



Quality of Life of Hospitalized Patients with Hematological Diseases

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Abstract

Hematological diseases have a wide age range of disease onset, repeated hospitalizations, long periods of treatments and hospitalization, special hospitalization conditions, isolation that lead to restrictions to their social life and impaired quality of life. The hospital is the place where patients, families, nurses and doctors come together for a common purpose, the restoration of the patient's health. Ensuring a quality of life in the hospital environment requires the participation of all the healthcare team and building a "healing environment". Nursing priorities for improving the quality of life in the hospital include ensuring comfort, psychosocial support, providing palliative and patient centered care and patient centered environment. A patient centered environment responds holistically to the needs of its users, including accessibility, safety, privacy and dignity, comfort and wellbeing, personal choice and control. The inclusion of arts, music, exercise and festivities improve quality of life during hospitalization. Family members also are welcomed to stay and care for the patients during long periods of hospitalization. Patients hospitalized for hematological diseases are a unique population with complex needs. So, research, innovation, and initiatives are needed to incorporate new methods to improve their quality of life during hospitalization.

Keywords: *Quality of Life, Hematological Diseases, Hematological Malignancies, Hospital Environment, Hospitalization, Patients.*

INTRODUCTION

Quality of Life and the Hematological Patient

Quality of Life is defined as the subjective perception of people about their place in life, within the context of the cultural characteristics of the value system of the society in which they live and in relation to their personal goals, expectations, standards and concerns [1]. Quality of life is a general model that seeks to record the patient's perspectives and expectations in quantitative terms. There are two basic characteristics related to quality of life, subjectivity and multidimensionality. Subjectivity is the view that the patient is the one who determines the quality of life and only after his direct participation can subjective factors be assessed. The assessment of quality of life is subjective and multidimensional. It includes physical, functional, emotional and social well-being [2].

The most common hematological diseases that require hospitalization are:

- Anemias (iron deficiency, aplastic, hemolytic Mediterranean, sickle cell)
- Hemostasis disorders (hemophilia, von Willebrand Disease)
- Malignant hematological diseases (myeloma, lymphoma, leukemia, myelodysplastic syndromes)
- Coagulation disorders (thrombocytopenic purura) [3].

The special issues of patients with hematological diseases are the wide age range of disease onset, repeated hospitalizations, long periods of hospitalization, special hospitalization conditions, such as isolation due to immunosuppression that lead to special precautions and to their social life. There is also a multitude of available treatments that, when combined, cause a variety of physical and psychological symptoms [4]. Chronic patients live under conditions and terms of existence and living that have a binding and restrictive effect on satisfying the need for a high level of quality of life [5].

Most studies on the quality of life of patients with hematological diseases have been conducted in patients with sickle cell anemia, malignant hematological diseases and in those undergoing hematopoietic cell transplantation. The main aspects that affect the quality of life of patients are the acute sickle cell painful crisis which is the most common cause of hospitalization in patients with sickle cell anemia, repeated hospitalizations and transfusions [6]. Psychological complications are identified in children and adults and these include inappropriate pain coping strategies, reduced quality of life due to limitations in daily functioning, anxiety and depression. The use of psychological interventions, patient education, cognitive behavioral therapy, effective pain management techniques is recommended to help improve the quality of life of patients [7].

In a study comparing the quality of life in the hospital between oncology and hematology patients, it was found that for

hospitalized hematological patients there was a lower quality of life and more severe symptoms, especially fatigue and loss of appetite. In addition, hematological cancer patients had their social functioning and social role more affected. Initially, the goal of treating hematological malignancies is to increase survival and improve patients' abilities as much as possible to continue their lives while maintaining an appropriate level of quality of life [8]. However, symptoms of hematological malignancies include dyspnea, nausea, vomiting, fatigue, mucositis, diarrhea, pain, anorexia, and delirium, and these problems can worsen or even begin with treatments for the disease. Repeated bone marrow biopsies are an additional burden for patients. Disease progression and the continued use of anticancer therapies and their side effects in patients who are often frail and malnourished may increase the likelihood that these patients will die in a hospital [9,10].

Anxiety and depression are common in patients with hematological malignancies and are associated with poor quality of life and poor functional status. In particular, patients with leukemia have lower quality of life scores and higher levels of anxiety [11]. With fatigue being the most common and serious problem that can dramatically affect their quality of life [12]. Furthermore, hospitalized patients are unable to participate in their usual role and have to spend a large part of their time in situations that do not engage them emotionally or intellectually, that is, in waiting periods during their hospital stay. In these cases, not only the anxiety of the diagnosis plays a fundamental role in the quality of life, but also the experience of boredom. Both the sense of absence of meaning and of a stimulating environment manifest themselves in a state of boredom and existential emptiness [13].

During hematopoietic stem cell transplantation, patients endure significant side effects and have hopes for a cure for the disease. Many studies have focused on the long-term outcomes of hematopoietic stem cell transplantation and the acute impact of hospitalization on patients' quality of life and mood is still under investigation. During hospitalization, fatigue and depressive symptoms increased and quality of life decreased. During hospitalization for allogeneic hematopoietic stem cell transplantation, patients are usually on prolonged bed rest, and complications from myeloablative therapy such as acute graft-versus-host disease (GvHD), drug side effects (immunosuppression & steroids), frequent infections, and psychological reactions can be debilitating. Health-related quality of life has been reported to be lower during hospitalization. In these patients, the most commonly reported symptoms are fatigue, diarrhea, insomnia, anorexia, decreased concentration, dry mouth, dyspnea, alopecia, and poor body image. Psychosocial well-being after allogeneic transplantation is influenced by oral mucosal toxicity (fungal infections), other side effects, and psychological factors such as anxiety, distress, and social support. Patients with an accurate perception of their prognosis had lower quality of

life, higher depression, and a sharp increase in depression during hospitalization for hematopoietic cell transplantation. Interventions are needed to improve prognostic understanding, providing appropriate psychosocial support during hematopoietic cell transplantation and psychological assessment before transplantation [14,15].

Nursing Priorities for Improving the Quality of Life in the Hospital

- Ensuring comfort: by relieving pain, by reducing stress, by enhancing spirituality. It helps in better adaptation to the disease and treatments. Patients who rely on their faith or spirituality tend to have increased hope, optimism, freedom from sadness, greater satisfaction with life and feelings of inner peace. Studies also show that spirituality can have a direct impact on quality of life, contributing to physical and mental health. Among the benefits proven in studies are reduced feelings of anxiety, depression, anger, loneliness, blood pressure, reduced alcohol and drug abuse and better control of pain, nausea and discomfort [16].
- Psychological support: initially includes assessing the patient's psychosocial situation, determining the existence of previous support mechanisms as well as assessing the family, work and social environment. Support and counseling, with active listening and then referral to a social worker or psychologist if necessary [16].
- Support groups: a significant positive contribution can be made by the patient's contact with members of a support group, who suffer from the same form of cancer and have undergone the same treatment, or – if this is not possible – with individual patients. In a support group, the patient shares with other sufferers, their experiences, learns new ways to handle situations, and discusses the reactions and feelings that have changed in their lives. Volunteers from these groups or other welfare organizations can help with psychological support issues [16].
- Patient education, before treatment-resolving doubts and concerns: patient education should be personalized, using documented and high-quality information. Patients who are informed before their treatments have better cooperation with the health team, better compliance with treatment, less stress and anxiety, feel self-control and are satisfied with the care provided [17].
- Patient centered care: New directions in healthcare systems focus on the patient as an integral and necessary part of the quality of health care [18]. It is patient centered when patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty. Patients have the opportunity to discuss their health beliefs, concerns and preferences, receive individualized care, are treated as a person and not a set

of cancer symptoms. It takes effective communication and is made by shared decision-making. Patients value nurses who recognize their individuality and the unique way in which each person experiences a condition and its impact on their life [19].

- Patient centered environment-healing environment: A patient centered environment responds holistically to the needs of its users, including accessibility, privacy and dignity, comfort and wellbeing, personal choice and control...“the environment can influence the healing process” [20]. Cleanliness and safety are essential requirements for any treatment environment. A hospital environment designed around the needs of people with cancer not only supports personal well-being, but also actively contributes to positive treatment outcomes, as well as improving the efficiency of services and staff performance.
- Palliative care: The literature shows that early access to specialized palliative care for patients with hematological malignancies is rare. The availability of specialized palliative care services can help health care providers manage patients’ symptoms and improve health-related quality of life inside or outside the hospital [21].

Ways to Improve Quality of Life in the Hospital

According to Ulrich (1991) and the theory of supportive design, the hospital environment will reduce stress if it fosters a sense of control, social support, and positive distraction. Simple, practical steps that can be implemented in everyday life [22,23]:

- Ensure that patients have some control over their environment and are offered personal choice, where possible, for example, regarding the number of pillows they have or the room they want, food within the allowed limits.
- Enable family members/caregivers to stay with patients.
- Ensure that there are views of the “outside world” and contact with nature. Studies show that even 3-5 minutes of contact with nature can reduce stress, anxiety, and fear and increase positive emotions. This can be achieved with indoor gardens, aquariums, and images of nature.
- Use art, light, and color to create a relaxing space, improving the patient experience and well-being. Access to daylight has been found to reduce pain, depression, hospital stay, and patient and staff satisfaction [24].
- Lounges and waiting rooms. Hospitals with large spaces where patients and families can be together [25].
- Noise reduction: reducing stress.
- Use of art: In recent years, music and the performing arts have been seen as key factors in creating a patient-centered therapeutic environment in hospitals. Art,

whose value in the health sector lies in its ability to comfort, reduces stress and anxiety levels, and promote well-being and good mood [22,23].

In general, introducing music into the environment helps to mask and possibly neutralize hospital noise. Referring to the effects of music, Campbell states that “music can affect the way we experience the space around us”. Spending time in a hospital waiting area can cause feelings of stress and anxiety, but these can be reduced or eliminated through the presence of music. As a positive distraction, the therapeutic properties of music promote mental and physical health. It has been found that music can slow down and equalize brain waves. A-waves of the brain occur when music with a pulse of approximately 60 beats per minute is played. A-waves are associated with increased awareness, calmness, and general well-being. Additionally, music works to regulate stress hormones, especially adrenocorticotrophic hormone (ACTH), prolactin, and human growth hormone (HGH). It is worth noting that the effects of bright, up-tempo music in a hospital setting can act to make time seem to pass more quickly. The physical benefits of music include slower breathing, a lower heart rate, lower blood pressure, reduced muscle tension, and overall improved immune function. During hospital care, the presence of music has an important role in maintaining positive body functions, even enhancing health [26].

- Exercise: Yoga can improve sleep quality, fatigue and discomfort in patients [27]. Physical exercise interventions are feasible without adverse effects during hematopoietic cell transplantation or chemotherapy. Exercise when tolerated from the patient improves strength, endurance and flexibility [28].
- Celebrations: For patients, the holiday season is anticipated with excitement. Spending time with family and friends, decorating the hospital room, putting on fancy lights, dressing staff with festive attire, sharing in joy and laughter and getting in the holiday spirit means so much to the patients and relieves distress while hospitalization. Also, organizing festive activities by engaging Patients and Staff is beneficial [29].

CONCLUSIONS

The hospital continues to be the place where patients, families, and nurses come together for a common purpose, the restoration of the patient’s health. Ensuring a quality of life in the hospital environment requires the participation of the entire interdisciplinary team. From the nurses’ perspective, research, innovation, and initiative are needed for new ways of improvement that respond to the specific and growing needs of patients with hematological diseases.

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