



Supportive Care

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Abstract

Hematopoietic stem cell transplantation (HSCT) care is highly complex. This chapter focuses on the aspects of supportive care required following HSCT.

Assessment tools are key component of nursing practice and are necessary for planning and providing patient-centered care. HSCT care must be planned, implemented, and evaluated and is underpinned by collaboration with the entire multidisciplinary healthcare team.

With supportive care following HSCT, we ultimately aim to improve the quality of life of our patients in the posttransplant period.

Supportive care extends beyond symptom management and includes social, psychological, and spiritual care. The needs of the patient are multifactorial and can be complex, considering multiple issues at the same time and involving multiple disciplines.

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Throughout supportive nursing care, our clinical competence is critical and is complemented by experience, knowledge, and awareness.

Keywords

Supportive care • Assessment • Early warning scores • Oral care • Nutrition
Allied health professionals • Transfusion • Physiotherapy • Spiritual care
Complementary therapies • Music • Touch • Massage • Pediatric

10.1 Nursing Assessment

Highly complex nursing care is essential for the disease- and treatment-related health problems of patients with hematological diagnoses (Kluin-Nelemans and Tanasale-Huisman 2013). The diagnoses within hematology are diverse but generally associated with a specific set of symptoms. Hematological diseases can be broadly divided into malignant and nonmalignant hematological diseases. The underlying hematological disease and cumulative effects of previous therapy can influence the degree and range of side effects and symptoms experienced following HSCT conditioning therapy. These effects can manifest as physical complaints such as fatigue, fever, infection, and bleeding and can result in complex illness necessitating specialist care and treatment. Psychological concerns are common and can frequently manifest as low-level anxiety and depression and less often as features of significant trauma. As a key element of the multidisciplinary team, nurses are ideally placed to identify and assess symptoms due to illness or treatment at an early stage. HSCT nurses have extensive knowledge that contributes to treatment optimization. Assessment is undertaken frequently to reflect the dynamic nature and rapidly changing clinical picture and will take into account the patient's vital signs, blood results, and symptoms as well as knowledge of their baseline physical function. By taking the medical and social history of the patient into consideration, we can increase our awareness of the potential care problems that may arise. The understanding and assimilation of information derived from these sources in conjunction with standardized assessment tools and

instruments enable measurable and objective care delivery.

10.2 Pain Assessment

In certain hematological diseases such as lymphoma or multiple myeloma, patients experience pain as a result of the compression of the lymph nodes or bone destruction. In some cases, patients are reluctant to report symptoms of pain to their attending physicians in case this is interpreted as a poor treatment response. It is imperative to consider both verbal and nonverbal signs and symptoms of pain to complete a comprehensive assessment.

The bedside nurse is well placed to assess their patient and explain the importance of adequate pain management using pharmacological and supportive measures. Improving the patient's comfort will enable them to better tolerate treatment and improve their experience.

In the HSCT setting, pain is most commonly experienced as a result of mucositis, but patients will also report other pain such as bone pain associated with GCSF, abdominal pain due to diarrhea, or general discomfort with fluid accumulation.

Not all reported pain symptoms or discomfort is treated in the same way. By explaining to our patients the possible cause of the pain and the treatment for it, we can also help to manage their expectations of the analgesia and other supportive interventions. We should inform our patients of the common side effects of analgesia like drowsiness and constipation and ways of reducing these effects.

When assessing pain, a standardized tool should be applied to ensure consistency across patients and between assessments. A comprehensive evaluation of the pain, location, characteristics, onset, duration, frequency, severity of pain, and exacerbating and relieving factors should be included. This assessment should be supported by the patient’s nonverbal reactions such as facial expression, pallor, tempo of speech, body position, etc. as well as their vital signs.

According to Kluin-Nelemans and Tanasale-Huisman (2013), a nurse can give the patient information and tips and tricks in the field of pain relief to the patient:

- Check to what extent the pain is present on performing her/his daily routine (getting up, going to the shower, or getting dressed). The use of a pain scale can give insight to the extent of pain the patient endures. Ask the patient how she/he scores the pain from 0 (no pain) to 10 (maximum pain). If analgesia is administered, you can monitor the effect by reassessing the pain score.
- Consideration of pretreatment with analgesia before starting the daily routine may permit the patient to move independently or with more comfort.
- Nonsteroidal anti-inflammatory drugs (NSAIDs) *should not* be prescribed for the HSCT patient. These can cause diminished function of the thrombocytes and kidney damage and complicate the monitoring of infections.

- If the patient is immobile for long periods, pain can increase. The nurse should assess pressure area risk and consider offering a pressure area mattress and/or gel cushion to increase comfort and reduce pressure area deterioration.
- In addition to pharmaceutical pain relief, complementary care can also be offered to reduce pain: heat-cold packs, relaxation by music therapy, distraction, or gentle massages (if possible with low thrombocytes).

10.3 The Role of Early Warning Scores

Adult

Observing vital signs is a crucial task in the care of the HSCT patient. The patient’s condition can change dramatically in a short period of time due to treatment and illness. Various measuring instruments allow us to monitor vital functions. The modified early warning score (MEWS) shows when values of vital functions deviate and indicates when intervention is required.

The MEWS (Subbe et al. 2001) scores various items (Table 10.1):

- Heart rate
- Blood pressure (systole)
- Breath rate
- Temperature
- Awareness (AVPU score)

Table 10.1 Modified early warning score

Score	3	2	1	0	1	2	3
Systolic blood pressure (mmHg)	<70	71–80	81–100	101–199		≥200	
Heart rate (bpm)		<40	41–50	51–100	101–110	111–129	≥130
Respiratory rate (bpm)		<9		9–14	15–20	21–29	≥30
Temperature (°C)		<35		35–38.4		≥38.5	
AVPU score				Alert	Reacting to voice	Reacting to pain	Unresponsive

Subbe (2001)

In addition, decreased urine production, $\text{SaO}_2 < 90\%$ with adequate O_2 therapy, and the nurse's awareness or "gut feeling" give increased value to existing scores (Ludikhuizen et al. 2012). If the score is moderately elevated, it is advisable to monitor the vitals more often and to inform the attending physician. When the score increases, continuous monitoring is necessary, and evaluation from an emergency intervention team or a medical emergency team should be requested. These teams are available in most HSCT centers and usually consist of a doctor and an intensive care unit (ICU) nurse/emergency nurse.

HSCT and Intensive Care The outcomes of HSCT patients have been greatly improved over recent decades due to new therapies and improvements in supportive care. An ICU admission is sometimes necessary to treat life-threatening situations that can arise following HSCT.

Reasons for admission might include:

- Respiratory failure secondary to infection
- Sepsis requiring intensive support
- Multi-organ failure
- Renal dysfunction
- Complications such as graft-versus-host disease after allogeneic stem cell transplant

Treatment in the ICU consists of:

- Mechanical ventilation
- Support of vital functions
- Treatment of sepsis/septic shock
- Continuation of chemotherapy

Over the past 20 years, the survival of the hematology patient on the ICU has been greatly improved, with reductions in mortality by 40–60% (Netters et al. 2010; Ven van der et al. 2009). When a hematological patient is admitted to ICU early in their course, the chance of survival is greater (Peigne et al. 2009). Early admission reduces further organ

dysfunction and increases the probability of reversing existing organ failure by delivering timely and appropriate organ support. The modified early warning score (MEWS) may contribute to this early recognition and prompt referral to ICU.

When the patient is well enough to return to the HSCT unit, fear of relocation may occur. This can happen because the continuous monitoring of vital functions ceases and the ward environment is very different from that of the intensive care. The patient may experience stress and anxiety and should be prepared at ICU for the transfer to the HSCT unit taking into account the psychological effect of relocation to both patient and family (Coyle 2001).

Pediatric

As noted by Agulnik et al. 2016, hospitalized oncology and HSCT patients are a high-risk population with frequent clinical decline requiring unplanned PICU transfer and high mortality rates. Complications developed by these patients, such as sepsis and respiratory failure, are known to have better outcomes with earlier identification and management.

It is important to know the normal vital signs in children in different ages. That is the basis which helps to recognize the early warning signs in children. The use of the pediatric early warning system (PEWS) scores in clinical practice is a new concept (Murray et al. 2015). In reference to Agulnik et al. (2016), PEWS has been implemented in many pediatric institutions. Their study demonstrates that the PEWS tool is valid in identifying pediatric oncology and HSCT patients requiring unplanned PICU transfer.

The use of PEWS scores as an assessment tool has the potential to quantify the severity of illness in children. It is hoped that this results in facilitating early identification of patients at risk for clinical deterioration and prompt intervention to avoid the need to transfer to a higher level of care (Murray et al. 2015).

10.4 Nutritional Assessment

The malnutrition universal screening tool (MUST) is a validated screening tool for recognition and treatment of malnutrition. The MUST form must be filled in accurately upon admission, asking for length/height, weight, and weight loss and whether the patient has no food intake for several days.

The HSCT patient often has a reduced dietary intake during and following conditioning therapy, but this is often not considered at the time of admission.

Sometimes weight loss is difficult to assess due to fluid gain. It is not possible using conventional methods to determine what proportion of muscle or fat components account for the weight loss.

The measuring instruments deployed to obtain information about muscle function and muscle mass are the hand clamp and the bioelectrical impedance analysis (BIA).

The hand clamping force gauge (see Fig. 10.1) can be used to measure the maximum crushing force. The maximal squeezing force of the hand gives a good estimate of the peripheral muscle function and is related to the total amount of muscle mass in the body. Hand force depends on age and gender. It can also be influenced by other factors, such as disease. By obtaining dif-



Fig. 10.1 Hand dynamometer (Photo credits www.nutritionalassessment.azm.nl)

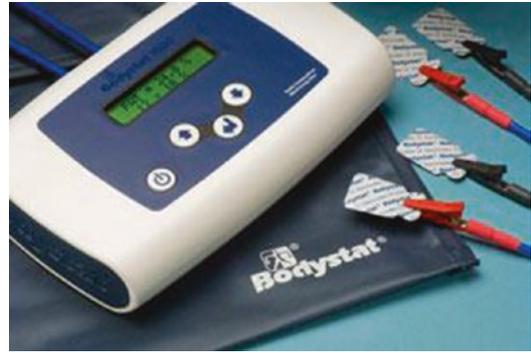


Fig. 10.2 Bioelectrical impedance analysis (BIA) (Photo credit <https://www.habdirect.co.uk/bodystat>)

ferent hand tightness measurements during the course of treatment, it can be determined whether the patient's muscle function increases or decreases.

A bioelectrical impedance analysis (BIA) (see Figs. 10.2 and 10.3) is a tool measuring the resistance that the body provides for an alternating current of 50 kHz. The fat-free mass is calculated using a formula incorporating the resistance, length, weight, gender, and age. With this measurement we can assess whether a patient with weight loss has lost muscle mass and/or fat mass. Determining the fat-free mass with the BIA is not reliable if there is an abnormal hydration status.

10.5 The Role of Allied Health Professionals

In the care of the HSCT patient, collaboration between different supporting disciplines is of great importance. Not only is medical and nursing care essential, but body, mind, and psychosocial care is necessary to facilitate the patient's recovery. Allied healthcare professionals (AHP) are essential members of the multidisciplinary team (MDT) and include:

- *Dietician*
- *Physiotherapist*
- *Occupational therapist*

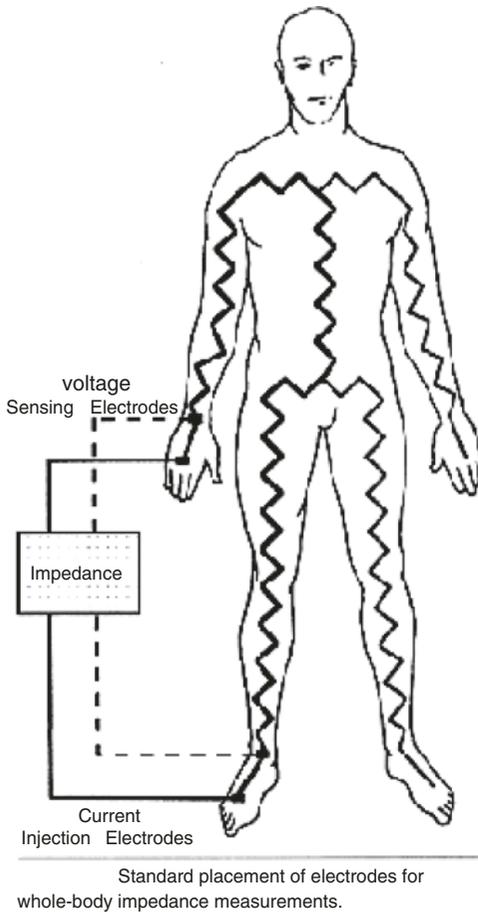


Fig. 10.3 BIA resistance (Photo credit <http://www.nutritionalassessment.azm.nl/algorithmena/onderzoek/lichaamssamenstelling/bia.htm>)

- *Wound or tissue viability nurse*
- *Pain nurse or specialist*
- *Spiritual worker*
- *Social worker*
- *Counselor/psychologist*
- *Consultative psychiatric nurse (CPN)*
- *Psychiatrist*

10.6 Principles of Nutritional Support

Patients undergoing HSCT experience intensive treatment with chemotherapy, sometimes in combination with total body irradiation (TBI).

10.6.1 Through the Treatment with Intensive Chemotherapy, There May Be the Following Nutritional Problems

10.6.1.1 Reduced Resistance to Infection

Following intensive chemotherapy, the patient has reduced tolerance due to neutropenia and/or increased intestinal permeability. In neutropenia, the number of white blood cells decreases significantly, resulting in the so-called aplasia with an increased risk of infection. The patient is neutropenic if the neutrophil granulocytes (subdivision of the leukocytes) are less than $0.5 \times 10^9/l$. An increased permeability of the intestinal wall is caused by intensive chemotherapy damaging the gastrointestinal mucosa. As a result, pathogenic bacteria (bodily bacteria or bacteria from the diet) can enter the bloodstream (sepsis or blood poisoning). The patient has an increased risk of infection due to the reduced resistance. If the patient is expected to be neutropenic for longer than 7–10 days after chemotherapy, antimicrobial prophylaxis may be given because of the high risk of infection. In some centers, the patient may commence this prophylaxis (selective intestinal contamination, SDD) at the time of conditioning therapy. These specific antibiotics select out the patient's own aerobic, potentially pathogenic intestinal flora and remove them.

To prevent food-mediated infections, the Hygiene Nutrition Directive or “neutropenic diet” or “clean diet” guidelines are implemented. This directive is usually followed from the start of conditioning therapy until discontinuation of the SDD or neutrophil recovery. The National Consultation Dietitian Hematology and Stem Cell Transplantation in the Netherlands has written the Hygiene Nutrition Directive, which is the basis for all hospitals in the Netherlands. There are small differences between several hospitals.

10.6.1.2 Food Aversion, Taste and Smell Changes, and Bad Taste in the Mouth

Intensive chemotherapy, as well as other medications such as antibiotics and antifungal agents, adversely affects the senses of taste and smell.

The influence of the disease itself can also affect taste, and taste may be reduced and/or there may be increased sensitivity to all flavors and smells. Aversions to specific foods, enhanced flavor or taste sensation, or a bad taste (metal, cardboard, or sand flavor) are frequently reported. Sometimes, the taste perception does not match the taste memory. Patients may also be more sensitive to odors and can find that many foods or products like perfume or cleaning agents smell unpleasant.

10.6.1.3 Nausea and Vomiting

Cytotoxic treatment is often associated with complaints of nausea and vomiting. Highly emetogenic cytotoxic agents used in HSCT regimes include carmustine and cyclophosphamide; moderately emetogenic are busulfan (iv Busilvex), cytarabine, and (high-dose) melphalan. Nausea and vomiting can occur independently. Medication to reduce nausea and vomiting (antiemetics) and hydration infusions are given and often adjusted. Nausea and vomiting after chemotherapy can occur acutely (4–24 h) and is often severe. The symptoms may also occur later (2 or several days to sometimes a few weeks after the chemotherapy). There is usually no association between vomiting and the type of diet used. As the patient undergoes multiple chemotherapy cycles, anticipatory vomiting may occur. In this case, vomiting occurs prior to the treatment in response to previous chemotherapies and is triggered by memory, experience, smell, taste, and sometimes visual cues.

10.6.1.4 Reduced Appetite and Early Satiety (Full Feeling)

Intensive chemotherapy, as well as other medications, infections, and fever, can cause a reduced appetite and feeling of early satiety or fullness. As a result, a reduced dietary intake may occur, which may adversely affect the nutritional state.

10.6.1.5 Mucositis (See Oral Complications Section for Further Information)

Mucositis (oral and gastrointestinal) frequently occurs after conditioning therapy. The grade depends on the type of chemotherapy. Chemotherapies that are associated with mucosi-

tis are busulfan, etoposide, melphalan, and methotrexate. Mucositis can occur in the mouth and throat (orally) and in the rest of the gastrointestinal tract (gastrointestinal).

Oral mucositis can vary widely from sensitive gums (mucositis grade 1), the patient is often able to eat everything, until blisters and ulcerations in the mouth, and then the patient has even difficulty drinking sips of water (mucositis grade 4, according to the WHO scale). Good oral hygiene is very important to limit complications associated with oral mucositis. Mucositis usually occurs 4–10 days after the conditioning and lasts about 2–3 weeks. As soon as the leukocytes start to rise to normal values, the mucositis heals rapidly.

In severe mucositis, oral nutritional intake is usually inadequate, and the patient is recommended for nutritional intervention. Gastric feeding with a tube through the nose (tube feeding) is preferred over parenteral nutrition, because it is physiologically more natural and reduces the risk for intestinal atrophy. The main contraindication of tube feeding is the risk of bleeding due to ulcerations in the gastrointestinal tract.

Insertion of a nasogastric feeding tube is safe when there is mucositis grade 1 or 2 and if there are sufficient platelets (at least $40 \times 10^9/l$). Otherwise the patient first needs platelet transfusion for placement of the tube. When the severity of the mucositis is too great to introduce a tube, parenteral nutrition is the remaining option.

Diarrhea, due to gastrointestinal mucositis, is a common complaint following conditioning therapy. It is important to pay attention to dietary fiber, electrolytes, and hydration. Patients with severe watery diarrhea have reduced nutritional absorption through the gut, and parenteral nutrition may be indicated.

When the patient is discharged from the hospital after HSCT, dietary intake is often still not optimal and particularly after allogeneic myeloablative conditioned (MAC) stem cell transplantation. The patient often reports a dry mouth, nausea, vomiting, and early satiety. These patients often need nutritional monitoring and support for some time in the outpatient setting. Additionally, these patients often have increased energy demands due to the treatment, and further

interventions may need to be considered such as tube feeding at home to limit further weight loss and restore nutrition.

In general, following autologous HSCT there are less complications and infection-related problems. However, following allogeneic HSCT it takes several months for the immune system to being to recover, and these patients are susceptible to infections for quite some time. In addition, the immune system is suppressed with medication to prevent graft rejection and to prevent or treat GvHD.

10.7 Transfusion

Introduction

Blood transfusion is an essential element of supportive care for many hematological disorders, and HSCT recipients will almost always require transfusion support during aplasia. Importantly, HSCT recipients will usually require product irradiation to prevent transfusion-associated GvHD (tGvHD). This section covers general information on blood transfusion. Please refer to your local and national transfusion directive or policy for further details.

Blood Products and Indication

Different types of blood products can be transfused: erythrocyte concentrate, platelet concentrate, and plasma. The most commonly used blood product is erythrocyte concentrate (Sanquin 2016). Erythrocyte concentrate is administered in severe anemia, where insufficient hemoglobin reduces oxygen transport capacity. There may be acute anemia, for example, due to bleeding, or chronic anemia, for example, due to a chronic disease.

Platelet concentrate is administered to correct thrombocytopenia to prevent or treat bleeding. The indication for administration of prophylactic platelets depends on the patient's condition and whether the patient requires a higher circulating platelet count to treat, limit, or prevent bleeding.

Plasma is administered to help correct coagulation factors. The indication for plasma transfusion is usually based on PT/APTT and fibrinogen content in the blood.

In summary, the indication for transfusion is based on the clinical situation of the patient and laboratory diagnostics.

Blood Groups and Pre-transfusion Investigations

In order to select the correct blood product for a patient, the determination of the ABO and Rhesus blood group is necessary. For transfusion of platelet concentrates and plasma, this is sufficient. In addition to the ABO and Rhesus blood group systems, there are many more systems such as *Duffy*, *Kidd*, and *MNS*. For the administration of erythrocytes, it is important to screen the patient prior to every transfusion for irregular antibodies in addition to the ABO and Rhesus blood groups. These antibodies are usually not naturally present in the blood but can be acquired at each pregnancy and may increase with chronic transfusion need. Depending on the number and type of antibody, it may be difficult to find the appropriate erythrocyte concentrate. Following allogeneic stem cell or cord blood transplantation, the stem cell donor blood group(s) as well as recipient blood group should also be taken into account. For example, in case of double cord blood transplantation, up to three different ABO blood groups may need to be taken into account. In case of emergency and if there is no time for determining a blood group, erythrocytes with blood group "O negative" must be administered. Blood group O negative is the universal donor for erythrocytes.

Platelet antibodies such as the HLA (human leukocyte antigen) antibodies may also need to be considered. These antibodies may develop after prior transfusions and/or pregnancy. Sometimes HLA antibodies result in no or low increment after platelet transfusion. For these patients, platelet donors are selected as the best possible match with the patient at HLA level. This is an intensive process, and sometimes only a very small number of platelet donors are identified for a particular patient. In these cases, it may

Table 10.3 Symptoms that may indicate possible transfusion reaction

Mild	Moderate	Serious
Temperature rise >1 or <2 °C	Moderate clinical decline during transfusion	Severe clinical impairment during transfusion
Urticaria	Cold shivering	Dyspnea
Itch	Temperature rise >2 °C	Respiratory insufficiency
Exanthem/erythema		Hypotension/shock
		Low back pain

Vademecum (2017)

take longer than usual to obtain platelets for the patient, and in an emergency, “random donor” platelets may be prescribed until the matched platelets become available. For plasma transfusion, only the ABO blood group is important. Note: Blood group AB is the universal donor. In plasma, the Rhesus blood group does not need to be considered since the Rhesus blood group is on the membrane of the erythrocyte.

It is known that some drugs can interfere with the accuracy of pre-transfusion investigations in the laboratory. An example of this is daratumumab (monoclonal Ab anti-CD38). It is therefore important, upon request of serological testing, to provide the laboratory with all relevant medical information and transfusion history, including transplantation, pregnancy, previous serious transfusion reactions, and the use of relevant medication such as fludarabine (purine analog).

Processed Blood Products

Sometimes blood products need to be processed. In addition, erythrocytes and platelet concentrates need to be irradiated and may be washed in some cases. Erythrocytes and platelets are washed in the case of previous severe anaphylactic transfusion reaction or in a patient with IgA deficiency. When washing blood products, the plasma proteins are removed as far as possible. In plasma this operation is not possible. Erythrocytes and platelets are irradiated to damage the T cells in the blood product, preventing these T cells from causing transfusion-associated graft-versus-host disease in patients with risk factors such as HSCT, anti-thymocyte globulin (ATG), alemtuzumab and fludarabine use, and Hodgkin’s lym-

phoma. Only thrombocyte and erythrocyte blood products can be irradiated.

Transfusion Reactions

Although today’s blood products are very safe, a patient sometimes experiences side effects from transfusion. The table below (Table 10.3) shows the symptoms of a possible transfusion reaction that may occur during and up to several hours after transfusion.

Acute transfusion reactions may be caused by administration of an incorrect blood product, volume overload, or bacterial or viral contamination of the transfused product. In addition, there may be an unexpected reaction from the patient. If transfusion symptoms are observed during a transfusion reaction, the transfusion should be discontinued immediately and the doctor should be alerted. Always leave intravenous access in situ and then follow the instructions of the physician. It is very important to inform the blood transfusion laboratory about the possible transfusion reaction so that the cause can be investigated. This may prevent a transfusion reaction at a subsequent transfusion.

In addition to acute reactions, blood transfusions can create long-term effects. For example, if a patient gets a lot of erythrocyte concentrates over a longer period of time, developing iron overload can lead to increased iron stores in organs such as the heart, liver, and kidneys causing severe damage. This process occurs because erythrocyte concentrate contains iron, and the body does not have a system to break this excess iron down and remove it. However, this can be treated by monthly venesection when the blood counts have normalized after HSCT and if the

hemoglobin is not sufficient, by medication such as Exjade or Desferal.

Hemovigilance

Hemovigilance is the systematic monitoring of side effects and adverse incidents throughout the donor to patient transfusion chain, as well as anything that contributes to safer and more effective use of blood products. In this context, hospitals report transfusion reactions and incidents to their National Hemovigilance Organization. Annually, serious transfusion actions are reported to the EU by the National Hemovigilance Organization.

Conclusion

For a safe blood transfusion, it is important that the correct indication is stated. The laboratory must have all relevant medical information to select the correct blood product. The nurse must verify:

1. The transfusion prescription
2. The identification of blood product
3. The patient and must always be performed by two nurses

In addition, the patient must be observed closely during transfusion and the doctor notified immediately of symptoms of possible transfusion reaction. The blood is an organ, and blood transfusion is an organ transplant which requires maximum care.

10.8 Physiotherapy and Exercise

Over the last years, several clinical trials have contributed to the growing body of evidence showing the beneficial effects of exercise in cancer patients and also in the field of HSCT. Exercise interventions at different time points during and after HSCT can improve physical performance, quality of life, symptom control, and fatigue. However, it is still not possible to give a clear advice regarding the best type, intensity, start, and duration of an exercise program (Steinberg et al. 2015; Wiskemann et al. 2015; Wiskemann

and Huber 2008; Cramp and Byron-Daniel 2012; Knols et al. 2005; Spence et al. 2010; Speck et al. 2010).

In the time period before and after the HSCT, a specialized oncology physical therapist can be useful to advise, coach, and support exercise (under supervision). By remaining mobile, complications can be prevented and the effects of the treatment can be optimized. Depending on the phase in which the patient is, the physical therapist will set goals (by using the “shared decision model” with the patients). The goal can be to stay at the same level during the treatment or improve condition before, during, or after treatment.

Due to the long hospitalization in isolation and the side effects from treatment, exercise can be a challenge. Most patients are not permitted to leave their room, so providing apparatus such as light weights, exercise bands, or static bikes can be helpful. The patient’s condition changes day to day, so the physical therapist will need to adjust the expectations to ensure they remain realistic. It is important not to force exercise to maintain safety and prevent strain or injury.

10.9 Psychological/Spiritual Care

Introduction

Psychosocial issues can lead to such a loss of energy that patients become dependent on their partner or caregivers. This is further compounded by fatigue. In addition, physical symptoms such as pain can enhance the sense of dependence. Reduced appetite, insomnia, and side effects of medication can cause depressive feelings, while anxiety and fear can contribute to restlessness, forgetfulness, nausea, and tension. It is important to regularly evaluate these patient’s care needs and any additional care or aftercare requirements.

- Patients often experience fear and powerlessness feeling a loss of control over the disease and its consequences. It is important to explain factual information about the diagnosis and

treatment procedures, possible side effects, and practical guidance to improve understanding.

- Patients often experience the stages of mourning (denial, anger, negotiation, and acceptance) and react in their own way to their diagnosis. They may also experience these emotions during their transplant. Anxiety, sadness, powerlessness, and/or a disturbed body image can cause dysfunction, and it is essential to support the patient to reduce fear and/or discuss their feelings. Enabling a social network around the patient will provide a vital source of support both during and after hospitalization. Prompt referral to a psychologist or possibly a consultative psychiatric nurse (CPN) or a psychiatrist may be necessary for those patients with a history of psychological issues, in those who appear unable to cope emotionally, or where there are any concerns for psychological well-being.
- Patients with younger children or grandchildren are advised to discuss their diagnosis and treatment with them. There are different information materials aimed at children of different ages.
- Within the family unit, there may be a change in the role of the patient or family members. Offering a social worker can be helpful in finding support to manage these changes.
- Through diagnosis and treatment, patients can develop low self-esteem. The treatment may affect their physical appearance in a way that makes them feel uncomfortable. Tips on personal care should be discussed. There are several organizations that can assist in counseling. Advise the patient and provide them with resources and signposting where possible.
- Finding a trusted person or talking with other patients can help the HSCT patient in discussing her/his feelings or fears. Patients should be directed to relevant patient associations prior to commencing HSCT treatment.

Basic Information of Psychological Care for the HSCT Recipient

Beside the physical impact of the HSCT treatment, there is great impact on the whole psychosocial well-being of the patient (and their

relatives). Physical problems continuously interact with the psychological state. The enduring nature of many physical problems demands a huge amount of resilience. This section describes the emotional impact of HSCT therapy and the importance of integrated care, with a focus on the role of the psychologist or consultative psychiatric nurse (CPN) and on the role of the bedside HSCT nurse.

Emotional problems such as depression and fear of relapse may occur and impact adversely on the patients' quality of life (QOL) (Syrjala et al. 2012). Emotional concerns are frequently referred to as psychological distress, which has been defined in Distress Management Version I (Practice Guideline Oncology of National Comprehensive Cancer Network (NCCN) 2002) as "a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment."

"Distress extends along a continuum, ranging from common feelings of vulnerability, sadness, and fears to problems that may become disabling such as depression, anxiety, panic, social isolation, and spiritual crisis" (NCCN 2002).

This description gives sufficient reason to organize an interdisciplinary team of caregivers around this special patient group. "Meeting the needs of a patient requires the multiple competences that many caregivers from different professions will have to share in order to offer the best quality of comfort and care. It is a common practice in which each team member will inculcate his own competencies. This is the essence of interdisciplinary" (Porchet 2006). Braamse, psychologist at Vrije Universiteit, Amsterdam (VUmc), wrote her doctoral thesis about psychological aspects of HSCT in patients with hematological malignancies (2015). Hematological malignancies as well as treatment procedures are associated with impairment in patients' QOL. According to the World Health Organization (WHO), QOL reflects a subjective concept, defined as an "individual's perception of their

position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO 2017). Impairments are caused by the original disease, prior treatment, and intensive conditioning therapy. Certain subgroups of patients have more difficulties adjusting to their disease and treatment and consequently experience a more impaired health-related QOL post-transplant compared with other patient subgroups. Suffering from (chronic) GvHD leads to problems with overall QOL and physical well-being. Braamse (2015): “Other subgroups that are at risk for worse psychological and social functioning are female patients, patients receiving low social support and patients experiencing pre-transplant psychological distress.” This is consistent with other research (Hill et al. 2011; Nordin et al. 2001) on psychological and social functioning in cancer patients. Receiving low social support had been shown to increase the risk of depression and anxiety. Braamse (2015) indicates that most HSCT patients were not in need of active interventions to improve psychological distress: most patients chose watchful waiting instead of a special online intervention program or additional psychological care. Braamse (2015) concluded that a discrepancy appears to exist between symptoms patients report in the year after transplantation and their need for additional care: it seems that a substantial number of patients who report emotional problems after auto-SCT do not engage in help-seeking behavior.” This highlights the great resilience of patients going through all different aspects related to undergoing a HSCT and their strength to cope with it without additional professional help.

Role of the Consultative Psychiatric Nurse for the HSCT Patient A consultative psychiatric nurse (CPN) visits the HSCT patients in the outpatient clinic, during the “waiting zone” before admission. The patients are screened by protocol which asks them to share their experiences about:

- Hearing the diagnosis
- Treatment
- Impact on different aspects of life

- Physical condition
- Sleeping pattern
- Influence on relationships and work
- Communication with caregivers

The CPN gives psychoeducation on various topics, for example, coping, loss of control, and loss of social roles. The screening includes some questions which indicate if there is a risk of psychiatric decompensation or other increasing problems. The CPN discusses the assessment outcome and possible needs with the patient as well as helpful resources. Extra support by the allied health professionals or other disciplines may also be suggested.

When there is preexistent psychopathology, a special care plan will be described in collaboration with the physician, the psychiatrist, and nurses from the ward. The CPN writes the conclusions and advice in the patient record.

During the hospitalization of these patients, the CPN visits them for a brief consultation and observes how the patient is coping. This is an informal way of counseling. CPNs take part of the weekly interdisciplinary meeting to discuss the complex cases with the nurses and other disciplines. The main goal of the meeting is to give practical advice about the communication and structuring the daily nursing care. The meeting also functions as a mechanism for supporting each other in our work with this patient group, which has great impact on all caregivers.

The experience of the CPN is that many HSCT patients after hearing the news about their diagnosis have a “rollercoaster experience.” At this point, there is often less time to think about the impact of therapy options due to the pressure to commence therapy. In the weeks between chemotherapy with its (side) effects and waiting for HSCT, patients often begin to consider their dilemma and contemplate their situation. Meanwhile, their physical condition is improving, and they are afraid of losing this as they begin their HSCT journey. Most patients share their experience (while they visit the CPN in the out-clinic setting) about the two emotional pathways: realizing that it is a possibility that they can die and trying to stay strong and positive toward the treatment. They lose their

innocence toward staying in isolation and dealing with lots of physical problems. Last but not least, they struggle with their social role and how to manage the loss of or changes to it.

Patients report many examples of when they felt understood by their doctors and nurses. But many patients also report experience of misunderstandings and difficult and complicated communication with caregivers.

Deweirdt and Vincke (2008) stated how patients report the importance of a family member being allowed to stay for rooming-in while the patient was anxious. For the patient it is important that their caregivers provide basic, personal attention, inserting in their experience, their concerns, and their irritations.

The phase of recovery varies between patients. Some of them have the feeling of being elderly or aged. Others use their first energy to spend time at work or with friends, which can affect home relationships and partner interaction.

HSCT patients are frequently readmitted because of infections, GvHD, or other complications. After a long stay in the hospital, each new readmission can add an enormous psychological burden. It is understandable that patients sometimes lose courage. In some cases, patients speak about their boundaries being further threatened by the treatment. They find it difficult to discuss because the doctor did so much good work and can mean that they don't want to refuse further treatment. It can be the role of the CPN to help patients communicate their wishes.

The Collaboration Between a CPN and Hematology Nurses on the HSCT Wards
Case Examples for This Population

Case One

Patient A, male, 21 years old, non-Hodgkin lymphoma (NHL).

Relapsed NHL (initially diagnosed aged 16). He is a student and living independent near the campus. He has a steady relationship for a year, but because of his treatment and functional decline, he has moved back home to live with his mother. His parents are divorced and don't communicate well. He enjoys online gaming until late at night and subsequently wakes up late in the morning.

During his hospitalization he had some difficulty with the ward routine such as waking up early in the morning and was unfriendly toward the nurses. His mother was very concerned, so she stopped working. She visited her son daily and remained by his bedside for the entire visit even when his girlfriend arrives.

He had fever for several days and mucositis requiring opioid administration, and he experienced nightmares due to analgesia. His thoughts and reactions were slower and at night, he became more anxious. He couldn't eat normally.

In this case the CPN can help the nurses with coordinating the communication and the daily routine and to observe for the signs of confusion or hallucinations that might occur despite his young age.

Case Two

Women B, 44 years old, acute myeloid leukemia (AML).

She has a known bipolar personality diagnosis for which she is prescribed lithium. Lithium has a specific therapeutic range and must be closely monitored through lithium blood levels. Nurses on general wards are often uncertain about the care of patients with a psychiatric diagnosis and about their own (communication) tools and skills. It is understandable that they are unsure about their observations because behavior change can occur as a result of the HSCT and existing psychopathology. The patient and the CPN can work together to process this and support the ward team in the care of these patients.

In these cases the patterns of reaction on the changed psychosocial situations are very understandable. Patients are not doing things wrong, but sometimes their reactions or behavior may not have a positive effect on recovery. For each case it is important that the HSCT nurses use their own observations to contribute to patient care.

In the nursing practice, it can be helpful to consider the following:

- Does the patient really understand the need to strictly follow a set medication regime after SCT?
- How is the hygiene at home in relation of infection risk?

- In normal life enjoying food impacts on quality of life. How can the nurse help their patient with the difficulties they experience around food?
- Diarrhea caused by GvHD has various effects on the psychological well-being of the patient. How can you help to support?
- The pattern of activities changes significantly in comparison with normal life, and the hospital room and environment can inhibit mobility.
- The sleep pattern and routine are disrupted because of intravenous therapies which can stimulate the need of going to the toilet. Other contributing factors are worrying about the diagnoses and social impact in their lives.
- Some patients do not understand their treatment regimen, either due to preexistent loss of cognitive functioning, dementia, low IQ, or the sheer complex nature of their therapy. This can cause increased anxiety and loss of control.
- Self-image is often a concern: roles and relationships change rapidly, and often there are feelings of being “on hold,” at the sideline.
- How do we facilitate intimacy and address sexual functioning concerns?

Nurses understand that body and mind continually interact, and they need to develop skills to structure and interpret their observations. They should discuss this in multidisciplinary meetings and consider appropriate interventions. Nurses need to be taught how to use evidence-based tools that assess and address this aspect of care.

The patient is the best source of information about the impact of their concerns, coping in normal healthy life and what might help them at that moment. To promote self-management and shared decision-making, it is necessary that nurses are aware of the diverse resources and how to use them in their own work setting. Even when there are many professionals involved in a patient’s care, it does not necessarily follow that they will work in a multidisciplinary manner. Interdisciplinary working is time demanding: time for meetings, dialogue, and questioning teamwork (Porchet 2006).

Coolbrandt (2005) wrote a thesis about keeping and losing courage, a qualitative research in HSCT patients at Gent University Hospital.

Coolbrandt (2005) noticed the active role of the nurses in the recovery story of HSCT patients. Like their medical counterparts, nurses contribute to the positive story and support patients in their therapy. Nurses protect the positive story by advising what the patient might expect. When things are going badly, they intervene by explaining the situation. Sometimes, it is appropriate to normalize a situation and the patients feel less panic. Nurses give positive feedback; patients told that it helped them when the nurses are optimistic. Nurses give comfort when they reassure that symptoms will resolve, and they identify solutions improve symptoms. Nurses are often searching for the balance between “realistic hope and hopeful realism.” This study of Coolbrandt (2005) is followed by a study in the same ward about the way hematology nurses care for HSCT patients through the most difficult part of treatment (Deweirdt and Vincke 2008). We already know, but this study confirms the great importance of an empathic attitude and expertise. This empathic attitude is characterized by understanding what the patient is going through, willingness to adjust the schedule if necessary for the patient, and to pay attention to the person behind the patient. The shown expertise, that nurses can normalize concerns and complications, creates confidence in the collaboration between patient and caregivers.

Psychologist Braamse (2015) learns that for some patients, there’s often no immediate solution for the problems. Patients have to go through the situation – and they know that very well. They don’t expect their nurses and relatives to wear their burden. Patients know that the isolation is inherent of their illness and treatment. But they still need the presence from caregivers and close relatives or to feel them nearby. In this way, they can feel the autonomy to choose their own way of coping with the situation. That autonomy is often affected by the disease and treatment.

Nurses can always reflect on themselves with the following basic questions:

- What do I observe?
- What do I signal?
- Which interventions can I do?
- What do I report in the dossier?

- Who can I ask for extra support?
And
- Which attitude is needed? Do I have it?
- Which knowledge is needed? Do I have it?
- Which skills do I need? Do I have them?
- What do I need from my colleagues?
- Who can I ask for counseling and coaching when I need it?

These questions can help you to go back to your nursing base when the complexity of the cases makes you problematize things too much. When you feel powerless because of the multiple problems, you don't have to forget that your presence is also an intervention.

10.10 Therapeutic Interventions, e.g., Complementary Therapies, Music, Touch, and Massage

In some countries there are well-being and relaxation departments for the oncologic patients. The goal is to provide the patients with a wide range of recreational activities and with that maximize their well-being during the treatment. Most of the time, such teams consist of a coordinator, an art therapist, a music therapist, and a group of volunteers. In the hospital they can make a "living room" where patients and their family can come to relax and optionally can partake in a creative activity or a workshop. It consists of four different subdivisions: activity therapies, art therapies, music therapies, and complementary therapies/care. Each division will be specified below.

10.10.1 Activity Therapies

Activity therapies consist of three different pillars: creative activities, social activities, and a rental service.

Creative Activities Patients can choose from a wide range of creative activities. They can do this on their own, with a volunteer, or with other

patients (workshop). For this patient group, most activities take place in the patient room.

Some of the creative activities that we offer include mosaic, jewelry making, painting, drawing, mandala, knitting, and crochet. Special creative volunteers help and provide the patient with creative material. Also workshops can provide special creative activities like (dry)flower arranging and seasonal workshops.

A creative activity provides the patient with a welcome distraction to get through the day. It also helps to keep the mind of negative things, and it is a way to make something nice for their loved ones.

Social Activities Patients regularly stay for long periods of time during their treatment. Some of the patients don't have a big social network and are at risk of becoming lonely during their stay. An initiative "life well-being and relaxation" has special "social" volunteers that visit the patients on a regular basis. The volunteers work with a cart that is filled with all kinds of magazines. With that cart the volunteer visits every patient on the ward. They make contact with new patients, hand out magazines, and tell what can be offered to them during their stay. They make extra time to visit and talk to lonely patients. Most patients really look forward to the weekly meetings with the volunteers.

Rental Service (in Some Hospitals/Organizations) Patients have the possibility to rent items that will make their stay more pleasant. They can get laptops, game consoles, e-readers, tablets, and audio book players. Patients can rent Dvd's directly from a webpage. Offering board games, puzzles, and handy tools like a book seat (a handy device that makes it possible to put a book or a tablet on the bed without the need of holding it) is some of the special offers you can give to the patient.

10.10.2 Art Therapies

Art therapy focuses on the power of the image, where color and form play an important role. Art therapy can give support when the body, mind,

and soul are out of balance because of the physical and mental pressure that comes with being ill. With art therapies a guiding question or a specific theme forms the basis for the therapy. Some possible themes are acceptance, come closer to your inner self, enlightenment, relaxation, and how to handle emotions. With art therapies the process is the most important aspect. It does not matter if the patient is creative or not; it only matters that the patient is willing and open for the therapy.

There are many different creative forms a patient can choose from: drawing, painting, felting, and molding. A combination of said techniques is also possible. Making a collage or writing poetry can also be offered. The materials that can be used are diverse: pastel chalk, aquarelle pencil, and aquarelle and acrylic paint. The art therapist decides together with the patient what material and technique to use.

Patients make regular use of art therapies. Because of their long stay in the hospital, the art therapist can offer lots of therapeutic sessions to the patients which make it easier to work on a certain set goal.

10.10.3 Music Therapies

Music therapy focuses on the power of melody, harmony, and rhythm. Music therapy can give support when the body, mind, and soul are out of balance because of the physical and mental pressure that comes with being ill. With music therapies a guiding question or a specific theme forms the basis for the therapy. Some possible themes are acceptance, come closer to your inner self, enlightenment, relaxation, and how to handle emotions. With music therapies the process is the most important aspect. It does not matter if the patient is creative or not; it only matters that the patient is willing and open for the therapy.

There are many different musical forms a patient can choose from, both in an active form and the recipient. The music therapist can play alongside the bed of the patient; the patient can choose to just listen, but he/she can also sing or play along with an instrument. It is possible for the patient to borrow an instrument, so that they can enjoy play-

ing their own music during the stay in the hospital. Listening to music alongside the music therapist is also a possibility (the therapist has a blue tooth speaker box for these occasions), and the patient can compose and then record his/her own song on CD. This is a great opportunity because the music is not only beneficial for the moment but also acts as a nice memory for a later time.

The musical instruments the patients can choose from are as follows: guitar, keyboard, sound bars, and a lyre (a kind of harp).

Patients make regular use of the music therapies. A lot of patients find the music that the art therapist plays very soothing, and they can let their emotions run free. Some patients even request that the music therapist plays music on their deathbed or at their funeral.

10.10.4 Complementary Therapies/Care

Because of the side effects of the disease or HSCT treatment, some complementary therapies like massage, manicure, and pedicure are limited or not possible for the patient group. The complementary therapies that can be used by the patients are:

Aromatherapy With the use of aromatherapy, the patient can experience a wide range of different aromas. Every aroma has its own use. Some will sooth or calm, while others will activate the patient. The use of electric scent streamers in the patient room distributes the aromas.

Therapeutic Touch Therapeutic touch is a technique to help people relax, relieve their pain, and help them heal faster. It is sometimes called a “laying on of hands” and is based on ancient healing practices. Therapeutic touch is thought to promote healing through balance in the body.

Philips Living Color Lamp The Philips living color lamp can change the color of the room to match the mood of the patient. Patients can change the colors with a remote, so that they can alternate between colors. Just like aromatherapy colors can also influence the well-being of the patients.

10.11 Skin Care (see also Chap. 11 GvHD about skin care)

Introduction

Our skin is important in many ways. Grégoire (1999) stated that the skin is the first line of defense against harmful influences of our environment. The skin prevents us from overheating, undercooling, or drying out. The skin has a sense of touch, so we can feel things and also perform complex actions, for example, with our hands and face. Our skin is unique to us and who we are as a person, recognizable to the people around us or through identification by fingerprints and scars.

The skin exists of three layers:

- The epidermis
- The dermis (leather skin)
- The subcutaneous connective tissue

Grégoire (1999) wrote in his book about pathology and physiology of the layers of the skin. The epidermis is the outer layer. This consists for the most part of horn cells. These cells are constantly newly formed in the lower layer of the epidermis. The cells multiply by division. The newly formed horn cells always move slightly to the surface of the skin because they are pushed upward by the continuous production of new cells. When the cells reach the top of the epidermis, they die. Our skin will form a very strong layer (like an armor), which is difficult to penetrate for pathogens and, in addition, counteracts dehydration of the skin. This dead horn layer is extra thick on some areas of the body, such as on the soles of the feet and on the palms of our hand.

There are also other cells in the lower layer of the epidermis between the horn cells: the melanocytes. The pigment cells make small pigment pellets that they pass on to the horn cells to place the pigment like an umbrella above their core nucleus. Vulnerable hereditary material in the nucleus is shielded against the damaging effect of ultraviolet radiation in the sunlight.

The Grégoire (1999) wrote about the leather skin (dermis) as a solid construction of connective

tissue and is much different in content than the epidermis which consists of a few types of cells. The leather skin is also the most important part of the active defense system of the skin: through which special white blood cells play an important role, viruses and bacteria can be recognized and directed harmlessly. The leather skin also ensures the elasticity and tensile strength of the skin. When the skin ages or is damaged by sunlight, the elasticity and resilience decrease. The leather skin is not constantly renewed, as happens with the epidermis. Damage to the leather skin will therefore always be visible as a scar. However, if only the epidermis becomes damaged, it will heal completely.

The subcutaneous connective tissue is the layer that separates the skin of the muscles and tendons in our body. There are blood vessels (food and oxygen supply), lymph vessels (drainage of waste), and nerves (touch sensation, pipeline, temperature sensation). The blood supply is ingenious and precisely regulates the supply of nutrients and oxygen to the leather skin and the lower layers of the epidermis. The blood vessels in the skin also play an important role in the body's temperature control. By dilating the blood vessels, extra heat can be delivered to the outside, and with vasoconstriction, the release of heat can be reduced so that no energy is lost.

Skin and Chemotherapy

When a patient receives chemotherapy, problems of the skin are common. The skin contains many fast-growing cells which will be affected by the chemotherapy.

Possible complaints are:

- A dry, flaky skin
- Rash
- Faster discoloration or skin damage by the sun
- Brown spots and brown discoloration
- White spots without pigment
- Acne
- Redness
- Itching
- Hyper-/hypopigmentation

Usually, after the end of chemotherapy, the skin will recover quickly.

The basic advice for chemotherapy patients (Erasmus MC (Care guide) (2009):

- The use of perfume or roller deodorant, after-shave, and razor blade is not advised. As a result of treatment, the skin may become more sensitive to these products and may lead to irritation or damage. When this happens, it increases the risk of infection. The use of shower gel, shampoo, and body lotion is allowed.
- Makeup may be used, as long as the skin and nail bed can be well observed. For example, eye shadow and noncolored lip balm are allowed, as they cover a very small part of the skin and are not specific. Rouge, powder, and similar products may not be used, as they cover a larger surface of the skin and possible skin abnormalities may be masked.
- Recommend wearing bath slippers and plenty of clothes. Clothes need to be changed when they are visibly dirty. However, in the presence of fever (perspiration), dry skin (skin scales), or cream use, changing the outfit is desirable. Washing can be done in a normal washing machine, with other people's clothes. However, they must be washed at least 40 °C.

Skin Responding at the Treatment

The skin changes depend on the type of chemotherapy the patient receives. For example, the skin is drier, darker (= pigmentation problem), or look dusky or gray. Also, the nails can change in structure. This is due to the effects of the chemotherapy. It is good to advise the patient to adjust the daily care of the skin to the changes that have occurred.

You can advise the patient (Erasmus MC (Care guide) (2009):

- Not to use very hot or very cold water during shower or bathing.
- Avoid alcohol-based products. They will dry out the skin.
- Do not use any perfumed soap during shower or bathing. A little (almond) oil in the bath water can help to keep the skin smooth.
- Use mild, unperfumed, moisturizing body lotion or cream.

Skin and Rash

If the patient endures itching, scaling, splitting, and burning, you can advise:

- Use soothing and protective creams and ointments. They keep the skin smooth and prevent the skin from drying out. Examples of non-dry skin creams: lanette cream and cetomacrogol cream. Examples in very dry skin: Vaseline lanette cream.
- Do not treat skin rash with anti-acne agents.

Skin and Acne

Chemotherapy can cause acne. This is a side effect that creates uncertainty in our patients. You can advise:

- Leave the skin alone.
- Wash the skin with not too cold or too warm water and do not use any soap. Or use a pH-neutral shower gel.
- Carefully dry the skin with the towel.
- Do not scratch or squeeze.
- A dermatologist may be able to recommend specific topical therapy.

Advice on Itching

Because of the treatment, the skin can dry out it which can cause itching or a prickling sensation that can be uncomfortable. You can advise:

- Do not scratch. Tell the patient to cut the nails very short and keep them clean.
- Itching gets worse sometimes by heat or by contact with clothes or bedding.
- Use a cool ointment or menthol powder (on localized areas) to relieve the itching. This only applies if the skin is not broken.

Skin and Risks of Bleeding and Infections

Chemotherapy may (temporarily) increase the risk of infection and bleeding. Observe the patient for wounds, blisters, or discolorations. In case of sudden redness of the skin or the occurrence of blisters, contact the attending physician. A little extra care for the skin is recommended.

Skin and the Sun

Advise caution with sun exposure and encourage the application of high SPF sunscreen (30–50). The patient needs to be careful in direct sun and also if they are in the shade due to reflected light. During the periods the patients undergo chemotherapy, they can take a walk or work in the garden but advise them against sunbathing. They should avoid the sun between 12 and 15 o'clock. Chemotherapy can cause the loss of hair and thinning of the hair on the scalp. The scalp is more at the risk for sunburn. After chemotherapy, the sun can cause more discoloration of the skin. Our patients must always protect their skin. Wearing a (sun) hat or cap and covering the arms are recommended. Using a sunscreen with a protection factor of 30 or more is extremely important.

10.12 Discharge from Inpatient Care

When a patient is discharged following HSCT, this is often an anxious time. They are now leaving the “safe” environment of doctors and nurses. Some of the patients feel that they don't have any trust in their own body to let them know when they are not well.

It is advisable to inform the patient about the general aspects/living rules so that they can pick up their daily routine at home: housework or social events.

School, study, and work

- Patients who are no longer neutropenic and when their physical condition allows may slowly take up their studies or activities.

Domestic work

- Patients can pick up and expand household tasks. For most patients, a full-day job is too heavy. Ask them to start slowly. It can be very stimulating for patients to feel “useful” again.
- If the patient is neutropenic, cleaning the residences from pets (birdcages, dog basket,

etc.) should be discouraged. Cat's litter boxes and bird cages can easily transmit germs (toxoplasmosis). If nobody can't take over this task, recommend the patient to clean the animal shelter with (household) gloves.

- The patient can do some gardening but advise to avoid contact with sand and/or soil with their bare hands (toxoplasmosis) and avoid moving leaves and debris which may release fungal spores. Ask them to use garden tools and wear (household) gloves.
- Fresh flowers and plants can stay in the home, but give the patients advice to regularly refresh the water of the flowers.

Social

- Patient should be advised if they want to take some outdoor trips, such as holidays or camping visits, to discuss this with their treating physician. This is especially important if the patient wants to go abroad following HSCT. The patient must consider the hygienic conditions or vaccinations that may be needed in the visiting country.
- The patient needs to avoid visits of family and/or friends from sick (contagious) people until they are out of their leukopathic phase and while they remain immunocompromised.

Driving

- The patient should consult with their attending physician when to resume driving. Some medications or having anemia can affect the ability to concentrate so that driving is not safe.

Sports activities

- Give the patient information about building up their physical strength and condition. Some rehabilitation sports programs can be given in the living area of the patient. The patient can also seek information from a physiotherapist in the area to improve their physical condition.

10.13 Readmissions to Hospital

Patients are often unsure about the rules of life and their physical condition during and after HSCT. It is important that patients from the outpatient clinic receive clear information when they can resume certain activities in their social and general life. It is important to inform the patient fully about the rules of life so that they can pick become independent more quickly after this intensive treatment period.

In the home situation, side effects or problems may occur after HSCT. The patient should contact the hospital or attending physician. In many HSCT centers, emergency call procedures are well established. The patient should be aware of these. According to the Erasmus MC (2009) Zorggids (care guide), the contact moments should be as follows:

10.13.1 Urgent Complaints

Following HSCT, they should contact immediately (inside and outside office hours) with the following complaints:

- Fever (temperature above 38.5 °C)
- Cold shivers
- Blood in stool or urine
- Nosebleed
- Hematomas or bruising without bumping
- Difficulty moving the arms and/or legs
- Sudden shortness of breath
- Persistent and constant vomiting
- Persistent diarrhea
- Sudden/new skin rash

10.13.2 Complaints

Following HSCT the patient should contact (within office hours) at:

- No stool for longer than 3 days
- Symptoms of anemia, such as severe tiredness or dizziness

- Pain in the mouth
- Difficulty and pain with swallowing
- Painful and burning sensation during urination
- Burning and/or painful eyes
- Insufficient drinking or passing urine

10.14 Pediatric Considerations

Advances in treatment and improved prognosis increase the number of children and families living through the experience of childhood cancer. Increased survival rates come at the cost of aggressive combinations of chemotherapy, radiotherapy, and surgery, each of which may be associated with adverse effects and psychosocial difficulties for families (Kieman et al. 2010).

Hematopoietic stem cell transplantation (HSCT) may affect children and their families inducing depression, anxiety, burnout symptoms, and post-traumatic stress symptoms, as well as post-traumatic growth (PTG) which includes feelings of inner strength, closer relationships with family members and friends, and a greater appreciation for life, factors that might lead to a general feeling of growth (Riva et al. 2014). Furthermore, these treatments can lead to physical late effects, which may also have psychosocial consequences to the patient and the family long after treatment has ended (Kieman et al. 2010).

It is important to understand the general impact of childhood cancer on families, like the emotional impact, the specific impacts for individual family members and extended family, and the disruption to family life. How the illness impacts on the social lives and networks of the family and the social implications for families needs to be taken into consideration (Kieman et al. 2010).

There are many specific psychological interventions to help children deal with cancer treatment. As quoted by Weinstein and Henrich (2013) in their research, the interventions that are mostly used to help children before they undergo

a painful or anxiety-inducing procedure are educating children by explaining the procedure, providing emotional support to children by listening and answering children's fears and worries or holding their hands, and distracting children through passive forms such as music, television, and books or through active forms such as playing, telling stories, singing, and using bubbles. Weinstein and Henrich (2013) explains the least commonly reported strategies that nurses used were breathing exercises to relax the child using books, tapes, and videos to educate children on their treatment and hypnosis. All these psychological interventions are effective in reducing pain and anxiety, along with enhancing acceptance of medical treatments (Weinstein and Henrich 2013).

Also Weinstein and Henrich (2013) stated that one of the primary benefits of these psychological interventions is that children shift from a passive and helpless state of pain and anxiety to a state of control and empowerment with an active adaptive attitude toward life. Through these interventions, children are considered an active participant within their own care. By preparing children psychologically for medical procedures and teaching them coping strategies, nurses may help reduce the risk of developing maladaptive behaviors and psychopathologies. Kieman et al. (2010) indicate that physicians and nurses working in pediatric oncology are in a unique position to identify and manage psychosocial issues in childhood.

In order to prevent feelings of isolation and helplessness, the children's rights in hospital (EACH 2016) stresses that steps should be taken to mitigate physical and emotional stress. The staff should avoid or reduce situations or actions described by the child as stressful. The staff should learn to recognize and act upon the fears or concerns of the child and families whether or not explicitly expressed. To mitigate emotional stress, the child and family should be offered emotional support.

It is important to work together with a multidisciplinary team members like the child life therapists, psychologists, and social workers who all can help to provide psychological support to

the child and their families (Weinstein and Henrich 2013). Contacts should be offered to social services, psychologists, and therapeutic healthcare professionals as well as religious support or counseling when requested, taking into account the family's cultural background and contact with self-help groups, relevant support groups, and patient or consumer organizations (EACH 2016).

For children it is important to try to make the life in hospitals as close to normal life as possible. School is an important part of it for school-aged children. School is also an important part of adolescents' and young adults' lives, and being diagnosed with cancer in childhood may affect perceptions of school. Cancer and its treatment have a negative impact on mental and physical health and often lead to an increased absence from school. Furthermore, treatments with radiation and chemotherapy, especially among patients diagnosed with a central nervous system (CNS) tumor, may significantly affect neurocognitive function and levels of education (Winterling et al. 2015).

Results from Winterling et al. (2015) studies show that survivors appear to achieve education levels comparable to those of control groups although some studies indicate that survivors more often repeat a school year and receive additional academic support.

Furthermore, worry over missing school is a great concern for adolescents starting chemotherapy.

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