Curr Hematol Malig Rep (2016) 11:280–287
DOI 10.1007/s11899-016-0328-z

Unmet Needs for Psychosocial Care in Hematologic Malignancies and Hematopoietic Cell Transplant

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Abstract Individuals diagnosed with hematologic malignancies experience significant unmet psychological, physical, informational, financial, and spiritual needs. The goal of the current review is to summarize and highlight recent research focused on these issues in the diagnosis and treatment periods and beyond. The review also describes the needs of adolescent and young adult (AYA) and pediatric patients. While a large body of research has reported on unmet needs among adult hematologic cancer patients, there is far less data regarding the challenges confronted by AYA and pediatric populations. Available data suggests that among all age groups, hematopoietic cell transplantation (HCT) is a risk factor for greater unmet needs. Recommendations for screening and evidence-based interventions to prevent or ameliorate unmet needs are provided. Future research is needed to develop additional evidence-based psychosocial interventions with a focus on hematologic cancer.

Keywords Hematologic neoplasms · Health services needs and demand · Hematopoietic stem cell transplantation · Child · Adolescent · Quality of life

This article is part of the Topical Collection on *Health Economics*

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Introduction

Hematologic malignancies are a diverse group of diseases that are optimally treated with a variety of regimens including chemotherapy, targeted therapies, and hematopoietic cell transplantation (HCT). Advances in treatment and supportive care have resulted in increases in survival, resulting in a significant population of survivors who may be struggling to cope with the aftermath of their disease and treatment. Increased awareness of the unmet needs of hematologic cancer patients has resulted in a sizable literature documenting the pervasive effects of a hematologic cancer diagnosis on patients' lives, although less work has evaluated interventions to meet patients' needs. The goal of the current review is to summarize and highlight recent observational and intervention research focused on unmet needs among patients with hematologic malignancies. Unmet needs are defined broadly as problems requiring assistance that may occur in one or more life domains including psychological, physical, informational, financial, and spiritual domains. The review will primarily describe unmet needs among adult hematologic cancer patients, with additional sections devoted to the needs of adolescent and young adult (AYA) and pediatric patients.

Psychological Needs

Overall, the burden of unmet psychological needs is very high among adult hematologic cancer patients, with 51 % of patients reporting at least one unmet need [1•] and 25 % reporting seven or more [2]. Across studies, the most common unmet needs are psychological in nature, including depression, anxiety, fear of cancer recurrence, and cognitive problems [1•, 2, 3]. There is evidence to suggest that psychological unmet needs such as depression and anxiety decrease over time among hematologic cancer patients on treatment [4]. However, unmet needs appear to be relatively stable following treatment completion [5, 6]. Rates of significant depression range from 13 to 27 % in HCT survivors [5, 7, 8], while significant anxiety is estimated to occur in 14 to 27 % [7, 8] and significant fear of progression in 23 to 29 % [6, 8]. Estimates of posttraumatic stress disorder after HCT range from 15 to 28 % [8, 9]. Less data are available regarding hematologic cancer patients receiving other treatment modalities, although it has been reported that 17 % of patients diagnosed with acute leukemia and 37 % of patients treated with a tyrosine kinase inhibitor (TKI) experienced significant depression [10, 11]. High levels of unmet psychological needs may be due to underdiagnosis and undertreatment of depression and anxiety. A recent study reported that of allogeneic HCT recipients reporting distress, only 39 % were taking antidepressant or anxiolytic medications and 22 % were receiving psychotherapy [8]. Similar findings were observed in patients with newly diagnosed or recently relapsed leukemia; among patients expressing significant worry and sadness, only 13 % received psychiatric or psychological support within 1 month [12].

Data suggest that psychological unmet needs are associated with a variety of negative outcomes among hematologic cancer patients. For example, depression is associated with worse quality of life and reduced social functioning, although not with return to work, after hematologic cancer [13, 14]. Among HCT recipients, depression is associated with nonadherence to the post-HCT regimen, increased hospital length of stay, greater mortality, and increased suicidal ideation [15–17], although evidence is conflicting [18].

Although the burden of unmet psychological needs is high, there is evidence to suggest that routine screening can detect distress among hematologic cancer patients and is associated with greater patient and provider satisfaction with care [7, 19, 20]. Relatively few studies have examined pharmacologic or psychosocial interventions to reduce distress among hematologic cancer patients. Nevertheless, there is evidence that telephone-based cognitive-behavioral therapy can reduce depression, distress, and posttraumatic stress symptomatology in patients previously treated with HCT [21]. In contrast, a study of an Internet-based coping intervention in HCT recipients found no effects on psychological functioning [22], perhaps due to the importance of the therapeutic relationship in this population [23].

Physical Needs

Physical unmet needs are frequently endorsed by hematologic cancer patients, including fatigue, impaired physical functioning, and cognitive changes [1•]. Patients have described these physical changes as “devastating,” “demoralizing,” and “difficult to accept” in terms of their impact on quality of life [24, 25]. A recent study found that 18 % of long-term survivors of hematologic malignancy reported significant fatigue [26]. Fatigue has also been reported in 50 % of patients treated with TKIs [27] and 42 % in hematologic cancer survivors previously treated with HCT [5]. In addition to its negative effects on quality of life, fatigue is associated with a reduced likelihood of returning to work after hematologic cancer diagnosis [14]. Among HCT recipients, physical functioning has been shown to drop precipitously following transplant, then return to baseline levels by 6 months post-HCT and remain relatively stable thereafter [28]. Among long-term HCT survivors, 11 % reported impaired physical functioning; risk factors for impairment included younger age, higher body mass index, no or part-time work, more comorbid diseases, autologous transplantation, and chronic graft-versus-host disease [29]. While little data are available regarding cognitive changes in hematologic cancer patients treated with modalities other than HCT, a meta-analysis of HCT recipients found no significant change from pretransplant to posttransplant [30]. However, because patients had been treated with induction chemotherapy prior to the pre-HCT assessment, the extent of cognitive impairment relative to pretreatment was not able to be determined.

Exercise may help to ameliorate some unmet physical needs among hematologic cancer patients. Meta-analyses of randomized controlled trials of exercise for HCT recipients have reported beneficial effects on self-reported fatigue, physical functioning, cognitive functioning, emotional functioning, and global quality of life in addition to objectively measured cardiorespiratory fitness and muscle strength [31, 32]. In contrast, although no studies have been conducted specifically in hematologic cancer patients, pharmacologic management of cancer-related fatigue or cognitive impairment with modafinil, methylphenidate, or donepezil have reported little to no improvement with significant side effects [33–35]. Consequently, physical therapy or a rehabilitation program should be considered first for patients who report significant fatigue, physical impairment, or cognitive problems.

Informational Needs

Informational needs are high among hematologic cancer patients. Recent studies have indicated that 82 % of patients wanted to have all available information and be involved in decision-making [36], while 66 % needed information communicated in a way they could understand, and 62 % needed up-to-date information [3]. In order of importance, needs included information on treatment, disease, diagnostic test results, physical functioning, and psychosocial functioning [36]. Patients with the highest needs for information were those who were younger and those who had lower socioeconomic status, greater comorbidity, and/or worse quality of life [36]. Among HCT recipients, a recent qualitative study found that many felt well-prepared for the acute transplant period but wanted more information regarding late effects and posttransplant quality of life [25]. A qualitative analysis of physician-patient communication found that while physicians talked at length with patients about prognostic information and treatment options, they rarely checked for patient understanding of the presented information [37]. Therefore, there may be a significant gap between the information communicated by clinicians and what is understood by patients. Unmet informational needs are important to address because satisfaction with information has been found to be associated with less distress and greater adherence to imatinib among hematologic cancer patients [38, 39].

Technology offers the opportunity to enhance patient-provider communication in the context of high clinic workflow. For example, an electronic patient portal entitled "BMT Roadmap" has been created to provide patient-specific laboratory and medication information from the electronic health record to caregivers of pediatric HCT patients during hospitalization [40]. A similar project has been undertaken for adult allogeneic HCT recipients [41]. In addition, an e-tool has been developed for patients with non-Hodgkin's lymphoma to provide personalized patient disease and treatment information as well as general disease information [42]. An Internet-based program to improve awareness of post-HCT survivorship care has also been developed and is currently being evaluated in a randomized trial [43]. While most of these initiatives have currently undergone only pilot testing, they provide promising avenues for future patient education efforts.

Financial Needs

There is increasing recognition of the financial toxicity of cancer treatment. Financial toxicity is especially relevant to hematologic cancer patients, many of whom undergo long and costly therapies such as HCT, with side effects that may prevent patients and caregivers from returning to work. Financial toxicity is widespread. For example, 36 % of patients with multiple myeloma reported that they requested financial assistance during treatment, 46 % used savings to pay for treatment, and 21 % borrowed money to pay for medications [44]. Among patients receiving TKIs, higher copayment costs are associated with reduced adherence to treatment [45]. Among HCT patients, 73 % reported that they had been hurt financially by their illness and 47 % reported significant financial burden such as a decrease in household income by at least 50 %, selling/mortgaging their home, or withdrawing money from their retirement accounts [46]. HCT patients also report bankruptcy, loss of a business, and divorce due to financial stress [47]. Among patients returning to work after HCT, job insecurity, discrimination, and delayed career goals have occurred [48]. Financial insecurity can significantly affect adherence to medical regimens; 19 % of HCT recipients reported cutting back or not purchasing prescription medication, 21 % reported not making an physician appointment or having a medical test performed, and 28 % reported deferring use of a medical service [46]. Of note, all patients who provided insurance information in this study reported being insured [46], suggesting that insurance does not prevent financial toxicity. Lower socioeconomic status is associated with a variety of negative outcomes among HCT patients, including decreased overall survival and increased treatment-related mortality [49]. Consequently, greater patient education, screening, and counseling are needed regarding the financial consequences of HCT and other hematologic cancer treatments.

Spiritual Needs

The physical and emotional adversity of cancer diagnosis and treatment can cause patients to question fundamental assumptions about their religious or spiritual beliefs and the meaning of their lives [50]. Nevertheless, patients often report that cancer has deepened their religious or spiritual beliefs [51]. Research regarding spiritual needs in the context of hematologic cancer has focused primarily on HCT recipients. A recent study found that spiritual faith increased after transplant, while patients' sense of meaning and peace decreased during the acute transplant period and returned to pretransplant levels by 6 months post-HCT [52]. Greater spiritual well-being among HCT recipients is consistently associated with better quality of life, reduced symptomatology, and less depression and anxiety [52, 53]. In contrast, one study has found that spiritual absence among HCT recipients is associated with lower overall survival [54]. These data point to the importance of considering spirituality as part of care of the whole cancer patient. Although intervention studies in hematologic cancer patients are lacking, a randomized controlled trial of group therapy to increase meaning in life in advanced cancer patients resulted in improvements in quality of life, physical symptom distress, depression, hopelessness, and desire for hastened death compared to supportive group therapy [55]. Consequently, efforts to enhance patients' meaning in life, regardless of their religious or spiritual orientation, may provide broad benefits across multiple domains.

Needs of Adolescent and Young Adult Patients

AYA patients, defined as those age 15–39 at diagnosis, experience unique needs and challenges related to quality of cancer care; physical health; peer and family relationships;

educational attainment and employment; financial independence; concerns regarding dating, marriage, and fertility; body image; and health behaviors [56, 57]. Much of the data regarding AYA cancer patients come from large studies of patients with hematologic malignancies or solid tumors. Regarding quality of cancer care, survival improvements due to treatment advances in AYA patients have lagged behind those observed in pediatric and adult patients. Lack of survival gains may be due in part to low AYA participation in clinical trials and a lack of awareness among community cancer physicians regarding specialized AYA treatment protocols [58]. A recent study observed that optimal treatment was received by only 56 % of acute lymphoblastic leukemia patients, 58 % of Hodgkin's lymphoma patients, and 73 % of non-Hodgkin's lymphoma patients [58]. These data suggest that more work is needed to ensure that AYA patients receive appropriate care.

Following treatment completion, AYA cancer patients report worse quality of life as well as greater symptomatology such as fatigue, insomnia, constipation, and cognitive impairment [59, 60]. Moreover, rates of frailty in AYA and pediatric cancer survivors, including low muscle mass, self-reported exhaustion, slow walking speed, and weakness are similar to that of adults aged 65 and older [61]. Physical deficits may interfere with social functioning; among participants in the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study, patients reporting a high symptom burden were more likely to report the desire to talk to their family and friends about the cancer experience and meet peers diagnosed with cancer [62].

Work and educational attainment can be a problem for AYA cancer patients as well. While 72 % of cancer survivors in the AYA HOPE study returned to work or school after cancer treatment, 50 % of full-time workers/students reported problems in these areas [63]. Regarding financial unmet needs, AYA cancer patients tend to have more lost productivity, greater healthcare expenditures, and increased likelihood of financial problems than patients diagnosed at older ages [64, 65].

Fertility preservation is also a significant concern for this population. Among patients of reproductive age treated with HCT, 22 % reported trying to conceive and only 10 % reported success [66]. Although fertility concerns may not be present at the time of diagnosis, they may arise during or after treatment and negatively impact patients' psychological well-being [67]. Recommendations regarding fertility preservation after HCT have recently been published to provide guidance to clinicians on this important issue [68••].

Psychological morbidity in AYA patients is high. The AYA HOPE study found that 41 % of AYA cancer patients reported an unmet need for psychological counseling 12 months after diagnosis [69]. Studies of AYA hematologic cancer patients have found that 69 % report fear of recurrence, 46 % demonstrate symptoms of posttraumatic stress, 28 % met criteria for depression, and 23 % met criteria for anxiety [70, 71]. No differences in psychological morbidity were observed between patients on treatment compared to early survivors [70]. Interestingly, providers' perceptions of patients' psychological morbidity was not related to patients' own perceptions [70], suggesting that better patient-provider communication is necessary.

Psychological interventions for AYAs must take into account multiple competing demands for their time such as school, work, and family [72]. Use of technology such as the Internet, smartphone apps, and social media may help to reach AYA patients. Resources currently available include blogs, Twitter, and Facebook to help AYAs learn about health topics and connect with other AYA cancer patients [73••], although their efficacy has not been evaluated. Randomized trials of psychosocial interventions for AYA cancer patients with hematologic or solid tumors have generally yielded nonsignificant results, suggesting that more impactful interventions are needed [74]. Recent national workshops focused on AYA cancer survivors have called for additional research on supportive care intervention studies to assist AYAs with their psychological, physical, occupational, financial, and social unmet needs [75, 76••].

Pediatric Unmet Needs

Research regarding the unmet needs of pediatric hematologic cancer patients is sparse, particularly those treated with modalities other than HCT. Cancer survivors diagnosed during childhood tend to report better quality of life than those diagnosed during adolescence or young adulthood [77]. Nevertheless, psychological distress, impaired physical functioning, cognitive dysfunction, behavioral issues, and financial hardship frequently occur during treatment and many years thereafter. Rates of clinically significant depression or anxiety range from 6 to15 % during treatment among pediatric patients with hematologic cancer or solid tumors [78–80]. Among pediatric HCT recipients, psychological morbidity is significantly higher, with 30 % of patients meeting criteria for an anxiety disorder prior to transplant and 10 % meeting criteria for depression [80]. Among long-term childhood cancer survivors with mixed cancer types, 7 % met criteria for clinically significant anxiety or depression, although 48–54 % expressed concerns about emotional functioning or unmet psychosocial needs [79, 81, 82]. Survivors diagnosed with leukemia report significantly greater levels of depression and anxiety than their siblings [83]. Among survivors treated with HCT, rates of depression and post-traumatic stress disorder are significantly higher than siblings [84, 85]. Few psychosocial interventions have been developed specifically for pediatric cancer patients during treatment or in the survivorship period [86, 87], although several studies have demonstrated the feasibility of screening for distress and other unmet needs in this population [88, 89] and national guidelines currently recommend annual screening of childhood and AYA cancer survivors for psychosocial distress [90••].

Physical functioning is a significant concern among pediatric hematologic cancer patients. Patients often contend with fatigue, nausea, and pain during treatment [91]. Although these symptoms tend to decrease over time [91], fatigue may become chronic among survivors [92]. Among long-term survivors of acute myelogenous leukemia (AML), 50 % reported chronic health conditions and 16 % reported severe or life-threatening health problems [93]. Rates of chronic health conditions and severe or life-threatening conditions are significantly higher among pediatric cancer survivors treated with HCT than other therapy modalities [94]. Childhood leukemia or lymphoma survivors are more likely than their siblings to report physical limitations; clinical risk factors include central nervous system irradiation and chemotherapy [83]. Thus, greater attention is needed to preventing and ameliorating late effects of childhood cancer treatment.

Cognitive impairment secondary to pediatric cancer and its treatment is a significant concern and may result in behavioral issues and decreased or delayed educational attainment and workforce participation. Greater than 20 % of childhood cancer survivors reported cognitive problems and 43 % reported concerns about their cognitive functioning [81, 95]. A study of functional neuroimaging in survivors of childhood acute lymphocytic leukemia (ALL) reported deficits in working memory despite significant compensatory activation in areas underlying working memory [96]. Cognitive impairment is also evident among patients treated with HCT, especially those who were younger than five at the time of transplant and those who received total body irradiation [97]. Regarding behavioral issues, failure in school performance, restricted group activity, and less social relations were observed in children with ALL treated with chemotherapy compared to healthy children, although healthy children displayed more social problems, attention problems, and oppositional and aggressive behavior [98]. In contrast, studies of adolescent survivors of childhood cancer have reported that those diagnosed with leukemia reported greater attention deficits, social skill deficits, and antisocial behavior relative to siblings [83, 99]. Regarding educational attainment, it has been reported that survivors of AML are less likely to complete college and more likely to be unemployed compared to their siblings [93, 100]. In light of evidence suggesting cognitive, behavioral, and educational deficits, it is currently recommended that pediatric and AYA cancer survivors complete neurocognitive evaluation at the transition to long-term follow-up and as needed thereafter for impaired educational or vocational progress [90••].

Financial hardship is also a concern for pediatric hematologic cancer patients and may adversely impact family well-being [101]. Among pediatric HCT recipients, 38 % of insured families experienced material hardship such as food, housing or energy insecurity in the year after their child's transplant [47]. Lower socioeconomic status is associated with increased mortality among pediatric leukemia patients [102]. Children with ALL living in high-poverty areas have been shown to experience significantly higher incidence of relapse, resulting in decreased overall survival and event-free survival [103]. Although data are sparse regarding the long-term effects of childhood cancer on survivors' finances, data suggest that survivors are more likely to receive supplemental security income and social security disability insurance compared to individuals without cancer [104]. Thus, childhood cancer may have a long-term negative impact on the financial well-being of survivors. Indeed, screening for material hardship, such as food, energy, and housing insecurity, should also be considered throughout the trajectory of health care [105].

Challenges in Addressing Unmet Needs

While there has been an increased awareness of the importance of treating the whole cancer patient, significant challenges remain in addressing patients' unmet needs. One challenge is improving patient-physician communication to ensure that the treatment team is aware of patients' needs. Screening guidelines and tools (e.g., the Distress Thermometer) have been developed but are still underutilized [106]. A second challenge is allocating enough staff time to help manage patient needs [107], particularly because reimbursement for these services is suboptimal. There are also relatively few evidence-based interventions for distress in hematologic cancer patients, particularly those treated with HCT and pediatric and AYA patients. More research is clearly required to fill these gaps. Following cancer treatment, fragmentation of care between the oncologist, primary care physician, and other specialists may contribute to overlooked needs. Survivorship clinics may help to remedy this problem moving forward. In sum, additional effort is needed in both research and clinical care to ensure patients receive adequate support during diagnosis, treatment, and beyond.

Conclusion

Hematologic cancer patients experience significant unmet needs in the psychological, physical, informational, financial, and spiritual domains. AYA and pediatric patients experience psychological and physical challenges as well as unique difficulties reaching developmental milestones in terms of cognition, behavior, social and romantic relationships, and educational and vocational attainment. Although a large body of literature has documented the needs of adult hematologic cancer patients, far less data have been amassed regarding AYA and pediatric patients. Thus, additional observational studies are needed to better understand the challenges of hematologic cancer diagnosis and treatment during childhood, adolescence, and young adulthood. In addition, randomized clinical trials of psychosocial interventions to address the unmet needs of hematologic cancer patients, regardless of age, are almost completely lacking. A concerted effort must be made to develop evidence-based interventions for depression, anxiety, posttraumatic stress disorder, fatigue, pain, cognitive impairment, and other concerns that will potentially be elicited from increased efforts to screen for unmet needs in this population. Similar efforts are required to prevent and treat late effects that can cause physical limitations and reduced quality of life. Additional progress on these fronts will help to ensure better quality of life for the many current and future hematologic cancer patients.

Compliance with Ethical Standards

Conflict of Interest Anna Barata, William A. Wood, Sung Won Choi, and Heather S.L. Jim each declare no potential conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- •• Of major importance

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