LIVED EXPERIENCE OF PATIENTS UNDERGOING ALLOGENEIC PERIPHERAL HEMATOPOIETIC STEM CELL TRANSPLANT

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ABSTRACT

Hematopoietic stem cell transplantation offers cancer patients hope for a cure. However, during the transplant process, patients experience great discomfort, which has a substantial impact on their psychological, social, and spiritual well-being and severely affects their quality of life. The objective of this study was to understand the lived experience of patients during the period from 100 days to 1 year after undergoing an allogeneic peripheral hematopoietic stem cell transplant. A phenomenological method proposed by Giorgi, purposive sampling, and in-depth interviews were used. We interviewed 14 patients (9 males, 5 females) in the hematology and oncology outpatient department of a teaching hospital in central Taiwan. Analysis of the interviews revealed 6 themes: interference of symptoms, interruption of important developmental tasks, low self-value, unbreakable shackles, support network, and living in the moment. Although the physical, psychological, and social functions of the participants gradually stabilized during the year after their transplant, several symptoms continued to interfere with their daily lives. They doubted their ability to contribute to their family, worried about their competence to have children, and faced threats of graft rejection, cancer recurrence, and even death. However, by leaning on social supports, thinking positively, and maintaining hope, participants were eventually able to return to normal lives and plan for the future. Health professionals should actively provide transplant patients with relevant information and should assist patients in alleviating physical and psychological pain and in maintaining social contacts and hope.

Keywords: Allogeneic peripheral hematopoietic stem cell transplant, Hematological cancer, Lived experience

INTRODUCTION

Malignant hematological diseases lead to hematopoietic dysfunction due to invasion of the bone marrow, and this dysfunction substantially increases the risk of various life-threatening complications. The traditional standard treatment for these diseases is high-dose chemotherapy with the objective of complete remission.1 However, compared to chemotherapy, hematopoietic stem cell transplantation can better control hematological malignancies to achieve the objective of a cure.2 However, the pre-transplant conditioning regimen, which consists of high-dose chemotherapy and total body irradiation, severely damages tissues and organs, including the skin and mucous membranes, and leads to severe myelosuppression, gastrointestinal disorders, endocrine dysfunction, sexual dysfunction, and other troublesome side effects. Moreover, patients undergoing allogeneic, as opposed to autologous, transplant face the threat of graft-versus-host disease (GVHD), which not only impairs their physiological functions but also impacts their psychological and social well-being, as well as their post-transplant quality of life.3 GVHD can be divided into acute and chronic forms, both of which damage the mouth, gastrointestinal tract, liver, lungs, and skin to varying extents. The symptoms of GVHD significantly reduce patients’ overall quality of life.4,5 Chronic GVHD usually occurs within the period from 3 months to 2 years after the transplant; in approximately 2/3 of patients, GVHD occurs within 1 year of the transplant.6,5 If patients’ perceptions of GVHD are to be fully assessed, this entire time period must be evaluated. A cross-sectional study showed that the health of patients gradually stabilizes and quality of life is recovered to a certain extent within 1 year of the
Each culture teaches specific values, beliefs, attitudes, and habits. Therefore, a multidimensional exploration of the experiences of patients undergoing allogeneic hematopoietic stem cell transplant, as seen from the patients’ perspective, is extremely important for improving healthcare personnel’s understanding of patients’ feelings. We wanted to investigate the perspectives of Taiwanese patients with cancer after undergoing allogeneic peripheral hematopoietic stem cell transplant. Therefore, we conducted in-depth interviews with Taiwanese patients who had undergone a transplant, with the goal of understanding their lived experiences during the period from 100 days to 1 year after the transplant. We believe that our results can help nurses to better understand the needs of patients and thus provide nursing care that meets those needs.

**METHODS**

**Research Design**

We used the phenomenological method proposed by Giorgi to conduct in-depth semistructured interviews and collect data with the goal of understanding the experiences of patients who received a allogeneic hematopoietic stem cell transplant for treatment of hematological cancer. The guideline for the semistructured interviews (Table 1) was created after discussions with 3 senior researchers who specialize in qualitative study, cancer nursing, and hematopoietic stem cell transplantation. Before the data were collected, a pilot study was performed to confirm the appropriateness of the interview guideline.

**Sample and Setting**

We used purposive sampling to select participants who (1) were aged 20 years or older, (2) had undergone allogeneic hematopoietic stem cell transplant at least 100 days and no more than 1 year prior to the study, (3) had no obvious cognitive impairments, (4) could communicate clearly in Mandarin or Taiwanese, and (5) consented to participate in the study. Patients were excluded if they had any medical condition that precluded participation in an interview session lasting 30 minutes. Participants were drawn from patients at a teaching hospital in central Taiwan. The participants chose the interview location, either in the privacy room at the hospital or at their residence, whichever was the most comfortable and relaxing for them.
Participants

For this study, we interviewed 14 participants (9 males, 5 females) between the ages of 21 and 59 (average age, 37.6 years). All were patients with diagnosed hematological malignancies, including acute myelogenous leukemia, acute lymphoblastic leukemia, chronic myelogenous leukemia, severe aplastic anemia, and lymphoma. The participants had undergone allogeneic hematopoietic stem cell transplant 102 days to 12 months prior to the start of the study.

Data Collection and Analysis

Permission (DMR101-IRB1-168) for this study was obtained from the Research Committee at the teaching hospital. Data were collected from July 2012 to July 2013. Interviews lasted approximately 50–70 minutes each, were audiotaped with the participant’s permission, and were transcribed verbatim immediately after the interview. Data collection was ended when saturation was achieved, that is, when no new themes emerged from the participants’ narratives, and the data were becoming repetitious. Phenomenological methods proposed by Giorgi were then used to analyze the data.

Trustworthiness of Data

Trustworthiness of data was established by means of the criteria established by Lincoln and Guba, credibility, transferability, dependability, and confirmability. The first author—who is a doctoral candidate in nursing, has been trained in qualitative interviewing, and has worked in an oncology unit for 10 more years—conducted all the interviews to maintain consistency of the interview process. In this study, the patients’ oncologists introduced the author to potential participants so that they could get know each other and establish trust for the interview process. Each typed transcript was carefully checked by re-listening to the corresponding tape to ensure the accuracy of the transcript; the use of controlling conditions and variations in the sampling analysis of a large volume of qualitative data established transferability. Dependability was validated by means of a peer review analysis process. Three researchers with doctoral studies training specializing in cancer care and qualitative studies conducted data analysis of the verbatim text and then cross-examined the analysis results. The participants were also invited to verify the results.

Ethical Considerations

To protect the participants’ rights and interests, we explained the purpose and procedures of the study in detail before the interviews, and the participants gave written informed consent. Participants had the right to request termination of the interview and to unconditionally destroy their interview records at any time. To protect the identity of the participants, the researchers used letters (A–N) instead of the participants’ real names in presenting documents or reports related to this study, and data were encoded before storage.

FINDINGS

Phenomenological analysis of the interviews revealed that the participants experiences could be categorized into 6 themes, each with several subthemes (Table 2): interference of symptoms, interruption of important developmental tasks, low self-worth, unbreakable shackles, support network, and living in the moment.

Theme 1: Interference of Symptoms

The participants experienced substantial post-transplant physical distress, including lack of appetite, loss of strength, and change in appearance.

Lack of appetite

The participants experienced a lack of appetite, caused by chemotherapy-induced taste bud alterations, which came in two forms: loss of taste sensation and distorted sense of taste. The form varied among the participants, as did the duration of alteration and the extent of recovery. For some participants, altered taste lasted for more than half a year.

Loss of strength

The participants experienced substantial post-transplant loss of strength and physical weakness lasting for approximately half a year.

“I feel very tired. I was even too tired to answer the cellular phone beside me.” (participant F)

Change in appearance

The participants experienced numerous changes in their...
appearance—including local and systemic skin peeling or skin hardening, skin pigmentation, hair growth, and edema—that led to psychological and social withdrawal.

“I feel that I am very ugly and I do not want to go outdoors....I am totally different from what I used to be....Sometimes, I feel sad when I think of such a change in appearance. I wonder how I become so ugly, and I fear that I’ll never return to what I used to be....I even intend to commit suicide.” (participant C)

Theme 2: Interruption of Important Developmental Tasks

Participants of childbearing age were concerned about the potential effects of chemotherapy and radiotherapy on their reproductive function. Therefore, they feared childbearing and intimate relationships.

Concerns about procreation

During the transplant process, participants received various anticancer therapies that can affect reproduction. Doctors asked participants of childbearing age whether they intended to preserve sperm or ova for future procreation after their disease was cured. Some participants suggested that surviving was more important than having children. However, most of the participants indicated that they were uncertain about whether to have children. They worried about passing on a genetic predisposition to cancer and about the possible effects of drug residues in their body on the health of their future children. Therefore, they were concerned about pregnancy.

“Undoubtedly, I am worried that I cannot have children....I had undergone radiotherapy. If I become a mother one day, I will be concerned about pregnancy since I have no idea whether there is any residual radiation in body....My body had been affected. I am afraid that my children will be unhealthy.” (participant B)

“My father requested me not to retain sperm since unhealthy sperm will lead to unhealthy children.” (participant G)

Termination of intimate relationships

Participants who were in intimate relationships worried that their health problems would lead to their becoming a burden to their partner. Thus, they actively terminated mutual relationships, and even felt as though they had lost the ability to love.

“I think that I will never fall in love again because the development of relationship may lead to marriage. However, being a patient will become a burden to your partner and his families....I broke up with my boyfriend before I was discharged from hospital.” (B)

Theme 3: Low Self-worth

After the transplant process, patients experienced physical discomfort, fatigue, loss of strength, low immunity, and other effects and felt that their lifestyle was restricted. They were unable to engage in prior interests or carry out their job duties. The changes in financial status and lifestyle threatened the participants’ self-worth.

Being unproductive

The participants, all of whom were adults, suggested that they should be productive at the current stage of their life. Their job not only was a source of income but also gave them self-confidence and a sense of achievement. However, because they were unable to work after the transplant, they lost their job, which led to financial difficulties. The participants felt that they were unproductive and a source of stress for their families.

Self-perception of uselessness

Most of the participants did not return to their jobs within 1 year after the transplant, and during this period, almost all of them relied on family support. Their financial dependence made them feel that they were useless and were not contributing.

Lifestyle restrictions
The participants continued to experience fatigue, loss of strength, and worries about infection, bleeding, and other potential complications for nearly half a year after receiving a transplant. They worried about going outdoors and thus could not engage in leisure activities or sports that they used to enjoy. Therefore, they felt that their lifestyle was restricted, and their self-worth decreased.

Theme 4: Unbreakable Shackles

The transplant process is painful and filled with uncertainties. The participants were bombarded with worries about post-transplant rejection, whether the transplant was successful, the possibility of cancer recurrence, and the threat of death. Consequently, they felt that they were bound by unbreakable shackles.

Expectation and distress of rejection

Approximately 100 days after transplant, the participants started to experience graft-versus-host reactions, which were expected but were nevertheless distressing to the participants. To a certain extent, rejection indicates that the donor’s hematopoietic stem cells are functioning in the body of the recipient. However, excessive rejection can also lead to physiological discomfort and reduced quality of life, and severe rejection carries the risk of death. Therefore, rejection was both expected and a source of distress.

Worry over recurrence

Every 3 months, the participants had to return to the clinic for monitoring of their disease progression. These visits tended to make the participants sensitive to their physical changes and remind them about the possibility of recurrence. The participants also indicated that they tended to be anxious while they were waiting for the results of bone marrow biopsy.

Returning to the starting point

Participants whose cancer did in fact recur felt that all their efforts had been in vain or were meaningless, and that they were forced to return to their starting point, which frustrated them a great deal. Some participants even suggested that they felt different about their cancer recurrence than they did about the initial diagnosis of cancer; they worried that recurrence indicated that no medication would work on their cancer in the future.

“I felt frustrated when the result of bone marrow biopsy came out. The doctor said that my cancer recurred. I was extremely depressed. Recurrence was really a shock to me because the result was not what you expected. I started to feel that the previous treatments were meaningless.”
(participant G)

Fear of death

While waiting for the results of follow-up examinations, participants experienced a sense of uncertainty. If they learned that patients that they knew had passed away, they would be confronted with the fact that they too might die of their cancer. Participants who had young children were particularly worried about death.

“Every time I came to the outpatient clinic, I felt like awaiting sentencing, especially when my blood cell count was low and I needed a blood transfusion. I really felt worried....I would think of my death sometimes after seeing patients that I knew passing away.”
(participant E)

Theme 5: Support network

The transplant process is challenging for patients. The participants experienced the most substantial changes within 1 year after the transplant, the time required for their physical functions to return to normal. The participants receiving long-term home care had to adjust their relationships with families and friends and had to face financial issues. These stresses made them feel that their support network was important during the recovery period.

Family support

The participants indicated that they needed care and assistance from their families after returning home. Close relationships with and support from family members were quite important for the participants to face cancer courageously. They expressed gratitude for the care, companionship, assistance, and efforts of their families. Participants also were grateful to siblings who had donated hematopoietic stem cells.

Support from friends and fellow patients
The transplant process can be lonely. In addition to being isolated immediately after the transplant, participants also had to isolate themselves after returning home. For approximately 6 months, they could not even go outdoors. During this period, friends could provide psychological support and relevant information over the telephone and the internet. Sharing experiences with fellow patients diagnosed with the same disease could also make participants feel supported.

Financial support

In Taiwan, most of the medical expenses associated with transplantation are covered by the national health insurance system, which substantially reduces patients’ medical expenditures.

Theme 6: Living in the moment

After their experience with cancer and the transplant process, the participants cherish every moment of their life. Some started to change their thoughts, to transform negative experiences into optimistic thinking, believing that an open attitude would enrich their life and help them recover; and they experienced the true meaning of quality of life. As their lives gradually returned to normal, they started to plan for their future, to expect that their life would get better.

Change of thought patterns

Changing their thought patterns enabled participants to face difficulties in life with a more positive attitude, which they felt to be an important part of recovery after transplant. They believed that their emotions would affect their disease condition; therefore, they were willing to face their situation with an open attitude in an effort to make themselves happy. They were also willing to view bad results with an optimistic attitude and without worrying excessively.

“I feel that my mind is opened. I think that I am happy, and I feel that things I used to care about are not necessarily the most important things in life....Of course, I am also worried about recurrence. However, I think that it is something that I cannot control and do not have to worry about.” (participant J)

Experiencing the true meaning of quality of life

The participants would think about the true meaning of quality of life as they considered their own life experiences. They suggested that they were satisfied with life, that they lived their life in their own way, and that they perceived the true meaning of quality of life.

Expectation of a better future

If the participants did not experience severe rejection or substantial sequela after transplant, they could return to their normal life whenever they regained their strength (approximately half a year), and their life would be back on track approximately 1 year after the transplant. At that time, the participants could return to their former lives and plan for the future; they could do what they liked and live a better life.

DISCUSSION

The participants in this study experienced interference of symptoms, interruption of developmental tasks in life, low self-worth, and unbreakable shackles of disease. However, they also perceived the support of their families and friends and thus developed the courage to live in the moment and face the future.

Studies have indicated that common physiological complications of allogeneic peripheral hematopoietic stem cell transplant include acute and chronic GVHD, immunosuppression, altered taste, dysphagia, damage to organs (e.g., liver, kidney, heart, and lungs), changes in appearance, infertility, sexual dysfunction, and fatigue. Most participants in this study experienced altered taste, which affected their appetite, as well as fatigue and loss of strength, which restricted their activities. They also experienced skin lesions (caused by GVHD) and changes in appearance caused by immunosuppressant medication.

Fatigue is the most common, and most distressing, symptom experiences by patients with cancer. Baker et al. reported that fatigue is the most common symptom occurring 6 months after transplant and that 40% of patients continue to feel fatigued 1 year after transplant. The main cause of fatigue is the high-dose chemotherapy and systemic radiotherapy that patients undergoing allogeneic transplant receive. The level of fatigue varies with time after transplant. It takes approximately 1 year for patients to recover from fatigue, which not only hinders their ability to perform
daily activities but also leads to depressive emotions. In our study, 9 participants mentioned that fatigue and loss of strength made them feel distressed and affected their sleep. The fatigue lasted for approximately half of a year.

The participants in our study experienced systemic skin desquamation and pain, darkening of the skin, hirsutism, and edema due to GVHD, and these changes in appearance had a substantial psychological impact. One of the female participants was fearful that she would never return to what she used to be, and she even developed suicidal thoughts. Rejection is the most common cause of changes in appearance among patients undergoing allogeneic transplant. Acute GVHD can lead to systemic skin rash, followed by the formation of blisters and peeling skin. Chronic GVHD can also lead to pigmentation, nail atrophy, dry eye, or red eye, and such changes in appearance are quite obvious. The use of the immunosuppressant cyclosporine can also cause significant pigmentation and hirsutism. The use of steroids can lead to edema, thinning of the skin, acne, and moon face. All these effects result in changes in appearance. Baker et al. found that patients did not regain their original appearance until 6 months to 1 year after transplant, and the duration of the changes further interfered with their body image. Russell et al. also reported that changes in appearance are a huge blow to patients’ self-confidence and that patients regard change in appearance as a primary threat to many adverse effects.

The average age of the participants in our study was 37.6. People at this age are generally involved in intimate relationships and are giving birth to or raising their offspring. However, pre-transplant adaptive treatments usually lead to reproductive dysfunction and infertility. Baker et al. reported that post-transplant infertility can affect sex life, self-esteem, and interpersonal behaviors. Sexual dysfunction not only decreases sexual satisfaction but also affects patients’ intimate relationships. The participants in our study indicated that they were worried about infertility caused by treatment, as well as about procreation. Some female participants were afraid that the residues of drugs and radiation in their body would affect the health of a fetus if they were able become pregnant. Although some of them envied their colleagues getting married, they did not dare to try marriage themselves. Other participants did not consider getting married, having children, or preserving sperm before treatment, owing to concerns about passing on a genetic predisposition to cancer. All these feelings caused the participants to feel regretful and to resent cancer’s interruption of this stage of their lives. Baker et al. also reported that patients are particularly concerned about infertility and sexual function.

Molassiotis and Morris investigated the perceived quality of life of patients in the United Kingdom who were diagnosed with chronic myelogenous leukemia and underwent unrelated donor bone marrow transplant and found that 1 year after transplant, “the sense of frustration caused by failure to perform living functions” and “restricted daily activities” were most distressing hindrances to patients adaptation and deeply affected their lives. Baker et al. found that 15% of patients indicated that they could not do what they wanted to do 6 months to 1 year after transplant. Polomeni and Lapusan also showed that patients were frightened that they would become weak and unable to deal with their status as being disabled, and they worried that they would become a burden to other people (which carries a social stigma). The participants in our study had to return to the hospital and outpatient clinic regularly within 6 months after transplant. Between visits, they were forced to rest at home because they had not regained their physical strength or their immunity; and because they were unable to make money and help with the tasks of raising their family, they became dependent on their families. They could not accept the fact that they needed other people’s assistance. One participant mentioned that his family suffered financial difficulties because he was sick and had to receive treatment. Many things made participants feel that they were not contributing to their family, and their lack of productivity made them feel useless. In addition, restrictions on their ability to engage in the leisure and entertainment activities that they had previously enjoyed eventually led to feelings of low self-worth.

Regarding to returning to work, most of the participants expected to return to their original jobs. Engaging in work means being able to generate income and contribute to the support of the family. However, some of the participants found that they were physically incompetent and felt that they delayed the progress of colleagues; eventually, some adjusted their work patterns, whereas others quit their jobs. Some participants suspended their jobs because their families were against the idea of their continuing to work, fearing they would fail to meet expectations, which would result in distress associated with returning to
work. In a hermeneutics study, Steeves\textsuperscript{27} found that post-transplant participants’ dream of becoming normal again and returning to work is an important theme; however, patients face many difficulties upon returning to work. For example, Wingard et al.\textsuperscript{28} found that nearly 23\% of 113 interviewed patients experienced discrimination at work, and 39\% encountered insurance problems. For the patients who had worked before they were ill, the loss of their job, the decline in their social functions, and chronic GVHD were associated with discrimination at work.

The participants’ worries did not end when the transplant process was completed. A study by Kopp et al.\textsuperscript{29} indicated that patients clearly suffered from physiological and psychological sequela (e.g., rejection, depression, and worry over recurrence) within 1 year after the transplant. Baker et al.\textsuperscript{3} also suggested that patients continued to worry about cancer recurrence for 1 year after transplant and mentioned that they had no idea when their cancer recurred. Leigh and colleagues\textsuperscript{14} assessed 36 patients undergoing allogeneic transplant and found that the incidence of depression remained high even 9 months after the transplant. There were many causes of the post-transplant psychological distress experienced by participants, including expectation of and distress associated with rejection, worries about the possibility of relapse, and fear of death. Baker et al.\textsuperscript{9} indicated that among patients who survived the transplant, worry about recurrence negatively affects their interpersonal relationships with other people.

Among all the hematological malignance, acute myelogenous leukemia has the highest recurrence rate.\textsuperscript{30} The 7 participants in our study who were diagnosed with acute myelogenous leukemia were extremely worried about recurrence. In addition, mild GVHD is associated with a relative low recurrence rate.\textsuperscript{30} Therefore, the participants expected a low level of rejection. However, severe rejection responses would lead to extreme discomfort and even death. Consequently, the participants’ experienced ambivalence about the possibility of rejection responses: they expected them but were also worried about them. Moreover, pre-transplant systemic radiotherapy and chemotherapy increase the risk of cancer and can lead to secondary tumors.\textsuperscript{9} Once cancer recurs, patients can feel that their previous treatment and the discomforts it caused were in vain and that they have returned to the starting point because they have to undergo chemotherapy again and deal with the symptoms of the recurrence. In addition, recurrence reminded participants of their mortality and triggered fears of death. To the participants, relapse made their disease feel like unbreakable shackles.

Family relations are meaningful to patients after transplant. Molassiotis and colleagues\textsuperscript{31} found that the nature of the relationship between patients and their families is significantly associated with their psychosocial functions. The support system of the participants in this study consisted mainly of their families; strong family bonds are part of Chinese culture. The participants received care from their families during post-transplant hospitalization and home care periods. In addition to offering physical care and company, families would also seek spiritual solace for the participants by going to temples and asking the gods for blessings. Moreover, siblings donated hematopoietic stem cells, which was extremely meaningful to the participants. The bond between siblings usually became stronger after transplant.

The support system also included friends and patients with the same disease. In addition to sharing emotions and offering support, friends assisted in the collection of information leaving the patients feel substantial assistance. Ussher et al.\textsuperscript{32} reported that peer support can offer patients empathic experiences, reduce patients’ feeling of isolation, increase cancer-related knowledge and coping strategies, and provide a sense of hope.

Owing to the national health system in Taiwan, the participants also felt financially supported. During treatment, most medical expenditures were covered by the government, and the participants had to bear only the co-payments.

Many of the participants experienced changes in their thought process and found that things they had cared about before their diagnosis were no longer important. They also suggested that mood affected their physiological condition; therefore, they felt that it was important for them to maintain an open mind. Some participants also endowed the recurrence of their cancer with meaning and expressed an intention to encourage other patients with the same disease using their own experiences. Sherman et al.\textsuperscript{21} reported that participants not only experienced increased understanding from other people but also were able to find new meaning in life, and to improve their quality of life. Moreover, they regarded their transplant as a
gift, and they perceived this gift through their experiences, including the discoveries that they had become more patient and that their ability to cope with life stress was enhanced. Saleh and Brockopp reported that patients found hope by controlling their thoughts and thus were able to find psychological comfort. They did not allow themselves to develop negative thoughts, focusing instead on positive thoughts, which they believed would increase the chances of a happy outcome.

Molassiotis and Morris reported that for patients suffering from chronic leukemia and undergoing unrelated donor bone marrow transplant, quality of life includes the concept of a “normal life.” The participants in our study indicated that their life gradually returned to normal within 6 months to 1 year after transplant. As their physical functions were gradually restored, they could start to travel or work, they became closer to their families, and their life gradually began to meet their expectations. Therefore, some of the participants described that they experienced the true meaning of quality of life and even felt that their post-transplant quality of life was better than before.

Baker et al. reported that once patients undergoing transplant experience a change in their role in relationships and lifestyle after becoming ill, their satisfaction with their personal life and their sense of well being are significantly affected. The participants in our study expressed their expectations about the future, including expectations of being able to reduced the number of visits to the clinic, of regaining their ability to work and participate in social activities, of regaining their sense of taste, of returning to school to complete their studies, of experiencing new things, and of planning a family. Most of the participants retained their positive expectations about the future and suggested that the suffering caused by their disease would become part of the past and that life would improve.

Clinical Implications

The data provided by our in-depth interviews about the lived experiences of patients undergoing allogeneic hematopoietic stem cell transplant revealed that patients experienced various levels of physical, psychological, and social disruption for up to 1 year after the transplant. On the basis of our results, we present the following recommendations for clinical nurses who provide care to transplant patients.

Provide sufficient information

After returning home, patients may have no fixed support network to consult with. Nurses are advised to use the pre-transplant briefing to provide patients with as much as information as possible to fully prepare them, reduce their anxiety, and improve their coping skills. Nurses are responsible for informing patients of reproductive age about the possible side effects to the reproductive system caused by adaptive treatment and should provide such patients with sufficient time to decide whether to preserve sperm or ova. Moreover, nurses should patiently listen to patients, help them to express their real feelings, and assist them in making objective decisions.

Assist with the maintenance of social contacts

We found that young patients usually used cellular phones, webcams, e-mail, blogs, or social networks to share their feelings, all of which are effective ways to obtain support from and maintain contact with friends and families. Nurses could suggest these approaches to other patients undergoing transplant.

Help patients to maintain hope

Hope for the future is very important. Nurses should help patients to express their expectations and beliefs, to clear their mind, and to discover meaning in experienced events to help them reflect on the nature of life. Nurses should discuss disease progression with the medical team, in order to help patients in making plans for returning to work or school and implementing those plans step by step.

Limitations

Although this rigorous qualitative study achieved its goals by emphasizing data saturation and a thorough understanding of a certain phenomenon on the experiences of patients during the period from 100 days to 1 year after undergoing an allogeneic peripheral hematopoietic stem cell transplant, this study was conducted in a single teaching hospital in central Taiwan. We recommend that researchers conduct interviews in other locations, such as northern, southern, or eastern Taiwan to ascertain whether geographical factors influence the experiences of receiving an allogeneic hematopoietic stem cell
transplant for treatment of hematological cancer.

CONCLUSIONS

We found that the physical, psychological, and social functions of the participants in this study gradually returned to normal within 1 year after transplant. During this recovery period, the lives of the participants were filled with uncertainty and the threats of rejection, recurrence, and death. Many of the participants expected to be able to return to their original life and to plan for their future. Because there have been only a few qualitative studies of the lived experience of transplant patients in Taiwan, assisting patients and their families with the problems encountered during treatment and recovery is difficult. The results of this preliminary study can be expected to serve as a reference for nurses and health professionals in their efforts to improve the quality of life of patients undergoing hematopoietic stem cell transplants.

ACKNOWLEDGEMENTS

The authors would like to express the sincere thanks to National Science Council (101-2314-B-227-005) for supporting the funding to accomplish this study.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

REFERENCES


