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What determines the well-being of adolescents and young adults with cancer? A meaning perspective

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The 2006 landmark report by the Adolescent and Young Adult Oncology Progress Review Group argued that adolescent and young adult (AYA) survivors – those diagnosed with cancer between ages 15 and 39 – had been largely overlooked, falling in the cracks between pediatric survivors and mid-to-late life adult survivors [1]. The release of this report spurred research focused on AYA survivorship experiences. Yet most of what we have learned is simply descriptive, highlighting AYA survivors’ many unmet needs and the negative impacts of cancer on their future lives. Surprisingly, little research has examined how AYA survivors’ experiences with cancer affect their well-being (i.e. their broadly-defined psychological and physical health-related quality of life (HRQOL)). We assert that a meaning-centered approach is helpful in making sense of the disparate literature regarding aspects of AYA’s cancer experiences relevant to their well-being. We conclude with promising avenues for future research and intervention.

AYA survivors tend to have lower levels of well-being and often continue to experience cancer-related distress. A review of 35 quantitative and qualitative studies of HRQOL found that AYA survivors reported lower HRQOL compared with healthy peers and with older cancer survivors [2]. For example, one study found higher levels of distress in AYA survivors compared to a matched healthy sample at one-year post-diagnosis [3], and a large study of multiple cohorts similarly found that AYA survivors reported poorer physical and emotional well-being than matched peers [4]. In addition, AYA survivors often report high levels of posttraumatic stress symptoms (i.e. re-experiencing, avoidance, and hyperarousal) [5]. Furthermore, AYA survivors, like other cancer survivors, have poorer health behaviors than does the general population. For example, one recent large-scale survey comparing AYA cancer survivors with the general population in the USA showed that survivors were more likely to be current smokers, obese, and lacking in physical activity than were respondents without a cancer history [6]. This is particularly important given that AYA survivors’ positive health behaviors and HRQOL are positively related [7].

These lower levels of well-being and heightened levels of distress are quite concerning and suggest a need for interventions specifically focused on the unique concerns of AYA survivors. However, it is important to note that, within each study, individuals vary greatly in how well they fare, suggesting that some AYA survivors are relatively psychologically resilient while others are less so. One central determinant of this resilience, demonstrated across many studies, is meaning, particularly the meaning AYA survivors make of their cancer experience and the meaning they ascribe to the cancer’s implications for achieving their future goals.

A cancer diagnosis is highly disruptive to an individual’s global sense of meaning, and AYA survivors who report more disruption of their life goals from cancer, especially their educational and work goals, report poorer mental HRQOL [7] and more posttraumatic distress [5]. In addition, in one large study, nearly half of AYA survivors perceived that their sense of control over their lives had been greatly diminished by their cancer experience [8]. Yet, as is true for the general population, AYA survivors’ sense of meaning and purpose is strongly associated with higher HRQOL and lower distress [7]. Very little research has been conducted on spirituality as a determinant of well-being, but many AYA survivors report that their spirituality was positively impacted by having cancer [8]. One sample of AYA survivors reported fairly low spiritual well-being (comprising a sense of meaning, peace, and faith), and spiritual well-being predicted psychological adjustment a year later. Further, those struggling with spiritual issues experienced poorer psychological adjustment a year later [9].

Cancer leaves tremendous uncertainty in its wake regarding survivors’ objective health risks and vulnerabilities, and AYA survivors who worry about their health and recurrence of cancer report lower HRQOL and higher distress [7,10]. In a large cohort of AYA survivors, nearly a third reported that having cancer reduced their confidence in their ability to take care of their own health [8]. These beliefs in one’s ability to efficaciously manage one’s health have been shown to mitigate the adverse effects of AYA survivors’ physical health problems on their posttraumatic stress symptoms [11].

Given their formative developmental phase, focusing on building their adult personal and professional lives, the way in which AYA survivors understand the meaning of the cancer for their future personal, social, and work lives is critically important to their longer-term well-being. Researchers have studied these meanings in several ways. In one approach, AYA survivors are asked to report the negative impact of their cancer on specific domains of their future lives, and examine
how these meanings relate to well-being. AYA survivors who perceive greater negative impact of cancer on their social relationships, for example, report more distress and lower HRQOL [7]. Similarly, perceptions that cancer negatively impacted one’s educational attainment or work status is common, and these perceived negative impacts are related to higher levels of posttraumatic stress symptoms [4]. In one study of impacts across many domains of life functioning, the most common negative impacts reported – by far were in the domains of fertility, sexual intimacy, cognition/memory, and vitality, and all of these perceived negative impacts were strongly associated with lower life satisfaction [12].

Another common method for examining the meaning of AYA survivors’ cancer experiences is to assess the extent to which they feel they have grown or benefited from the cancer, often referred to as ‘posttraumatic growth.’ Reported levels of posttraumatic growth are high. For example, several studies have found that nearly all AYA survivors reported at least moderate levels of posttraumatic growth [13,14]. As in the broader psycho-oncology literature, however, these reports of growth are not consistently related to well-being. In one study of five-year AYA survivors, posttraumatic growth was unrelated to posttraumatic stress symptoms but positively related to depressive symptoms [14]. In another, AYA survivors’ posttraumatic growth was positively associated with psychosocial functioning and posttraumatic stress symptoms but inversely associated with physical functioning and depressive symptoms [13]. Authors of another study of AYA survivors interpreted their findings that posttraumatic growth was positively related to an aspect of posttraumatic stress symptoms, re-experiencing as indicating that posttraumatic growth reflected efforts to cognitively process their cancer experience and understand it in a broader framework of meaning [15]. Perceptions of growth may, in fact, represent very different phenomena to different survivors, and may, therefore, serve multiple functions. One interesting study found that posttraumatic growth mitigated the effects of AYA survivors’ fears of recurrence on their HRQOL and well-being [16].

Yet another way through which AYA survivors ascribe meaning to their cancer experience is in the post-cancer identities they adopt. Research with other age groups has shown that identities such as survivor, victim, or cancer community member, are strongly associated with myriad aspects of well-being. So far, only one study has probed the different identities of AYA survivors and examined their relations with well-being [9]. That study found that AYAs several years out of cancer treatment adopt many different post-cancer identities. Identifying as a survivor or a member of the cancer community was related to perceptions of many positive impacts of cancer but was unrelated to perceived negative impacts or HRQOL, while identifying as a victim or patient was related to higher perceived negative impacts of cancer and poorer HRQOL.

In sum, multiple aspects of the meaning that AYA survivors make of their cancer experience are intricately and pervasively related to their well-being. These aspects of meaning include perceived impacts of the cancer, perceived growth, and post-cancer identity as well as changes in global beliefs and a sense of meaning and purpose in life. However, while promising, research linking these aspects of meaning with well-being tends to be primarily conducted using cross-sectional study designs and lacking in strong theoretical grounding, which limits our ability to truly understand how meaning is involved in AYA survivors’ psychosocial adjustment and well-being.

Much more research based on stronger theoretical frameworks is needed to further our understanding of what predicts the differing recovery trajectory for AYA survivors following cancer. The meaning making model [17] provides such a framework, specifying relations between global and situational meaning (beliefs and goals). This theoretical model has been adapted specifically to cancer survivors [18] and with additional elaboration could serve as a strong basis for future research on processes of stress, coping, and adjustment for AYA survivors.

Importantly, these meanings may serve as useful targets for intervention – they are modifiable and thus amenable to therapeutic change [5]. A review of intervention research with AYA survivors showed that various approaches (e.g. health promotion, social media, rehabilitation) may improve their quality of life and well-being. However, most of the studies reviewed were poorly controlled and did not examine maintenance of treatment effects. Although none of the interventions appear to have explicitly targeted aspects of meaning, several showed improvements in potentially relevant outcomes such as ‘courageous coping’ [19]. Thus, interventions that help AYA survivors to reframe their cancer experiences in more benign ways, reducing discrepancies between global and appraised meanings and renewing a sense of goal agency [17] may lead to better post-cancer adjustment. Further, establishing or re-establishing a strong sense-of-life meaning, perhaps through spirituality, and contextualizing the cancer experience in this larger system of meaning may be a fruitful direction for promoting resilience.

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   - Landmark report highlighting concerns and needs of this underserved group.

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   • Excellent largescale study demonstrating quality of life across domains in AYA survivors compared to a carefully matched non-cancer-survivor sample.
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   • Important theoretical overview and review of empirical literature in meaning-making.
   • Excellent review of existing psychosocial interventions for AYA survivors.