The Coping Process in Adults With Acute Leukemia Undergoing Hematopoietic Stem Cell Transplantation

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ABSTRACT

Background: The increasing numbers of leukemia cancer survivors treated with hematopoietic stem cell transplantation (HSCT) face numerous challenges after their transplant procedure. Little information has been published regarding the coping process of this population. Understanding how they cope with this life-threatening disease can assist healthcare professionals to provide holistic care.

Purpose: This study was designed to elicit the coping process of adults experiencing acute leukemia who underwent HSCT therapy.

Methods: This longitudinal qualitative study and grounded theory took place during 2009–2011. Ten adults with acute leukemia scheduled for HSCT were recruited from Shariati Hospital in Tehran, Iran. A series of pretransplant and posttransplant interviews were held in the hospital’s HSCT units. Final interviews took place 2–6 months posttransplant in the hospital’s outpatient clinic.

Results: The five categories that emerged from the data included perceived threat, suspension between fear and hope, rebirth, contextual factors, and coping strategies. Although patients vacillated within the coping spectrum (i.e., the “buffer zone” between fighting and acquiescing), “finding meaning” was identified as the final outcome of their experience that indicated effective coping.

Conclusions/Implication for Practice: Each patient perceives leukemia and HSCT therapy uniquely. This life-threatening disease can significantly affect patient perception and change patient lives both temporarily and permanently. Nurses can apply effective interventions to help patients cope with their unique situation, find meaning and hope, and allay fear and stress.

KEY WORDS: coping, grounded theory, leukemia, longitudinal qualitative design, stem cell transplantation.

Introduction

Hematopoietic stem cell transplantation (HSCT) is an established therapeutic modality for a number of life-threatening hematological malignancies including leukemia (Russell, Harcourt, Henderson, & Marks, 2010; Stephens, 2005). Nearly 100,000 patients annually receive HSCT worldwide, and the number of HSCT survivors is rapidly increasing (Gratwohl, Baldomero, Fraendorfer, & Niederwieser, 2008). Shariati Hospital’s Hematology-Oncology Research Center and Stem Cell Transplantation (HORCSCT) in Tehran, Iran, has registered over 3,000 transplantation cases to date (HORCSCT-Data Management Office, 2010).

Cancer diagnosis is almost always stressful and has the potential to permanently alter individuals’ lives (Miedema, Hamilton, & Easley, 2007). It can lead to serious psychological problems because cancer is considered to be synonymous with hopelessness, unbearable pain, fear, and death (Arsalan, Celebioglu, & Tezel, 2009). HSCT may produce physical and emotional stress associated with regimen-related toxicities (high-dose chemotherapy with or without radiotherapy), the transplant process, and long-term outcomes (Stephens, 2005). Experience with the disease and HSCT may impact patients’ sense of well-being. This study was undertaken to address the lack of information in the literature regarding the coping process of leukemia patients undergoing HSCT. Although coping was described in Lazarus and Folkman’s theory of psychological stress and coping (1984; cited in Khodayarifard & Parand, 2006), it has never been studied in the context of HSCT. Patient experiences may vary according to contextual factors including socioeconomic status, culture, religion, disease stage, and interpersonal context. In Iran, the vast majority of the population is Muslim, and religious culture dominates the society. Followers of Islam pray five times a day, seek guidance from the Koran, and believe that it has power

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99
over every aspect of life. Over 80% of Iranians perform daily prayers regularly as part of their religious commitment (cited in Ebadi, Ahmadi, Ghanei, & Kazemnejad, 2009). Muslims believe that their diseases are in Allah’s hands, and, at times of difficulty, seek help through prayer and religious meditation. Iranian studies have indicated that prayers and spiritual healing were the most commonly used complementary therapy strategies (cited in Ebadi et al., 2009). In addition, Iranians are social and emotional people. Family and friends are great sources of support during difficulties. Therefore, it is possible that the life experiences of Iranian patients will differ from those in other cultures. Because our aim was to understand the coping process of adults with acute leukemia undergoing HSCT, this study used a qualitative approach.

Methods
This study is part of a longitudinal qualitative study using a grounded theory approach. Longitudinal qualitative research using serial interviews offers advantages in understanding patients’ evolving and dynamic experiences (Pinnock et al., 2011). Principally longitudinal research will always involve the collection and analysis of data on more than one occasion over a specified time (Molloy & Woodfield, 2002).

Participants
All participants were recruited from HORCSCT. Inclusion criteria included the following: aged 18 years or older, able to understand and speak Persian, diagnosed with acute myeloid leukemia (AML) or acute lymphoblastic leukemia (ALL), and in adequate mental and physical condition upon participation. All participants were also able to reflect on their experiences and feelings and articulate their thoughts and were willing to participate in the study.

HORCSCT staff nurses helped the investigator recruit the first participant based on the inclusion criteria. Purposeful sampling then continued using theoretical sampling as the data/theory highlighted the sampling direction. Theoretical saturation was established once the logics of the grounded theory analysis were achieved and the final interviews generated no substantial new information.

The sample consisted of 10 adults (five women and five men) with acute leukemia undergoing HSCT. Six had AML and four had ALL. Participant ages ranged between 18 and 48 years (mean = 29.3, SD = 10.1 years); seven were married and five held academic degrees, with three high school graduates and two primary school graduates. All participants were Muslim. Participants were isolated during hospitalization, although relatives were allowed to visit.

Data Collection
In-depth interviews were the main data collection method used to facilitate a comprehensive understanding of the phenomenon under study. The first investigator conducted semistructured interviews with the participants either in their private inpatient rooms or, if postdischarge, in a private outpatient unit room. A series of interviews were scheduled during both the pretransplant and posttransplant periods in the HSCT units. The final interview took place between 2 and 6 months posttransplant, after participants had been discharged from inpatient units. This enabled patient experiences with threatening situations to be captured and examined in depth. Researchers developed guidelines and questions for pretransplant and posttransplant interviews. The first interview focused on participant experiences with the disease from their diagnosis until the present. The opening question was: “Can you tell me about your experience thus far? What was it like to be diagnosed? How did you feel going through the previous therapy?” The next interview began with the question: “Tell me how the last few weeks have been since we last spoke?” Questions also focused on participant perceptions of their disease and HSCT, coping strategies, and factors that facilitated or hindered coping. Subsequent interviews were done to follow up the issues raised in earlier interviews. Repeat interviews helped reduce recall bias and improve data quality (Lawton, Parry, Peel, & Douglas, 2005). Each interview lasted from 40 to 120 minutes. A total of 18 interviews were conducted with participants during the study period from 2009 to 2010. Participants also provided three written narratives. Sufficient data were generated to reach data saturation and answer the research question.

Ethical Considerations
The Research Council of the Tehran University of Medical Sciences approved this study, and the HORCSCT director gave permission before data collection. Data collection was carried out after obtaining verbal and signed informed consent in accordance with the Declaration of Helsinki from participants (Burns & Grove, 2009). The informed consent process provided participants the opportunity to ask questions and consider all options. Participants could refuse to participate or withdraw from the study at any time.

Data Analysis
The procedure used for data analysis in this study was based on a technique described by Corbin and Strauss (2008). Interviews were audio-recorded and transcribed verbatim. Open, axial, and selective coding allowed a structured data analysis process. Coding was conducted immediately after the first interview. Differences between and similarities within codes were identified using the constant comparative method, and similar codes were clustered in the same categories and conceptualized. Codes were revised, and previously coded data were re-coded as needed based on coauthor discussions. The longitudinal approach also involved each interview being analyzed individually and
compared with earlier or subsequent interviews to determine how experiences changed over time (Worth et al., 2009). In fact, longitudinal design dictated that analysis work be conducted in complicated matrices, as it compared both intraphase and interphase (Lin, Macmillan, & Brown, 2010). Baseline and follow-up interview data were compared for those patients who completed the full series. This comparison focused on similarities and changes in situation, perceptions, experiences, and coping strategies between the three time points. Integration occurred around a central explanatory concept, and major categories were related to it through explanatory statements of relationships. Several techniques were used to facilitate the integration process, including asking questions related to code notes, comparing data, writing a storyline, using diagrams, and sorting and reviewing memos.

**Trustworthiness**

Investigators employed prolonged engagement over a 1-year period to increase data credibility. Findings were also checked by some participants and two expert supervisors. External audits by two qualitative research experts were also used to enhance data credibility and trustworthiness, as outlined by Lincoln and Guba (cited in Corbin & Strauss, 2008).

**Results**

Five categories emerged from data analysis, including (a) perceived threat, (b) suspension between fear and hope, (c) rebirth, (d) contextual factors, and (e) coping strategies (Figure 1). The longitudinal qualitative design of the study elicited in-depth understandings of the how and why behind changes in patient perceptions, activities, interactions, and emotional responses over time.

The main theme of the study was the core category of “rebirth.” All main categories were related and subordinated to the core category. Rebirth appeared frequently in the data during all stages of the disease. “Tendency to survive” and “tendency to return to normal life” were found to directly affect coping strategies. “Tendency to survive” was more prevalent in the early stages of the disease, whereas “tendency to return to normal life” increased in prominence after the transplant procedure. “Finding meaning,” indicating effective coping, and the final outcome of patient experiences rose in prominence over time.

Findings showed that passage of time and experience with different disease stages correlated with level of perceived threat to life. “Perceived threat” has a direct effect on level of fear and hope, tendency to survive and return to a normal life, and coping strategies. Level of “perceived threat” diminished after the transplant procedure and with increased time.

Fear increased at diagnosis and immediately before transplant and decreased after chemotherapy and the transplant procedure. In contrast, hope increased during the early stages of chemotherapy and weeks immediately after the transplant procedure. Most patients expressed feeling little hope during the diagnosis phase. Fear and hope in the patient coping process, thus, exhibited a vacillation pattern.

“Contextual factors,” including the passage of time and internal and external factors, either facilitated or hindered coping. These factors directly affected threat perception, level of fear and hope, tendency to survive and return to a normal life, and coping strategies.

Participants used various strategies to cope with threatening situations, most of which had no practical starting or ending points in time but were rather rooted in prior experiences and developed throughout the leukemia and HSCT experience.

**Perceived Threat**

This category included four subcategories, “disregarding disease signs and symptoms,” “sensitivity,” “perceived risk and limited time,” and “changes to everyday life,” which occurred in linear progression over time.

**Disregarding disease signs and symptoms**

Prior to diagnosis, most participants did not pay any attention to the signs and symptoms of their illness. They chose rather to relate such to prior experiences or other diseases:

> I felt an absolute weakness. I always suffer from leg fatigue and my stomach was couldn’t digest food. I thought those symptoms were due to my stomach. I consulted with another specialist about my stomach and he found the low level of platelets in my blood. Unfortunately, he did not mention that low platelet levels are quite vital for health and that I must be quite vigilant and follow continue monitoring this level. I remained ignorant of my condition afterward too. I didn’t pay attention to the disease, especially after I mentioned it to my doctor and he showed no reaction. I finally requested an operation myself. I showed my diagnoses to a specialist and had the operation based on that. (P2)

**Sensitivity**

With the passage of time and increasing perception of disease symptoms, anxiety overcame participants. They became more sensitive to symptoms and tried to identify underlying causes:

> The first night that I had to stay in the hospital, the doctor asked my sister whether there was such a disease among other members of the family. Did anybody else suffer from blood cancer or other cancers? When my sister came back and I saw her red eyes, I realized that there was a serious problem. (P1)
Perceived risk and limited time

When patients recalled their reactions to the diagnosis, most expressed recognition of the possibility of death. One participant wrote about his feelings at the moment he was informed about the disease diagnosis:

That moment was quite hard. Do I suffer from cancer, the most terrible disease, and the hardest to cure? Is it curable? Will I die? I was quite silent for two hours; upset and disappointed with these questions. (P5)

Perceived limited time of life was a common experience that most participants mentioned:

It was a very terrible feeling. I was walking for a week, going back and forth. I was staring at everything as if it was for the last time, a very awful feeling. For two weeks I thought that I would die very soon. (P3)

The participants believed cancer to be a death sentence for most individuals. Some believed cancer to be the worst illness. In the early stages of the disease, they thought about difficulties of treatment and the incurability of their disease:

At first, I was quite astonished; it was hard to believe that I suffered from such a harsh disease with that terrible name, too harsh. Well, ALL and AML type cancers are the most malignant. (P5)

Most participants realized the seriousness of their problems after being informed about the urgency of the transplant procedure. Some believed transplantation to be a difficult surgery with doubtful results. A participant who underwent a second transplantation mentioned:

When I knew that I had to undergo transplantation a second time, I cried hard because transplantation was too hard to bear. (P10)

Changes to everyday life

This subcategory included “changes in physical function,” “endangering core personal ideals,” and “dissocializing.” Immunosuppression and toxicity related to high-dose chemotherapy and HSCT contributed to many difficulties with physical functions. Participants showed a significant decline in physical function as treatment side effects increased. Fear of death gradually overcame them. Most patients reported resuming routine activities some months after the transplant procedure. Some symptoms and side effects remained over the long term.
Participants understood the need to sacrifice some of their ideals to survive and maintain health. They coped with the situation by changing priorities. A participant said:

I felt the disease had destroyed my future. I got a semester off. I was building a good future. I was a smart boy. I was saving money... but this disease annihilated everything. (P3)

Socially, participants reported social isolation and frustration. Because participants experience many side effects during hospitalization and recovery period, their ability to engage in social activities was disrupted. They spoke about their experiences in the isolation room and about the torrents of negative thoughts and distress. They were “birds in a cage” with a desire to fly again. Reflection, patience, resignation, and reliance on faith were often-used strategies in the isolation room. Participants longed to return home. Findings showed that patient social well-being declined while in isolation and increased during the recovery period. Participants believed seeking social support from family, friends, and professional staff to be the main strategy used to cope with this situation.

Suspension Between Fear and Hope
Findings indicated “fear of death” to be the “basic psychological problem” that changed naturally over different disease stages. It reached an extreme level at some stages and decreased in others. For instance, at diagnosis and immediately before transplant, “fear of death” reached its highest level. After chemotherapy and the transplant procedure, fear of death decreased significantly. In the posttransplant stage, fear of death decreased further but did not dissipate completely—even after many months. Participants believed the fear would accompany them for the remainder of their lives. The only factor that made this feeling more tolerable was “hope to survive.” This concept, like the previous ones, changed over time. For instance, in the early stages of chemotherapy and initial posttransplant weeks, “hope to survive” increased. However, most of the patients expressed being hopeless during the diagnosis phase. Both fear and hope had a vacillating pattern across the coping process. Patients spoke of being “suspension between fear and hope” and this “in vivo code” was the “basic psychological process” that emerged from the data. This category included “feelings of uncertainty and anticipation,” “fear,” and “hope.”

Feelings of uncertainty and anticipation
Uncertainty and doubt about the ultimate outcome of their treatment lingered with most patients for months after transplant. They spoke about feeling as if left hanging in the sky. The day after transplant, a participant said:

I am waiting for results of my last bone marrow biopsy. It is a feeling between fear and hope, a situation between successful or unsuccessful transplantation. Let’s think transplantation is successful, what about the rest?! What shall I do with the infection? These are feelings that person cannot explain. It is like hanging from the sky, neither falling or flying. It is a vague feeling. (P5)

Fear
One of the most important themes that emerged from the data was the concept of fear. Investigators focused particular effort to describe “fear” and identify its origin. Fear of death, fear of chemotherapy or and the transplant procedure, fear of transplant rejection/recurrence, and fear of invasive procedures were frequently expressed fears. Although patients chose coping strategies (Farsi, Dehghan Nayeri, & Negarandeh, 2010) to ameliorate their negative feelings, most continued to have them. Fear of death was a recurring worry and one of the most important mental disturbances faced by participants. Some resorted to euphemism and avoided using words such as death and dying. They chose instead used phrases such as “unpleasant incidence,” “invasion of negative ideas,” “observing Azreal,” “rejection of transplantation,” and “losing chances.”

When participants came into contact with other patients’ deaths, their stress and fear increased overwhelmingly. In fact, learning of other patients’ deaths highlighted the closeness of their own death. These feelings can be experienced in healthy individuals as well. Some participants claimed that an important reason for desperation to be healthy and to survive among those who have cancer is fear of death and not having lived a proper life. Such stresses and fears began from the initial disease diagnosis and sometimes continued months after transplantation. Talking about the transplant procedure, a participant said:

I imagined that something very bad was going to happen. I did not know why I was frightened. Just an hour before the procedure, when the instruments were brought in, I began to cry without any reason. (P4)

Another participant said:

I don’t fear death; I fear agony, because someday we all have to die. Nobody knows the time of their own death, but I don’t like to die with agony. I would like to die suddenly, because human beings all have to deal with it someday. (P10)

Although all the participants had experienced feelings of fear from the early stages of their diagnosis, they spoke about gradual reduction of their fears over time. Their reasons included “not being affected by the earthy world
anymore’’ and ‘‘accepting death as inevitable.’’ It appeared that those with stronger faith in God and who believe in an afterlife were less frightened.

**Hope**

Initiating the treatment (chemotherapy and/or transplantation) led to increasing hope for patients. A participant described his feelings about the first chemotherapy:

*From now on, I will be healthy again. (P3)*

Participants stated that hope was a vital force in their lives. Hope was an important factor in their successful adjustment to this threatening situation. Faith in divine mercy, love of family, trust in oneself, and the health of other cancer patients facilitated increased hope among participants.

*Though, God shut a door, He opened another one. (P4)*

The transplant procedure itself was perceived as a major source of hope:

*I was frightened in the early stages. Later when I knew that there were treatments and I could undergo transplant, I felt comfort and hope. (P7)*

Overall, all participants with a ‘‘hope to survive’’ and ‘‘return to a normal life’’ accepted the difficulties of treatment and tried to cope. One participant explained how he tolerated the agony of treatment to realize his hopes:

*I tolerated with the hope that there would be a happy ending to this agony some day. (P10)*

Being informed about cancer symptoms, the potential for relapse and transplant rejection, the death of other patients, and the pain of treatment and symptoms as well as being discouraged by others about transplant outcomes resulted in despair and hopelessness:

*...When I heard its name (cancer), I was in a bad mood for several days—in complete despair. (P4)*

**Rebirth**

This category included ‘‘tendency to survive,’’ ‘‘tendency to return to a normal life,’’ and ‘‘finding meaning.’’ Participants focused on new life and rebirth. They believed the HSCT experience was analogous to being reborn.

**Tendency to survive**

Will to survive persisted within patients throughout all disease stages. The feeling was more prominent during the early stages and reduced, but did not disappear, after the transplant procedure. A participant who explained his fight with the disease gave the following answer to the question, ‘‘What is your main reason for fighting this disease?’’:

*I don’t know; well, maybe life is too valuable. Maybe…. (P9)*

Another participant mentioned:

*I think I was born again after transplantation. (P3)*

The above was a point similarly made by nearly all participants.

*One chooses even the least possible way, even if it is too hard, he accepts it. (P10) ‘‘Why does one choose to undergo such a difficult experience?’’ (Investigator) Because everyone wants the chance—the chance to be healthy again. Nobody likes to be crushed by a disease that…anyway, everybody knows that cancer is the end of the line, and given that situation (deciding to undergo the transplant procedure) one holds onto the hope that it may work and you can be healthy once again. (P10)*

**Tendency to return to a normal life**

Changes to everyday life annoyed patients. Changes experienced by the patients might be permanent, and the post-transplant individual was not physically, psychologically, emotionally, socially, and spiritually the same person who underwent transplantation. Patients were anxious to finish the treatment process and return to a normal life. After the transplant procedure, ‘‘tendency to return to a normal life’’ increased, enhanced by greater hope.

*...Humans fight with their disease in order to return to normal life. If there was no hope for surviving, then they wouldn’t undergo transplantation. (P4)*

Posttransplant life as a separate time period represented a new beginning and a reclaiming of the future.

**Finding meaning**

‘‘Finding meaning’’ was the final outcome of participant experiences. This concept included ‘‘experiencing the meaning of cancer,’’ ‘‘changing perceptions of treatment,’’ ‘‘changing perceptions of death, life, and health,’’ and ‘‘moving towards perfection and sublimity.’’

Patients discussed connectedness to a higher power (God), connectedness to self and relatives, and changing perceptions of the universe. They reported praying more frequently, resorting to consulting religious leaders (Imams), increasing tendency to mosque attendance, and greater religious faith. They believed that HSCT was their last chance for life and that they had made the right choice. One patient mentioned:
Participants viewed disease and death as part of life. They experienced increased closeness to Allah. A posttransplant participant remarked:

I think I moved towards perfection. (P1)

Patients believed that faith helped them cope with their disease and find meaning in life. Patients’ spiritual faith provided meaning to their experiences, which increased their confidence that they would endure the treatment and recover after their HSCT. They believed HSCT to be their last chance for life.

**Contextual Factors**

This category included three subcategories: “time,” “internal factors,” and “external factors.” Some participants believed that the passage of time allowed them to accept and cope with their situation. Length of disease and hospitalization, however, hindered coping. One participant said:

It was difficult at first, but over time I coped with it. (P5)

Internal factors such as feeling deficient or abnormal, experiencing a changed body image, feeling shame or uneasiness, being prepared physically and emotionally, and having intuition tended to facilitate or hinder coping. External factors such as emotional–social relationships, professional factors, finances, facilities, access to HSCT centers, finding a donor, and concomitant issues tended to facilitate or hinder coping. One patient said:

I experienced feelings of uneasiness and shame from my physical complications. I had concerns about going out in public. Some people looked at me as abnormal. (P10)

Finding a donor and treatment costs were important factors hindering coping, whereas positive emotional–social support was the main factor found to facilitate coping. Although the hospital’s board of trustees covered nearly all HSCT-related expenses, most participants reported being troubled by financial problems. Consequently, they sought financial support from family, friends, insurance providers, and benefactors. They reported financial support as a key coping factor. Also, participants believed emotional support to be a main resource for coping positively with leukemia and HSCT. Some participants requested their physicians to leave the room in order to enjoy family support. Visits from close family members elicited joy and renewed energy and gave patients the feeling that they were still important to others. In addition to the moral support mentioned above, participants gave even greater weight to support from family support with regard to decision making, including the transplant procedure. One participant mentioned:

I lost my job and it (HSCT) required a lot of money, but I didn’t have the funds. I had concerns about cost of hospitalization, transportation, rent, medicines and so on. My family helped me handle the situation. (P5)

**Coping Strategies**

Participants used various coping strategies to manage their stressful situation. Some strategies that emerged from the data included attribution, denial and avoidance, connection with divine purpose (acceptance of fate, reliance on faith), organizing treatment (running about seeking treatment, gathering information), seeking social support, modifying (changing priorities, managing treatment side effects), reflection (comparison with others, positive thinking and optimism, dichotomy, pursuing distractions, lenience, setting targets), and patience and resignation (Farsi et al., 2010). In the early stages of the disease, attribution, denial, and avoidance were highlighted most often. Patients distanced themselves from their problems with patience and resignation when no other strategy was effective. Other strategies were present at all stages of the disease and treatment process. In this study, the coping process comprised cognitive and behavioral actions to survive, protect health, and restore equilibrium within the constantly changing new situation. In this study, coping was found to be effective when coping strategies for managing the situation was effective. Outcomes of coping included coming to terms and relief:

I accept Allah’s will. After the disease, I experience more closeness to Allah. I am able to cope with the situation. (P9)

Coping was ineffective when coping strategies for managing the situation were ineffective. No efficiency or acquiescence resulted from coping:

For a long time, I couldn't believe that I had cancer. (P4)

Most strategies used were effective. Some strategies such as denial and avoidance were also associated with positive outcomes when used soon after the onset of stress but resulted in poorer outcomes over the longer term. All participants were Muslim, and a connection with a divine purpose was a commonly accepted coping strategy. Patient religious beliefs led most to accept the situation. Participants saw faith as helping them accept the problem, cope with the situation in a positive way, and overcome difficulties.

The coping process was nonlinear, and participants exhibited different reactions. Stress level, contextual factors
(facilitators and inhibitors of coping), and coping skills were effective coping factors. Although patients vacillated in coping spectrum between fighting and acquiescing, “finding meaning” was the final outcome of their experience, which indicated effective overall coping. Participants fought for life and life values. A participant said:

I fight with disease. (P1)

In contrast, another participant mentioned:

Sometimes, I want to die. Days and nights, I wish to die. (P3)

Discussion

In this study, investigators aimed to understand the coping process in adults with leukemia undergoing HSCT. Almost all patients reported severe physical and/or emotional strain related to their illness and HSCT and the consequences of such. Data analysis showed participant perception as an important component of the patient experience. Perceived threat was a main theme that emerged from data. Some patients made preleukemia diagnosis attributions of their symptoms to prior experiences or other diseases. Koenigsmann, Koehler, Regner, Franke, and Frommer (2006) also reported that adult patients with acute leukemia attributed their symptoms to other illnesses. Patients described their experience learning of the diagnosis as a momentous event in their lives. Patients spoke about feelings of having their lives threatened, either directly or indirectly. Results from other studies offer similar insights (Cohen & Ley, 2000; Koenigsmann et al., 2006; Stephens, 2005).

Another theme elicited from data was suspension between fear and hope. In threatening situations, a sense of hope can provide meaning and sense of purpose (Saleh & Brockopp, 2001). Hope can thus play a major role in helping patients cope with cancer and HSCT. In contrast, feelings of hopelessness increase the severity of depression (Arsalan et al., 2009). Fear and hope in cancer patients have been discussed in the literature (Cohen & Ley, 2000; Doumit, Huijer, Kelley, Saghir, Nasser, 2010; Stephens, 2005). Our findings illustrate that fear was balanced with hope among our participants. This is in line with the results of Cohen and Ley (2000), who studied patient experiences in early stages of the disease. They described their experience learning of the diagnosis as a momentous event in their lives. Patients spoke about feelings of having their lives threatened, either directly or indirectly. Results from other studies offer similar insights (Cohen & Ley, 2000; Koenigsmann et al., 2006; Stephens, 2005).

In this study, some participants expressed pessimism about their situation and the future. Kvale (2007) noted that supporting optimism as an aspect of maintaining hope without lying is probably the most difficult aspect of communicating with cancer patients.

Sources of hope include faith, heartfelt beliefs, support from others, successful recovery of other patients, and...
transplantation. These factors were also reported in other studies (Ersek, 1991; Taleghani, Parsa Yekta, & Nikbakht Nasrabadi, 2006). In this study, participants expressed the need for family support and believed that attendance by family members simplified coping. Saleh and Brockopp (2001) also reported religious practice and family members as the most frequently identified sources of hope in patients with cancer who are hospitalized for BMT. Contrary to Cohen and Ley’s (2000) study, participants in this study longed to return to home. Taylor et al. (2004) quoted from several studies that, “Westerners tend to view a person as independent and separate from other people, whereas Asians tend to view a person as fundamentally connected with others.” Hence, Asians and Asian Americans should be more likely than ethnic Europeans to enlist the help of their social support network to cope with stressful situations (Taylor et al., 2004). Coping via social support is common among Iranians, as helping one another is a core tenet of Islam.

Our findings showed death to be ever present at all stages of the patient experience. The ultimate goal of participants was, first, to survive leukemia and HSCT. This was similar to the finding of Miedema et al. (2007). Participants in this study likened their experience to being reborn. Although “rebirth” is not a theme reported in the literature, some investigators have presented a similar idea. For example, Cohen and Ley (2000) described transplantation as a life-altering event or liminal passage. Although participants described major restrictions in their everyday life, the disease process had made them more mature. The data showed participants moved toward perfection and found meaning in sublimity. In fact, “finding meaning” was the final outcome of the patient experience. Studies have found that each person is motivated by a search for meaning in all life experiences and that it is possible to find meaning in sickness, suffering, and pain (Landmark, Strandmark, & Wahl, 2001). All participants in this study expressed feeling closer to God after getting their disease, which indicated effective coping. Followers of Islam use their beliefs to achieve higher levels of spirituality, and Islamic culture differs significantly from other cultures (Ebadi et al., 2009). Some studies have been identified a possible positive sequel to transplantation involving development of a new life philosophy, greater appreciation for life, making personality changes, and improving relations with family and friends (Cooke, Gemmill, Kravits, & Grant, 2009). Results from this study point in a similar direction.

The predominant goal for participants after discharge from the hospital was to return to a normal life. This finding was similar to that of Miedema et al. (2007), who reported that the prevailing goal for young adults through the cancer journey was to achieve what they called “normalcy.”

Findings also showed that coping with leukemia and HSCT was related to time and internal and external factors. Some of these factors have been reported in other studies (Doumit et al., 2010; Frick, Fegg, Tyroller, Fischer, & Bumeder, 2007). The expense of treatment, particularly as related to transplantation, was considered a major problem for participants, most of whom sought financial support early on in their therapy. Their strategy included seeking financial support from family, securing partial coverage through insurance, borrowing from lending institutions or friends, and requesting donations from welfare agencies or benefactors. Participants stated that financial burden increased their stress. Mosher, Redd, Rini, Burkhalter, and DuHamel (2009) also noted that financial insecurity may precipitate distress among HSCT survivors. Therefore, learning how to use supportive systems seems to be a useful strategy for patients with leukemia who undergo HSCT. This strategy may be useful over the entire course, from initial diagnosis through hospital discharge. All participants considered emotional support from close family members and friends as the most important factor facilitating acceptance of and coping with their disease and transplantation. Muslims are obliged to visit patients and enquire about their health (Halligan, 2006). Such visits gave significant comfort to participants.

Conclusions

Having leukemia and experiencing HSCT are events that are perceived uniquely by every patient. This life-threatening situation can significantly affect patient perception and cause temporary and permanent changes in their lives. Study findings emphasize the importance of exploring how leukemia patients who are recipients of HSCT are affected by threatening events over the course of their diagnosis, treatment, and recovery as well as the impact that the disease and treatments have on their life perception. Healthcare professionals can help patients cope more effectively by better understanding the coping process and providing more effective interventions. Supporting hope and helping patients allay their fears are important roles that nurses play in cancer patient care. Nurses can help patients express their feelings and provide supportive counseling. Healthcare professionals can also help these patients cope by implementing effective interventions that include reinforcing facilitating factors and modifying hindering factors, giving greater attention to patient spiritual needs, helping them find meaning in their unique experience, focusing more attention on family, considering religious and cultural patient care concepts, providing efficient facilities, enriching the available stem cell bank, and establishing a network of HSCT centers nationwide. Finally, the authors hope these findings will assist healthcare providers to better understand patient perceptions and design better resources and interventions to deal with unique patient needs.

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接受幹細胞移植的成人白血病患者之適應過程

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背景 雖然越來越多的血癌患者接受造血幹細胞移植（Hematopoietic Stem Cell Transplantation, HSCT）而存活，然而他們仍面臨許多挑戰。鮮少文獻探討這群血癌患者的因應歷程，瞭解他們面對此威脅情境的因應歷程，將有助於健康照護人員提供整體性照護。

目的 本研究的目的，在於瞭解接受造血幹細胞移植的成人急性血癌患者其因應歷程。

方法 本研究為縱貫性的紮根理論質性研究，於2009至2011年進行。從伊朗Shariati hospital in Tehran招募共十位罹患急性血癌並接受HSCT的病人參與本研究，分別於移植前、後，在HSCT的單位進行一系列的訪談，最後一次的訪談時間安排在移植後的2至6個月，於門診單位進行。

結果 從訪談資料中可形成五個類別，分別為感受威脅、在恐懼與希望中游移、重生、脈絡因素與因應策略。雖然病人在因應光譜中移動（從反抗到默許），但最終「發現意義」的經驗作為其能夠有效因應的指標。

結論／實務應用 罹患血癌並經歷HSCT對病人來說是獨特的經驗，這些威脅生命的情境，嚴重影響病人的覺知，並造成他們生活上短期或永久的改變。護理人員能夠協助病人因應這些情境，從中發現意義與希望，並透過有效的介入措施減少恐懼與壓力。

關鍵詞：適應、紮根理論、白血病、長期追蹤質性研究、幹細胞移植。