

Synthesis of self-management strategies used by young adults who have undergone hematopoietic stem cell transplantation: A narrative review

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ABSTRACT

Hematopoietic stem cell transplantation is frequently used to treat young adults with hematologic cancer. The treatment can cause a range of side effects that require patients to self-manage their symptoms. However, there do not seem to be any studies that review the literature on self-management strategies used by this group. The purpose of this paper is to summarize the self-management strategies used by young adults (18–39 years old) who have received a hematopoietic stem cell transplant for leukemia or lymphoma. A narrative review conducted in the CINAHL, MEDLINE and PsycINFO databases returned 11 papers. An analysis of these data shows that young adults use self-management strategies, including managing their emotions, turning to spiritual beliefs, seeking support from others and changing their behaviours. The results stress the importance of nursing care in supporting these self-management strategies used by young adults who have undergone hematopoietic stem cell transplantation.

Keywords: self-management, young adults, stem cell transplantation, hematopoietic stem cell transplantation, review, leukemia, lymphoma

INTRODUCTION

Thanks to medical and technological advances, hematopoietic stem cell transplantation (HSCT) is frequently used to treat certain types of cancer, including leukemias and lymphomas (Antin & Raley, 2013). These cancers are commonly seen in young adults (National Cancer Institute, 2021) and are an indicator for allogeneic (i.e., from another donor) HSCT (Mosesso, 2015). However, allogeneic HSCT is known to elicit a number of side effects, such as graft-versus-host disease that can affect various systems, including the skin, mucous membranes, musculoskeletal system, gastrointestinal tract, lungs and bone marrow (Kelly et al., 2015). This situation therefore requires patients to self-manage their symptoms, which sometimes prove to be chronic (Howell et al., 2017). However, young adults with cancer have limited life experience to be able to overcome these challenges, including those related to self-management (Zebrack & Isaacson, 2012). Self-management can be defined as a dynamic and continuous process that refers to “the individual’s ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition” (Barlow et al., 2002, p. 178).

Upon hospitalization, young adults undergoing HSCT must self-manage their symptoms, maintain a certain level of autonomy and control their emotions (Haase et al., 2020). Complications may appear later in young adults who are transplant recipients that require significant lifestyle changes (Brauer et al., 2018). To the best of our knowledge, very few studies have reviewed the literature on self-management strategies (SMSs). The purpose of this paper is therefore to summarize the SMSs used by young adults (18–39 years of age) who have undergone HSCT as a treatment for leukemia or lymphoma.

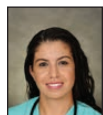
METHOD

A narrative review was conducted to synthesize the available studies and highlight existing knowledge on the topic (Paré et al., 2015). A combination of keywords and descriptors was used in CINAHL, MEDLINE and PsycINFO. The keywords and descriptors were associated with three concepts: 1) self-management (self-care, coping, etc.); 2) young adults (Generation Y, millennial, etc.); and 3) hematopoietic stem cell transplantation (HSCT, bone marrow transplantation, BMT, GCH, etc.). Research criteria were: 1) be written in English or

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French; and 2) be a primary study. All scientific papers published between 01/1970 and 09/2020 were selected to ensure the scope was as comprehensive as possible.

Initially, 207 papers were found using this research strategy. The results were imported into Covidence, following which 37 duplicates were removed. The titles and abstracts of the papers were read by BV, and their eligibility was assessed. The references of the selected papers were then reviewed, and another paper was added to the list as a result. The extracted data (i.e., author, year of publication, purpose and design of the study, types of cancer targeted, and number and age range of participants) were compiled in an Excel spreadsheet and analyzed to determine similarities and differences. The quality of the papers was not assessed as this is not a standard practice in a narrative review (Paré et al., 2015). A flowchart illustrating this process is included in Figure 1.

RESULTS

A total of 11 papers were selected: six grounded theory studies, one randomized clinical trial, one ethnographic study, one phenomenological study, one mixed design study and one unspecified qualitative design study. Of these, eight

studies were conducted in the United States and three in Iran. Together, they covered 83 women and 95 men aged 11 to 48 years of age. Table 1 lists the characteristics of the selected studies. An analysis of the data revealed a number of SMSs related to managing emotions ($n = 16$) (e.g., reducing stress, distracting oneself, adopting a positive attitude) and seeking support from others ($n = 5$) (e.g., involving family members in care, talking to young adults who are HSCT survivors). The results also indicate that spiritual beliefs ($n = 7$) (e.g., relying on one's faith, seeing cancer as a divine test, accepting one's fate), individual behaviours ($n = 15$) (e.g., changing eating habits, avoiding high-risk behaviours) and involvement in care ($n = 10$) (e.g., seeking out treatment alternatives, setting goals and taking an active interest in one's own care) are SMSs that are commonly used by young adults after HSCT. Our results also show that reliance on spirituality is a major SMS for young adults who have undergone HSCT. This strategy was emphasized in five studies (Cooke et al., 2011; Farsi, 2015; Farsi et al., 2010; Farsi et al., 2012; Haase et al., 2020). Despite the different cultures and varying spiritual beliefs touched on in these studies, they all report that spirituality can play a critical role in providing post-HSCT support to young adults.

Figure 1

Flow Chart

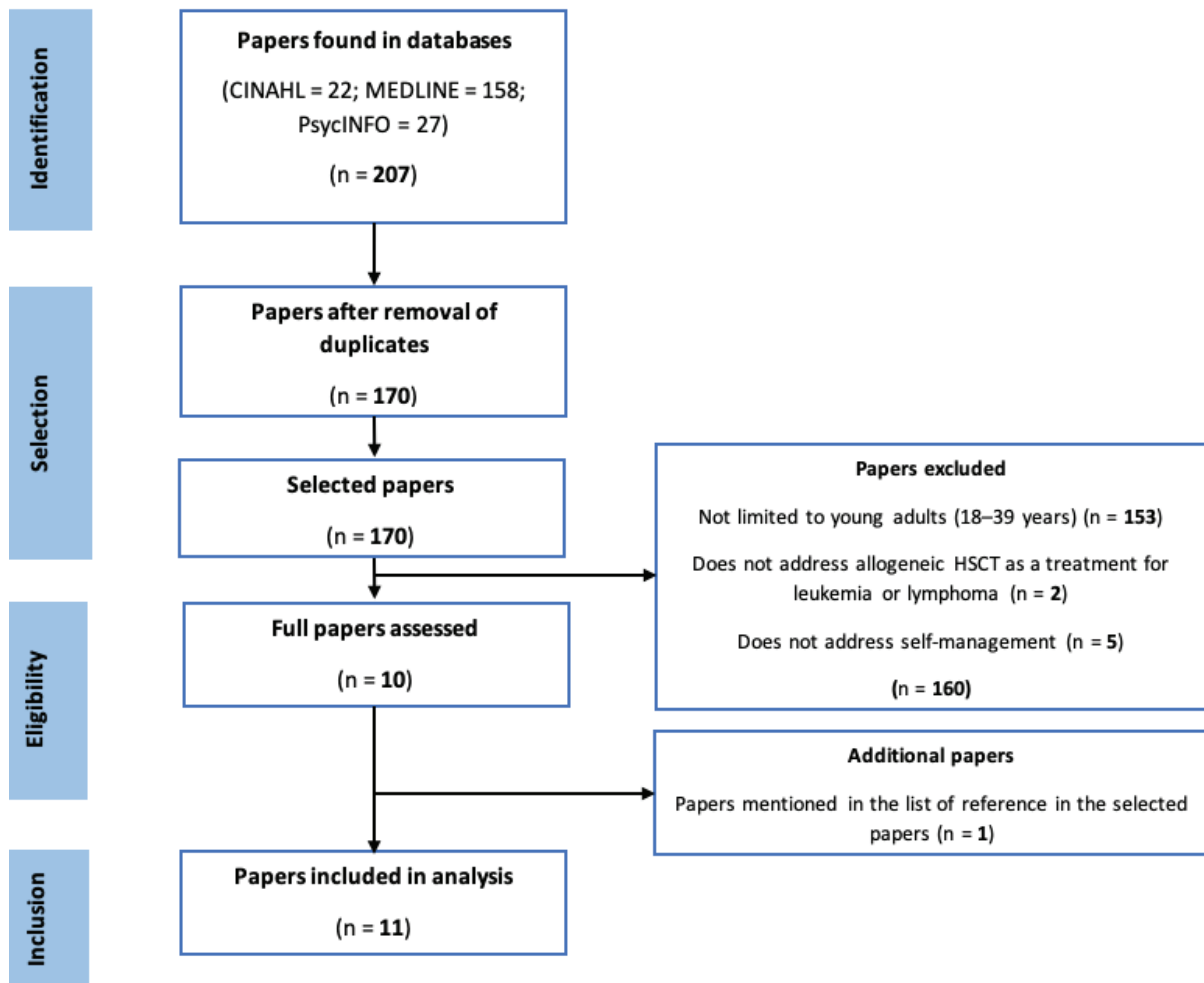


Table 1		
<i>Description of Selected Papers</i>		
Authors (Year) Country, Method	Goal	Characteristics
Brauer et al. (2017) USA, GT Brauer et al. (2018) USA, GT	Explore return-to-work and return-to-school processes for YACs following HSCT Explore transition to self-care in a sample of YACs following HSCT	18 YACs aged 18–29, 8–60 months after HSCT (women <i>n</i> = 7; men <i>n</i> = 11) ALL: 5, AML: 10, HL: 2, NHL: 1
Cooke et al. (2011) USA, mixed longitudinal	Describe the experiences of YACs in the year following their HSCT	24 YACs aged 18–25 having undergone HSCT (women <i>n</i> = 13; men <i>n</i> = 11) acute leukemia: 20, Hodgkin's disease: 2, CLL 1, myelodysplastic syndrome: 1
Farsi (2015) Iran, GT Farsi et al. (2010) Iran, unspecified qualitative Farsi et al. (2012) Iran, GT	Explain how the meaning given to disease and spiritual responses to stressors influence the experiences of adults undergoing HSCT Explore coping strategies of Iranian adults with acute leukemia who are undergoing HSCT Articulate the coping strategies of adults with acute leukemia undergoing HSCT	10 YACs, aged 18–48 undergoing HSCT (women <i>n</i> = 5; men <i>n</i> = 5) AML: 6, ALL: 4
Haase et al. (2020) USA, phenomenological	Describe the experiences of YACs who took part in an intervention during their hospitalization for HSCT as part of a randomized clinical trial	14 YACs aged 13–22 having undergone HSCT (women <i>n</i> = 4; men <i>n</i> = 10), sample from Robb et al. (2014)
Morrison, Martsof et al. (2018) USA, GT Morrison, Pai et al. (2018) USA, GT	Describe how YACs manage their medications following HSCT Present facilitators and barriers for YACs following HSCT	17 YACs aged 13–25 undergoing HSCT (women <i>n</i> = 9; men <i>n</i> = 4) AML: 2, ALL: 1, HL: 3, other: 11
Nance and Santacroce (2017) USA, ethnographic	Analyze how a blogger describes stressful elements, neuropsychological symptoms and coping strategies during HSCT	1 woman undergoing HSCT; AML: 1
Robb et al. (2014) USA, randomized clinical trial	Examine the efficacy of therapeutic music video intervention during the acute phase of HSCT	113 YACs aged 11–24 having undergone HSCT (women <i>n</i> = 48; men <i>n</i> = 64)
Abbreviations: GT: Grounded theory; YACs: young adults with cancer; HSCT: hematopoietic stem cell transplantation; HL: Hodgkin's lymphoma; ALL: acute lymphocytic leukemia; AML: acute myelogenous leukemia; NHL: non-Hodgkin's lymphoma; CLL: chronic lymphocytic leukemia.		

The next few paragraphs provide more details on the SMSs included in each of the selected studies.

Brauer et al. (2017) conducted a grounded theory study in the United States involving 18 young adults aged 18 to 29, and the results led to two separate studies. The goal of the first study was to explore the return-to-work and return-to-school process for young adults following HSCT. The findings indicate that participants used different SMSs to save energy (e.g., using a wheelchair or adding rest periods). To avoid becoming overtired, they tended not to engage in sports or opt for precooked meals instead of preparing their own. To offset the cognitive problems resulting from treatment, the young adults reported using calendars and lists. However, as stated by Brauer et al. (2017), the results only barely touch on the return-to-work process given the young age of the subjects in their sample. Overall, the findings show that young adults are

capable of mitigating the impact of certain symptoms, especially when returning to school.

The second study by Brauer et al. (2018), also carried out in the United States, explored the transition toward self-management for young adults who have undergone HSCT. The authors point out that young adults seek support from the people around them to help manage the various symptoms associated with HSCT in order to make activities of daily living and domestic tasks easier. Brauer et al. also indicate that young adults require the simultaneous support of multiple caregivers (e.g., relatives, friends, roommates, romantic partner). Finally, they state that, by doing domestic tasks, caregivers may be making young adults temporarily dependent on them, which can hinder the journey to self-sufficiency.

The U.S. study conducted by Cooke et al. (2011) sought to describe the experiences of 24 young adults aged 18 to 25

during the year following HSCT. The results show that young adults use a range of technology tools to distract themselves (e.g., computer, mobile phone). Some sign up for online classes as a way to pass the time while in the hospital and upon their return home. They also tend to reach out to their social circle to overcome obstacles both before and after HSCT. In addition, the study indicates that young adults verbalize their concerns to nurses about their sexuality (e.g., fertility, fear). However, these conversations rarely take place in the presence of a romantic partner or parents, given the awkwardness it can cause.

As part of the qualitative study conducted in Iran by Farsi et al. (2010), the authors talked to 10 young adults aged 18 to 48 to determine what SMSs they were using. The results show 17 SMSs used at various points along the post-HSCT journey, among them denial, gathering information, seeking social support, changing priorities and positive thinking. Some of the documented strategies were associated with spiritual beliefs. As the authors point out, some SMSs, like prayer, are based specifically in young adults' spiritual beliefs, allowing them to be more accepting of their diagnosis and find meaning in the experience. It is nevertheless important to be careful when considering these results since beliefs of this nature vary from one participant and one culture to the next.

As part of a grounded theory study performed in Iran, Farsi et al. (2012) mapped out the coping process of these participants in illustration form. The study's authors report that patients use different SMSs to control negative emotions and maintain hope (e.g., avoiding thinking about a problem, exhibiting patience and resignation, relying on faith). They explore different SMSs that are influenced by internal contextual factors (e.g., feeling guilt, feeling abnormal, experiencing body changes), external factors (e.g., relationships with loved ones, access to healthcare institutions) and the passage of time.

Another grounded theory study conducted by Farsi (2015) in Iran, using the same sample, explains how the meaning given to disease and spiritual responses influence the experiences of adults who have undergone HSCT. Farsi emphasizes that young adults tend to cling to their faith throughout HSCT and construe cancer as a divine test or a punishment for past behaviours. Assigning meaning to their cancer helps promote self-management and alleviates some of the burden they feel. All in all, the results show that faith can be a self-management strategy that aids in overcoming the unpleasant symptoms and experiences that young adults encounter during and after treatment.

The randomized clinical trial conducted by Robb et al. (2014) in the United States with 113 young adults aged 11 to 24 was designed to test the efficacy of a therapeutic music video intervention during the acute phase of HSCT. The intervention included suggesting SMSs to facilitate self-care in young adults undergoing HSCT. The aim of these SMSs was to encourage the young adults to participate in their own self-care, focus on the elements they deemed the most important in their life, articulate their desires, and reach out to family and friends, in addition to helping them communicate with others. Overall, this study shows that a therapeutic music video intervention can be a source of support for young adults during HSCT by helping to promote self-management.

The phenomenological study done by Haase et al. (2020) in the United States aimed at describing the experiences of 14 young adults aged 13 to 22 who had undergone HSCT and participated in therapeutic intervention documented by Robb et al. (2014). Participants credited the intervention with helping to alleviate the psychological distress they sometimes felt by using certain SMSs, such as comparing their situation with other cancer survivors, expressing their gratitude at being able to do various activities (e.g., physical exercise) and celebrating important dates after HSCT. This intervention also let the young adults create pleasant memories and establish new relationships with their caregivers and healthcare professionals. Finally, participants added elements to the videos that were symbolic of the spiritual beliefs that helped them through their HSCT and subsequent complications.

In the United States, the same grounded theory research led to two studies involving 17 young adults aged 13 to 25 years. The first study, conducted by Morrison, Martsolf et al. (2018), indicated that the teens and young adults undergoing HSCT use various SMSs to manage their medications (e.g., keeping their medications organized, reading the documentation given to them by healthcare professionals). They also adopt different SMSs to limit their negative experiences (e.g., using analgesics during their hospital stay, breaking off contact with other people, blocking negative experiences to protect themselves). These young adults also use various SMSs related to organizing their care (e.g., making to-do lists, setting goals, using rewards to keep themselves motivated).

The second study, conducted by Morrison, Pai et al. (2018), identifies the obstacles, facilitating factors and SMSs used by young adults following HSCT. The study findings indicate that young adults undergoing HSCT use various SMSs to make it easier to manage their self-care on their own (e.g., using a pill organizer or a mobile app, arranging the necessary self-care supplies in a structured way). The authors indicate that these young adults put various SMSs in place to limit the impacts of certain psychological symptoms by using distraction, adopting a positive attitude, relying on spiritual beliefs and avoiding the Internet to steer clear of misinformation. In addition, young adults undergoing HSCT can accept they have limited control over their situation, reach out to friends and family members for support or talk to another person living with cancer. In short, this study provides insight into the SMSs used by young adults who have undergone HSCT in order to manage their medications and deal with their emotions. However, the authors do not explore SMSs used to alleviate physical symptoms, as their focus is solely on the psychological aspect.

Lastly, as part of an online ethnographic study, Nance and Santacroce (2017) analyzed the blog of a young adult who had undergone HSCT, as published in the *New York Times*. The authors identified various SMSs used by the blogger, including distraction, rationalization and the development of problem-solving skills. The authors mention that the use of social media was helpful in allowing the young adult to stay in touch with her loved ones, lower her stress and document her experiences. The results are novel in that they show how social media can be used to self-manage symptoms. However, since

this study involved a single participant, it would be advisable to repeat it using a broader sample.

To summarize, these studies identified multiple SMSs employed by young adults following HSCT to relieve or control certain symptoms. The SMSs mentioned in these studies are very diverse and intended to allow young adults to manage the physical, psychological and spiritual aspects of their condition. These SMSs include techniques related to saving energy, seeking support from caregivers, taking medications, relying on spiritual beliefs and distracting oneself. However, the papers included do not break down SMS adoption by gender. Moreover, information about moments and situation that prompted participants to choose one SMS over another is scarce.

DISCUSSION

This narrative review helped identify various SMSs used by young adults with leukemia or lymphoma who have undergone HSCT. As far as we know, this is the first synthesis of knowledge focusing specifically on these elements and this group. Surprisingly, only 11 studies were included in the review, despite the broad selection criteria and the very large range of years of publication. It is well known, however, that HSCT patients can experience a host of adverse impacts related to their physical, psychological, social and spiritual well-being (Atilla et al., 2017). The dearth of scientific literature in this regard may also be attributable to the small number of studies involving young adults with cancer, as mentioned in the Canadian Partnership Against Cancer report (2017).

The analysis of the data showed that the most frequently reported SMSs are the ones used by young adults to manage their emotions (e.g., reducing stress, distracting themselves, adopting a positive attitude), control individual behaviours (e.g., changing eating habits, avoiding high-risk behaviours) and be actively involved in their own care. These strategies are often integrated into educational programs to support the self-management efforts of those affected by cancer (Howell et al., 2017). The results of this synthesis add to the state of knowledge in this regard by outlining the SMSs used by young adults, such as reaching out to others for support (Brauer et al., 2018; Morrison, Pai et al., 2018) and finding meaning in the experience through spiritual beliefs (Farsi et al., 2010; Farsi et al., 2012; Farsi, 2015).

The results of this narrative review are consistent with the findings of Taylor et al. (2015), which indicate that young adults, when confronted with an ordeal like cancer, sometimes turn to their spiritual beliefs. In fact, according to Zeighami and Sadeghi (2016), young adults with cancer may lean into their spirituality to relax, feel better and be more hopeful. These findings are in line with ours, which suggest that SMSs related to spiritual beliefs can help young adults post-HSCT gain more control over select psychological symptoms (e.g., anxiety, depressive symptoms), continue to hope, lighten their burden and be more self-sufficient. The results of this narrative review are interesting in that they stress the importance of spiritual beliefs following a cancer diagnosis to help find meaning and manage emotions.

Our results highlight the role nurses can play in assisting young adults who have undergone HSCT by responding to their concerns about sexuality (Cooke et al., 2011), providing social support (Farsi et al., 2010; Farsi et al., 2012; Haase et al., 2020) and actively involving them in their care (Morrison, Pai et al., 2018; Robb et al., 2014). This shows how important nurses are in terms of support and SMS-related learning for these patients. This echoes other literature that examines the role of oncology nurses in helping patients with cancer by coaching them and providing them with psychosocial and spiritual support (Canadian Association of Nurses in Oncology, 2018).

Finally, it has been noted that a number of the studies identified concentrate exclusively on certain aspects of SMSs used by young adults who have undergone HSCT, such as medication management and spirituality (Farsi, 2015; Morrison, Martsof et al., 2018). Given that self-management is a complex and continuous process (Barlow et al., 2002), it seems vital that future studies embrace a holistic vision when considering SMSs used by young adults who have undergone HSCT rather than concentrating on individual components. The use of a holistic vision of this nature is already showing promising results in managing the symptoms of young adults living with cancer (Erickson et al., 2019).

STRENGTHS AND LIMITATIONS

This narrative review provides a unique look into SMSs used by young adults living with cancer who have undergone HSCT. Its main strength lies in the broad literature search in three databases, combining a large selection of keywords and a very large range of years of publication. That being said, the results of this narrative review returned a mere eight studies conducted in the United States and three in Iran, thereby limiting the scope of the results, especially in that the backdrops against which these studies were performed may differ from the reality of care delivery in Canada. Furthermore, the quality of the studies was not assessed and data extraction was carried out by a single person (BV), which may limit the transferability of these results to clinicians. It is important to keep these limitations in mind when interpreting the findings.

IMPLICATIONS FOR NURSING

The results of this narrative review highlight what nurses working in oncology can suggest and support the use of multiple SMSs by young adults who have undergone HSCT (e.g., to help them manage their emotions, encourage them to be actively involved in their care and highlight their spiritual beliefs). However, it is important that the SMSs put forward by nurses fit the sociodemographic characteristics of the young adults in question (e.g., socioeconomic level, sex/gender, degree of literacy). As indicated by Linder et al. (2017), the SMSs they use may vary based on different sociodemographic characteristics, one of which being the gender they identify with. Young women may be more open to complementary treatment, whereas young men may tend to turn to substances such as marijuana and caffeine (Linder et al., 2017). Nurses working in oncology can themselves develop clinical

tools such as checklists, brochures and educational videos to provide information about certain SMSs for young adults who have undergone HSCT. Finally, based on the current state of knowledge, it would seem there is a gap to be filled in terms of information about self-management coaching and the development of initiatives designed specifically to support young adults who have undergone HSCT. These initiatives could take the form of a series of online training modules, text messages or instant messages, as has been suggested by Devine et al. (2018).

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CONCLUSION

To the best of our knowledge, this study is the first time SMSs used by young adults who have undergone HSCT have been synthesized. The results show that young adults utilize an array of SMSs to self-manage physical, psychological and emotional symptoms while in the hospital and when they return to their home, school and workplace. Surprisingly, only one intervention (Robb et al., 2014) was found that showed a gap in the current state of knowledge in terms of the nature and efficacy of various modes of support.

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