

Facilitators and Barriers to Self-Management for Adolescents and Young Adults Following a Hematopoietic Stem Cell Transplant

Journal of Pediatric Oncology Nursing
2018, Vol. 35(1) 36–42
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DOI: 10.1177/1043454217723864
journals.sagepub.com/home/jpo



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Abstract

Adolescents and young adults who experience hematopoietic stem cell transplant are at risk for self-management difficulties based on development, psychological comorbidities, and the complexity of the care regimen. Recommendations for practice change were designed to address facilitators and barriers to self-management for adolescents and young adults following hematopoietic stem cell transplant. As part of a grounded theory research study, 30 participants (17 adolescents and young adults and 13 of their caregivers) were individually interviewed and asked about facilitators and barriers to managing care and advice for health care providers. Participant responses were coded into categories, which were named with terms used by the participants. The number of participants who provided data per category was recorded. Self-management is generally characterized only in the ability to follow a prescribed care regimen. Participants indicated mental and emotional experiences as a result of treatment were indistinguishable from self-management activities. Facilitators included having a positive attitude, social support, organization, motivation, and information. Barriers included physical and psychological symptoms, isolation, difficulties with the medication regimen, single parenting, and having a bad attitude. Advice for health care providers included communicating effectively, treating patients holistically, and providing social support.

Keywords

adolescents and young adults, AYA, bone marrow transplant, BMT, hematopoietic stem cell transplantation, HSCT, self-management

Introduction

Every year, at least 20,000 people in the United States are eligible for a hematopoietic stem cell transplant (HSCT); 1 in 5 are children, adolescents, or young adults (Health Resources & Services Administration, 2015). HSCT is a life-saving inpatient treatment, but it has high risk of mortality with an overall survival rate of 50% to 60% (Pasquini & Zhu, 2015). Moreover, following discharge, patients must self-manage complex outpatient medication and care regimens. Failure to correctly administer the prescribed regimens (ie, nonadherence) can have serious consequences such as infection or disease relapse (Pasquini & Zhu, 2015).

Adolescents and young adults (AYA) are at particular risk for nonadherence to treatment regimens due to normative developmental behaviors that directly conflict with the post-HSCT regimens, such as increased risk-taking behaviors, independence from parents, and

importance of their peer group (Coupey, 2008; Radzik, Sherer, & Neinstein, 2008). Overall, AYA are also at increased risk for mental health disorders (eg, depression and anxiety), which are compounded by illnesses like cancer (Kutcher & Chehil, 2008; Zebrack et al., 2014). Mental health symptoms further interfere with self-management and adherence behaviors (DiMatteo, Lepper, & Croghan, 2000; Kennard et al., 2004).

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AYA have been shown to have difficulties with adherence to medication and isolation protocols following HSCT (McGrady, Williams, Davies, & Pai, 2014; Phipps & DeCuir-Whalley, 1990). Adherence rates, meaning the number of times an activity is performed over the number of times prescribed (Modi et al., 2012), for this population range from 50% to 80% (McGrady et al., 2014; Phipps & DeCuir-Whalley, 1990). Bhatia et al. (2012) found that children with leukemia with oral chemotherapy adherence rates below 95% were twice as likely to relapse. Low adherence rates have been related to delayed treatment (Butow et al., 2010), disease relapse (Bhatia et al., 2012; Butow et al., 2010), graft failure (Dobbels et al., 2010), patient mortality (Ganesan et al., 2011; Kennard et al., 2004), and significant cost to the health care system (DiMatteo, 2004). Thus, the need for change in adherence rates and self-management by AYA after HSCT is crucial.

There is little evidence on adherence and self-management in AYA during the acute phase of HSCT treatment (ie, 100 days posttransplant). Thus far, only age (McGrady et al., 2014) and symptom experience (Martin et al., 2012) have been shown to be risk factors for poor adherence among AYA HSCT recipients. Self-management and adherence literature in AYA with cancer has also identified several risk factors for nonadherence, including depression (Kennard et al., 2004; Zebrack et al., 2014), unclear delineation of responsibility, and single-parent households (Malbasa, Kodish, & Santacroce, 2007). The larger self-management literature also shows that AYA developmental needs and parental support are important determinants of self-management and adherence behaviors (Karlsson, Arman, & Wikblad, 2008; Moore & Beckwitt, 2004; Stinson et al., 2012).

Although difficulties with adherence and self-management are better documented in AYA cancer patients (Bhatia et al., 2012; Butow et al., 2010; Moore & Beckwitt, 2004; Mosher & Moore, 1998; Stinson et al., 2012), there is only emerging evidence on how AYA receiving an HSCT self-manage and adhere to prescribed medication and self-care regimens (McGrady et al., 2014). This article addresses the knowledge gap by presenting facilitators of and barriers to AYA self-management following an HSCT, based on evidence from a grounded theory research study.

Method

A grounded theory research study was undertaken to examine the process AYA use to manage their care following an HSCT. Since HSCT is a physically demanding procedure that necessitates having a caregiver, and developmentally AYA are often not independently involved in their own medical care, caregivers were also included in

the sample to gain a better understanding and richer description of self-management for AYA patients who have undergone an HSCT. Following institutional review board approval and participant consent/assent, individual semistructured interviews were conducted with 30 participants: 17 AYA who had an HSCT between the ages of 13 and 25 years, and 13 of their caregivers.

Individual interviews were conducted in person or by phone, by the same investigator using an interview guide. All interviews were at least an hour in length with the exception of two that were under 30 minutes with AYA participants (13 years old and 15 years old). During interviews, participants were asked what was helpful or made it easier to manage their care regimen (facilitators), factors that made managing care more difficult (barriers), and what advice they have for health care providers.

All interviews were digitally recorded and transcribed verbatim. Participant responses were coded into three categories: facilitator, barrier, or advice. Data were then grouped within each category into subcategories and quantitized. Quantitizing refers to attaching numerical value to segments of text, which enhances the ability to recognize patterns in the data (Sandelowski, Voils, & Knafl, 2009). The number of participants who provided data in each subcategory was recorded. The majority of participants responded with more than one facilitator, barrier, and/or advice for health care providers. Tables 1, 2, and 3 display the percentage of participants and the number of responses for each facilitator, barrier, and advice recommendation, respectively.

Results

Sample

The sample ($n = 30$) was primarily Caucasian (97%). AYA ($n = 17$) were typically male (65%) with an oncology diagnosis (59%). The majority of the caregivers ($n = 13$) were female (69%) and married (92%). The average age of caregivers at interview was 50 years of age. Average age of AYA at the time of HSCT was 18.5 years (13-22.3 years) and 20 was the average age at interview (14.3-25.3 years).

Facilitators

Facilitators fit into two subcategories: (a) helped with the management of daily regimen activities and (b) helped participants be mentally or emotionally prepared to manage their care. Social support was mentioned as assisting with both daily care regimen and psychological and emotional support.

Table 1. Self-Management Facilitators.

Facilitator	% Participants (n = Responses)
Helped with daily regimen	
Health care workers providing education and supply delivery	43.3 (13)
Pillbox	13.3 (4)
Organization	16.7 (5)
Baseline knowledge as a nurse	3.3 (1)
AYA wanted to be involved in care	3.3 (1)
Good insurance	3.3 (1)
MyChart	3.3 (1)
Helped mentally or emotionally	
Hobby/keeping busy	16.7 (5)
Positive attitude	10 (3)
Having a motivator	6.7 (2)
Talking to a survivor	3.3 (1)
Faith	3.3 (1)
Acknowledge not in control	3.3 (1)
Avoid internet for treatment information	3.3 (1)
Social support	
Friends and family	46.7 (14)

Abbreviation: AYA, Adolescents and young adults.

Daily Regimen Facilitators. Organization of supplies, calendars, and medications were facilitated self-management of the daily regimen for AYA following HSCT. Four participants specifically mentioned the pillbox as the major way in which they managed their medication regimen. Pillboxes were large, with slots available for each day of the week, and filled weekly by adolescents or caregivers. Organizing supplies for procedures, such as central venous catheter care, helped families feel in control and prepared for care management. Supplies and medications were generally kept in one location throughout treatment.

Another facilitator of daily self-management of the regimen was health care worker support through educating patients and families on procedures and the care regimen, and delivering supplies. Three AYA mentioned that health care workers who provided education and supply delivery were also a source of social support during their time in isolation. One caregiver was a nurse and felt having a baseline medical knowledge as well as an awareness of many of the medical procedures was helpful in managing her son’s care. Another caregiver felt that having an AYA who was interested in being involved in his or her own care facilitated self-management of the daily regimen.

One caregiver mentioned that the MyChart (Epic Systems Corporation, Verona, WI) mobile application was helpful for getting updates on laboratory test results and clinic appointments. Having good insurance (ie, insurance as covering health care expenses and providing

Table 2. Self-Management Barriers.

Barrier	% Participants (n = Responses)
Hindered daily regimen	
Physical symptoms	16.7 (5)
Nausea	
Fatigue	
Pain	
Single parenting	13.3 (4)
Difficulties with medication regimen	10 (3)
Bad home care experience	6.7 (2)
Caregiver returning to work	3.3 (1)
Rare cancer/lack of information	3.3 (1)
Hindered mentally or emotionally	
Isolation	36.7 (11)
Psychological symptoms	30 (9)
Posttraumatic stress syndrome	
Depression	
Anxiety	
Fear	
Monotony	6.7 (2)
Bad attitude	3.3 (1)

Table 3. Advice for Health Care Providers.

Advice	% Participants (n = Responses)
Effective communication	
Effective communication	63.3 (19)
Age appropriate materials	
Accessibility of HCP	
Treat patient with respect	
Consistency of information between HCP	
Offer options when possible	
HCP positive attitude	20 (6)
Estimated rounding times	3.3 (1)
Symptom management	3.3 (1)
Holistic health	
Treat mental health	16.7 (5)
Treat patient holistically	10 (3)
Social support	
Offer social support services	13.3 (4)
Assist organizing supplies/planning self-management activities	3.3 (1)

Abbreviation: HCP, health care provider.

assistance navigating the health care system) was also listed as a self-management facilitator by a caregiver.

Mental and Emotional Facilitators. Having a positive attitude throughout the treatment process helped AYA and caregivers manage their care. There were three main contributors to a positive attitude: (a) making a personal decision to have a positive attitude, (b) gaining positive attitude from family and friends, and (c) gaining a positive attitude from health care providers. Several

participants mentioned that having a positive attitude not only enhanced their ability to self-manage their care but also aided in the healing process.

In addition to having a positive attitude, having a hobby to pass the time was mentioned by five AYA participants as a self-management facilitator. Hobbies mentioned by AYAs included video games, remote-controlled planes, shooting guns recreationally, playing musical instruments, and art projects. Motivators, both physical and mental, were also useful in keeping a positive attitude and looking toward the end of treatment. Physical motivators were usually gifts or rewards, and often had to do with hobbies. For example, an AYA received a remote-controlled airplane as a motivator and a reward for completing a phase in treatment. Two AYA mentioned “keeping the eye on the prize,” or knowing continuing with treatment and managing their care will only benefit them and to focus on treatment, being a temporary but necessary phase of their life.

One caregiver said acknowledging that he was not in control and having faith in God were two facilitators that helped him mentally and emotionally so that he could care for his family. Before he gave up control, he felt stressed, felt overwhelmed, and experienced anger that prevented him from effectively participating in support and care activities. This same caregiver also mentioned he avoided the internet due to the overwhelming amount of information and not knowing what to trust. Instead, he relied on the health care team to provide information from trusted sources. One AYA mentioned that talking to an AYA HSCT survivor was helpful in confirming experiences as typical during the treatment process. The AYA survivor also provided encouragement and peer reinforcement to adhere to isolation guidelines.

Social Support. Nearly half the sample viewed social support from friends and family as a self-management facilitator. The primary caregiver was an essential source of support for AYA participants. Social support from hometown communities was helpful and a stress reliever. Communities provided resources families needed to function, such as meals, fundraisers or financial assistance, help with well-sibling activities, and encouragement in the form of cards and letters.

Barriers

Barriers to self-management fell into two subcategories: (a) those that hindered daily regimen activities and (b) those that hindered mentally or emotionally from engaging in care activities.

Barriers to Daily Regimen. As a result of treatment, about one third of the AYA in this study reported experiencing physical symptoms (weakness, fatigue, pain, nausea)

that affected their ability to manage their own care, at least initially. Fatigue and weakness were considerable and affected the AYA’s energy levels and their ability to complete activities of daily living, such as bathing and walking, without assistance. Nausea affected the AYA’s ability to eat and take medications. Several AYA experienced pain, such as mucositis pain, that affected their ability to eat, or joint pain that prohibited certain physical activities.

Being the lone caregiver and essentially functioning as a single parent was also a barrier to self-management. About one third of caregivers shared experiences about difficulties they faced as the only caregiver. Experiences ranged from difficulty taking breaks to refresh, leaving a sick adolescent unattended to go run errands in a crowded environment, and the strain of responsibility for all areas of care. One caregiver had to return to work after her son was discharged, which required her to rely on her son to complete his own care activities. Not only did this hinder her ability to participate in the daily regimen, but she also had to give up some control and trust her son to follow the care regimen.

Two caregivers and one AYA listed difficulties with the medication regimen as barriers to self-management. Difficulties with medications included frequent changes in medications or dosing that were confusing and interrupted their system of organization, large pills that made swallowing difficult, and resistance from the adolescent that affected timely medication administration. Two caregivers talked about bad experiences with home care. In both cases, participants indicated that home care nurses were not knowledgeable about a device or machine, which left them with feelings of uncertainty and fear. Having a child diagnosed with a rare cancer meant there was little information available to make decisions and on which to base the care regimen. AYA and their caregivers initially experienced feelings of uncertainty and fear, which led to trust in the health care team’s knowledge and experience to prescribe effective treatments.

Mental or Emotional Barriers. Nine participants, both AYA and caregivers, felt that going through HSCT affected their mental health in such a way that it became a barrier to self-management. Psychological symptoms participants experienced during treatment included depression, anxiety, fear, and posttraumatic stress syndrome. Two caregivers feared their son or daughter would harm themselves due to depression or distress. One caregiver was diagnosed with posttraumatic stress syndrome. More than one third of participants, both AYA and caregivers, mentioned isolation from social support as a major mental and emotional barrier to self-management. One AYA felt he had a bad attitude as a result of being a teenager separated from his peers. Two AYA described the monotony of

extended isolation as a barrier to self-management that contributed to isolation protocol nonadherence.

Advice to Health Care Providers

Participants had advice for health care providers in three subcategories: (a) effective communication, (b) holistic health, and (c) social support.

Effective Communication. Effective communication incorporated interpersonal communication skills with how patients and families wanted information delivered. Seven participants wanted health care providers to be social and personable. Both AYA and their caregivers talked about needing more social support from health care providers since they were able to understand what families experienced. Six participants indicated the importance of health care providers having a positive attitude when communicating to patients and families to enhance spirits and provide encouragement. Several AYA mentioned respect and treating them as adults and part of the team. One adolescent suggested offering options, such as type of central access device for treatment or if they want lidocaine prior to port access.

Participants also wanted health care information provided in simple language, using age-appropriate materials, with consistency between providers. Two caregivers mentioned educational materials were appropriate for parents with young children but devoid of any tips for parents of teenagers who are testing boundaries. Another caregiver wanted an estimated health care team rounding time while inpatient to help her plan her day. One AYA felt her symptoms, particularly pain, could have been better managed with better communication between herself and the health care team.

Holistic Health. Three participants specifically wanted holistic treatment, acknowledging the body and the mind, medical treatment, and everyday life. As an extension of holistic health, five participants thought disease treatment was excellent but mental health treatment was lacking, and stress and distress were not adequately addressed. Few AYA received mental health treatment beyond prescriptions for antidepressants. Anxiety, fear, distress, and depression were indistinguishable from self-management for both AYA and caregivers in this study.

Social Support. Several participants, particularly AYA, discussed the need for more social services and support outside of health care providers. AYA and caregivers felt social support services with peers or outside organizations would help combat the isolation experienced during HSCT and would give families the opportunity to interact with others going through the same experience. One AYA

advised health care providers, particularly home health care, that assistance and advice in organizing supplies for would be welcome and helpful in planning self-management activities.

Discussion

Self-management is generally characterized as the ability to follow a prescribed care regimen. Nonadherence to care regimens has direct implications on nursing practice and organizational policy. Participants identified both facilitators and barriers in managing daily care regimen activities. Participants found it helpful to have an organizational system for supplies and medication, particularly a large pill-box. Frequently changing medication regimens and pill size were some challenges both AYA and caregivers identified. Participants, particularly caregivers, also identified education and information from health care providers as facilitators. Interventions around medication management should incorporate education on the medication regimen, particularly when changes are being made. It would also be beneficial to do a check-in with patients to see if they are having any trouble with their regimen and offer suggestions on how to minimize identified problems. Establishing home health staff competency on patient care equipment would also be a meaningful intervention.

Research participants related how depression, anxiety, and fear drove their behaviors. AYA and caregivers in this study described being socially isolated and depressed, which compounded symptom experiences of fatigue and generalized weakness. AYA are at an increased risk of having mental health comorbidities while suffering from a chronic illness, which could affect daily functioning and ability to manage care regimens (Zebrack et al., 2014). For this reason, mental health screenings with both AYA and caregivers are essential throughout the treatment course (Kearney, Salley, & Muriel, 2015; Steele, Mullins, Mullins, & Muriel, 2015).

Limitations

This sample was primarily Caucasian and married, limiting the generalizability of the results. Future work should strive to acquire more diverse samples both ethnically and demographically. Recall bias is an inherent limitation of the methodology; there was on average 1.5 year's lapse between HSCT and the interview. However, using constant comparison methods, participant responses were very similar regardless of time elapsed since transplant.

Implications for Practice

Patient education, care coordination, bedside care, and initial triage and assessments are nursing responsibilities.

Nurses should be involved in the assessment and treatment of the psychological aspects of treatment as well as adherence to the prescribed regimen. Medication reconciliation has been identified as a National Patient Safety Goal (NPSG.03.06.01) by The Joint Commission (2015). In the National Patient Safety Goal, organizations are to have an accurate record of medications the patient is taking and how they are taking them, the education the patient received about medication administration, and how this information is communicated between health care units and settings (The Joint Commission, 2015). As part of the medication reconciliation process, nurses should not only ask what medications patients are taking and when their last dose was taken but also if they think they have missed any doses in the last week and, if so, what interfered with taking their medication (Pai & McGrady, 2015). These questions should be asked in an open, matter of fact, and inviting way to encourage accurate patient response. Honest feedback from patients is critical to personalizing self-management strategies.

Interactions between health care providers and families should be respectful, positive, and informative. Families desired information to be presented in a way that was easily understood by laypersons, from a trusted source, and consistent across care providers. Information should also be available for different developmental levels. Suggested practice changes include developing educational materials for each developmental stage, and recognizing that patients and families desire social interaction with health care providers. Families' desire to interact socially with health care providers may increase the likelihood of boundary crossings. Organizations should establish social media guidelines and train staff on appropriate social behaviors and coping with the potential emotional burden.

There were also facilitators and barriers in mental and emotional aspects of self-management for this population. Care should be holistic and take into account not only the patient's physical health and disease status but also his or her mental health and social needs and how medical care affects everyday life. A potential practice change participants identified includes incorporating mental health and psychological assessments and services into each patient's plan of care. Caregivers indicated this is an area where they struggle as well; practitioners should consider having resources or services available to the entire family. The importance of a positive attitude both personally and in those providing support was evident in participant responses. It is important for health care providers to maintain a positive attitude while communicating honestly and transparently with families and to find personalized sources of positivity and motivation for each patient.

Opportunities to socialize, particularly with peers who have experienced HSCT, may be helpful for both AYA and caregivers. Isolation and monotony were identified as barriers and social support as a facilitator to self-management. Finding ways to integrate socialization into care and activities, particularly when patients are under isolation protocols, could be helpful for patients and caregivers. Some suggestions include having Skype, Facetime, or another social media outlet for socialization with family, friends, and school.

Conclusion

Recommendations for practice change were designed to address facilitators and barriers to self-management for AYA following HSCT. Evidence was based on participants' responses from a grounded theory research study. Practice changes designed to address AYA self-management should integrate patient perspectives so they are applicable and relevant. All practice changes should be monitored for feasibility, fidelity, cost-effectiveness, and sustainability.

Acknowledgments

Thank you to all the patients and families who participated in this research.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project was funded by the DAISY Foundation Research Grant.

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