of clinical practice guidelines and existing guidelines for psychosocial care, noting these do not focus on needs of survivors. Also notes that calls for survivorship care planning and practice guidelines for post-treatment oncology care can help to guide development of psychosocial care guidelines specific to survivors
<b>2011</b>	
Coscarelli et al <sup>23</sup>	Part of an edited volume on health services for cancer survivors; this chapter reviews the published work on risk factors and adjustment problems in survivors, summarises assessment methods and intervention strategies, and describes strategies to support integration of psychosocial care into survivorship care
<b>2012</b>	
Stanton <sup>7</sup>	Reviews the published work on psychosocial needs of survivors and the evidence supporting interventions to address them. Recommendations for implementation and future research are also included
Forsythe et al <sup>24</sup>	Results of a survey of a national sample of oncologists and primary care physicians about their perceived role in providing psychosocial care to survivors of breast and colon cancer, as well as their knowledge and confidence in providing this care
Chubak et al <sup>25</sup>	Qualitative study of 48 oncology providers, working at one of ten large integrated health-care delivery systems in the USA, who were asked to describe how survivors are cared for in their clinical setting
<b>2014</b>	
Aaronson et al <sup>10</sup>	Overview of common psychosocial issues in survivors, supportive care and health behaviour interventions, methods for assessing survivors' health-related quality of life, and use of cancer registries to support survivor research and some recommendations for care and research
<b>2015</b>	
Stanton et al <sup>26</sup>	Describes both physical and psychological health effects of cancer and summarises common challenges experienced by survivors and the behavioural interventions available to treat them. Recommendations for psychological research and clinical practice to address survivors' needs
<b>2016</b>	
Syrjala et al <sup>9</sup>	Begins with a summary of common psychosocial issues and associated risk factors, and provides a succinct overview of the published work about psychosocial needs and interventions for adult cancer survivors



**Table 3**

Steps for integration of mental health services in a survivorship model of care

	<b>Goal of step</b>	<b>Requirements to reach goal</b>
Define psychosocial needs and health behaviours to be screened and then treated or referred	Define parameters for what is and is not part of the care offered to survivors	Understand internal and external expertise and resources
Select assessment methods	Make psychosocial and health behaviour evaluation and monitoring a routine component of survivorship care	Define clinically relevant measures, methods of measurement (online and other options), remote or local, and assessment timepoint(s)
Identify survivors requiring psychosocial or health behaviour intervention	Designate screening and triage plan	Designate markers for moving from screening to intervention: select measures with clinically relevant cutpoints indicating need for services; ensure measures are scored in real time with triage pathways defined for specific raised scores, including when behavioural health providers are included in care. Ensure results are accessible and visually clear for health-care providers. Define feedback and access to results for survivors to improve patient-provider communication
Include psychosocial needs in survivorship care plan	Highlight psychosocial needs as part of comprehensive care and ensure needs and interventions to address them are understood by all providers	Prepare survivorship care plans with input from psychosocial providers. Provide survivors with comprehensive survivorship care plans that include psychosocial needs
Promote patient-provider communication	Facilitate intervention understanding, shared decision making, and follow through on the care plan	Coach providers in communicating and following up on psychosocial screening results. Incorporate psychosocial needs in medical history forms completed by patients and providers. Define potential pathways for care based on screening results and patient factors (eg, resource access, finances, reluctance, or other barriers to mental health care)
Establish co-location of care for survivorship specialist and behavioural health provider	Remove stigma and other barriers to initiation of care	Ideally, the behavioural health provider should be near the survivorship clinic for connecting when needed for a so-called curbside consult or meeting patients with needs beyond the survivorship clinician's expertise or the goal of the visit. Reduce barriers to care through accessibility in real time of behavioural health specialists for a so-called warm hand-off that includes a personal introduction, description of services, and arrangement for an immediate or follow-up visit, or a personal introduction to reduce barriers known to inhibit follow-up when referrals are made
Establish multidisciplinary meetings and case conferences, that include psychosocial and medical providers	Promote team building and integration of psychosocial and medical perspectives on survivorship care	Hold regular meetings in which survivors are discussed by a multidisciplinary team
Include psychosocial information in a shared medical record	Ensure that all providers have access to pertinent information about survivors' psychosocial needs and related interventions	Shared medical records that include both medical and psychosocial information that is available to providers within the practice
Include case management and navigation services as routine preparation for survivorship visits	Anticipate and prepare resources to meet survivors' needs	Review screening and intervention pathway plans in regular case management meetings. Share medical records to improve formal communication and follow through. Use navigation services to assist providers and survivors in finding resources that fit their needs
Address financial barriers directly	Reduce finances as a barrier to access to any care	Identify free or low-cost services or resources locally or nationally through online or telehealth methods that might provide alternative options if cost is a barrier to care

	<b>Goal of step</b>	<b>Requirements to reach goal</b>
Prepare a range of referral resources for specialised care as well as other needs (eg, financial or stigma barriers)	Reduce barriers to care that result from lack of identified resources to address survivors' complex needs, including medical, psychosocial, material, and non-health-related needs	Identify mental health, community, and national resources that might respond to a variety of survivors' social, emotional, and health behaviour needs, including self-help, home-based, and online resources that are available outside the typical health-care setting
Plan for psychosocial follow-up	Avoid survivors becoming lost or forgotten after referrals or transitions in care	Specify a plan for routine follow-up to check on implementation of care plan, including who will do it and at what frequency, and how changes in the plan will be recorded and communicated
Specify roles and responsibilities of survivorship providers, including behavioural health providers	Prevent so-called turf issues and avoid gaps in care from assumptions about who will do what in relation to providing follow-up care	Discuss and periodically review the steps above and how the providers will interact and communicate regarding the care of survivors. Clarify the areas of mental health care provided by the survivorship clinician and when referrals will be made to the behavioural health clinician or to other resources, recognising that these might vary by individual need and might change over time for individual patients

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**Table 4**

Medical care models relevant to psychosocial care for cancer survivors

	<b>Model</b>	<b>Brief description</b>
Author Manuscript	Robinson and Reiter (2007); <sup>76</sup> Funderburk et al (2013); <sup>79</sup> Tsan et al (2012) <sup>80</sup>	Primary Care Behavioral Health Model and Primary Care–Mental Health Integration initiative In these care models, behavioural health providers are placed into primary care settings to work collaboratively with the primary care team to provide integrated mental health care. The role of the behavioural health provider includes providing assessment, consultation, and brief focused mental health care in the primary care setting, as well as referral to mental health specialty care when needed
	Alfano et al (2012); <sup>77</sup> Wade and de Jong (2000) <sup>81</sup>	Rehabilitation model The rehabilitation approach emphasises an integrated approach to care aimed at helping patients to maximise their functioning across physical, social, psychological, and vocational or educational domains. The rehabilitation model emphasises the need to assess the overall burden of symptoms and to provide coordinated care, an emphasis on optimising function, and the importance of patient education and self-management
Author Manuscript	Coleman et al (2009); <sup>82</sup> Adams et al (2007) <sup>83</sup>	Chronic care model The chronic care model is designed to improve care for patients with chronic disease by providing planned and proactive outpatient care to minimise the need for acute and reactive interventions. The model advocates changes in care delivery, health-care organisation structure, increased use of patient self-management and community resources, and information technology to make it easier for providers to deliver evidence-based patient-centred care
	Katon et al (1995); <sup>84</sup> Dwight-Johnson et al (2005) <sup>85</sup>	Collaborative care model The collaborative care model addresses both physical and psychological symptoms of patients with chronic conditions, typically by providing upfront mental health services to medical patients in a way that is convenient and efficient. Applications of the model often include care managers and care planning initiatives to increase communication, as well as patient education and individual or group-based behavioural health interventions
	Chodosh et al (2005); <sup>86</sup> Bodenheimer et al (2002); <sup>87</sup> McCorkle et al (2011) <sup>88</sup>	Illness self-management model The illness self-management model emphasises the value of educating and empowering patients with chronic disease to take an active role in monitoring and directing their care. Interventions based on this model can include a variety of specific activities including goal setting, self-monitoring, decision making, planning, and engaging health promoting behaviours, as well as self-evaluation
Author Manuscript	Sia et al (2004); <sup>89</sup> Ferrante et al (2010); <sup>90</sup> Sprandio (2012) <sup>91</sup>	Patient Centered Medical Home model. Routine care is delivered by a personal physician who coordinates with other providers to ensure that care is patient-centred, accessible, and comprehensive. The Patient Centered Medical Home model emphasises systemic initiatives to support patient access to personal physicians, standardisation, and coordination of care, as well as changes to payment models and performance indicators to support the activities needed to maintain these services and ensure their function as the patient's medical home
Author Manuscript	Haaga (2000); <sup>92</sup> Reid et al (2003) <sup>93</sup>	Stepped-care models Stepped-care models minimise cost and patient burden by providing interventions in sequence with easily deliverable, low-cost interventions offered first, with more resources and time-intensive interventions reserved for patients who do not respond to the initial intervention