The Self-Care Deficit Nursing Theory and Allogeneic Stem Cell Transplantation

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A Project Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF NURSING

in the School of Nursing, Faculty of Human and Social Development

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Abstract

The self-care deficit nursing theory (SCDNT) provides a foundation for the exploration of the relationship between nurses and people in need of self care. The aim of the SCDNT is to describe how nurses can assist people to meet self-care needs. Self-care is posited in this theory as a requirement of every person, thus, if self-care needs are not met or maintained, illness, disease, or death will occur (Orem, 1971). Self-care requisites, classified as universal, developmental, and health-deviation requisites (Orem, 2001), must be met to maintain and promote health and to prevent further illness or complications from illness according to the SCDNT. Adults who have undergone an allogeneic stem cell transplant (SCT) are presented with challenges that test their ability to meet these self-care requisites. As integral members of the SCT care team, nurses are well-situated to assist patients with identifying self-care needs related to, and beyond, the experience of SCT. In this paper, the concepts of self-care, self-care deficit, nursing systems, basic conditioning factors, self-care requisites, nursing processes, and self-care operations will be analyzed with a specific focus on the supportive-educative nursing process, as conceptualized within the SCDNT in the context of allogeneic stem cell transplantation. Limits of the SCDNT used to guide care of this patient population will be discussed and recommendations arising.
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Introduction and Background

“What do I need or what can I do to help myself live longer, healthier, and perhaps happier? Do I need help from others to do this? What do I need to help me fulfill these goals? Who can help me, teach me, assist me, or do this for me?” The purpose of asking these questions is to stimulate thought into the beneficial role a nurse has in the lives of others which will be described in this paper. The self-care deficit nursing theory (SCDNT) can be used as a framework to explore the relationship between people in need of self-care and nurses who assist people with meeting their self-care needs. The purpose of my project is to explore the concepts of the Self-Care Deficit Nursing Theory (SCDNT) and how they can be used to guide nursing practice with allogeneic stem-cell transplant (SCT) patients. It was not until I had begun to work on my project that I realized the foundation for this work really started three and half years ago when I began the Advanced Practice Leadership (APL) option of the Masters of Nursing (MN) program. Dorothea Orem was one of the theorists I chose to study during the nursing theory course in this program. I came to appreciate that Orem's SCDNT was comprehensive and practical for my area of nursing. Thus, the SCDNT is utilized as the theoretical foundation for this project.

The SCDNT provides a framework for the nurse working with patients and families to answer the questions initially identified above. The concepts of self-care and patient education, concepts central to my practice as an oncology nurse are also central to this theory. Thus, it seemed appropriate to use this theory as a framework to guide my exploration of these concepts and to examine how they link together. In addition, the concepts of self-care deficit, nursing systems, basic conditioning factors, self-care requisites, nursing processes, and self-care operations will be analyzed. Also presented are the relationship among and between these
concepts, my area of clinical practice, and the provision of nursing care for patients with complications of SCT, specifically graft-versus-host disease (GVHD).

Adults who have undergone an allogeneic stem cell transplant (SCT) are presented with challenges that test their ability to meet self-care requisites. As integral members of the SCT care team, nurses are well-situated to assist patients with identifying their self-care needs related to, and beyond, the experience of SCT. In this paper the concepts of self-care, self-care deficit, nursing systems, basic conditioning factors, self-care requisites, nursing processes, and self-care operations, will be analyzed with a specific focus on the supportive-educative nursing process, as conceptualized within the SCDNT in the context of allogeneic stem cell transplantation.

Situation Myself

My nursing career has focused on children and adults undergoing blood and marrow (BMT) or stem cell transplantation treatment. I have maintained this focus for 15 years and continue to be amazed by the advances that have occurred over this time period. I have provided care for patients and their families in all phases of the transplant process including direct patient assessment and care, such as delivery of medications and monitoring of physical status. I have been involved with providing education aimed at preparing patients and their family members for the SCT process. At this time, I also work with patients and their family members to identify their issues and concerns as they attempt to cope with the proposed treatment plan and accept the uncertainty and risk associated with SCT.

Overview of the Self-Care Deficit Nursing Theory

The SCDNT is a general theory used by nurses to guide nursing practice, develop and validate nursing knowledge, and teach and learn nursing (Taylor, 2002). The SCDNT is concerned with identifying what the subject matter of nursing is and what role the nurse has
with regards to self-care that makes it unique to nursing and not other disciplines, such as medicine. According to Orem (2001):

the condition which validates the existence of a requirement of nursing in an adult is the health-associated absence of the ability to maintain continuously that amount and quality of self-care that is therapeutic in sustaining life and health in recovering from disease, or injury, or in coping with their effects. With children, the condition is the inability of the parent (or guardian) associated with the child’s health states to maintain continuously for the child the amount of quality care that is therapeutic. (p.22)

The SCDNT is composed of three interrelated theoretical frameworks. These are, the theory of self-care that explains what is meant by self-care and outlines self-care requisites; the theory of self-care deficit that aims to describe and explain when nursing is needed and why people can be helped through nursing; and, the theory of nursing systems that has the purpose of describing and explaining how the patient’s and family’s self-care needs will be met by the nurse, patient, or both (Orem, 2001; Taylor, 2002; Foster & Bennett, 2002; Cox & Taylor, 2005) p.249).

Self-care behaviours can be learned and, according to the SCDNT, the nurse must assess an individual’s ability to meet their self-care needs by applying a three-step nursing process. Step one requires that the nurse assess the situation, make a nursing diagnosis, and provide recommendations regarding care. Step two focuses on designing the nursing system, also referred to as the care plan, and implementing the care plan. Step three revolves around the production and management of nursing systems, planning and controlling resources and provision of care (Foster & Bennett, 2002). The nurse applies the nursing system by examining
the actions required as a result of the illness or situation and the individual agent’s ability and aptitude to perform the required task(s) (Cox & Taylor, 2005).

Facilitating self-care and preparing patients to cope with “potentially threatening events” (Dodd, 1983, p.45) is a vital part of providing quality nursing care (Dodd, 1982) and promoting good health, defined by Orem in congruency with the World Health Organization definition as “a state of physical, mental, and social well-being…not merely the absence of disease” (Foster & Bennett, 2002, p.133). Nurses have a unique opportunity to influence health care action and health promotion, by advocating for “doing with, not to others” (Kellehear, 1999, p.76). They do this by participating in partnership with patients, their families, and the SCT care team.

Concepts in the Self-Care Deficit Nursing Theory

Concepts are “the building blocks of theories” (Bishop, 2002, p.51) upon which ideas are explored, and assumptions are created and evaluated, with the goal of advancing nursing knowledge and improving the delivery of nursing care. The basic concepts in Orem’s theory include self care; self-care requisites; self-care agency; therapeutic self-care demand; self-care deficit; nursing agency; nursing systems; and, basic conditioning factors (Orem, 2001).

Self-Care

Self-care is “a requirement of every person… and when not maintained, illness, disease, or death will occur” (Orem, 1971, p.2). The idea of self-care was first introduced by Orem in 1956 as she tried to express when and why people require nursing and how nursing could help people to perform self-care (Denyes, Orem, & SozWiss, 2001). Self-care involves the deliberate performance of activities that an individual executes to maintain life, health, and well-being (Orem, 1971). For most adults this practice is voluntary. The adult who knows their self-care
requirements and performs purposive actions to regulate their function and development (Taylor, 2002) is regarded as a self-care agent. The self-care agent provides self-care with the goal of promoting normal functioning, maintaining normal growth, preventing, controlling or curing disease processes or injuries, and compensating for disability. Provision of self-care may be required by all persons on a continuing basis during all stages of the life cycle but others are required only in the event of disease or injury (Orem, 2001).

**Self-Care Deficit**

A self-care deficit occurs when human beings do not have adequate abilities to meet their therapeutic self-care demands. The deficit may be complete or partial. People require knowledge to guide their actions and when they lack this knowledge they require the assistance of a self-care agent, such as a nursing agent or a dependent care agent (family member). Self-care agency is the reason nursing is needed (Allison, 2007). In an illness situation, complex self-care measures exist. In an attempt to promote the ability of an individual to meet their self-care needs, specialized knowledge must be acquired through training and experience. The individual requires the help of another person, such as a nurse, to facilitate the ability to provide self-care. The nurse, as a nursing agent, is the expert who helps people learn how to perform self-care so that they may attend to the self-care demands required in life and those brought about by illness (Orem, 2001).

**Nursing Systems**

Orem explains that nurses help others with meeting their self-care needs by “acting for or doing for another; guiding and directing; providing physical or psychological support; providing and maintaining an environment that supports personal development; teaching” (Foster & Bennett; 2002). Nurses in all facets of healthcare, including the area of SCT,
accomplish all of these tasks at some point in the care trajectory. There are three nursing systems described in the SCDNT that describe how the nurse accomplishes the task of assisting patients to overcome a self-care deficit. The first is wholly compensatory. In this scenario, the nurse compensates for the self-care deficit on behalf of the patient. Secondly, in the partly compensatory nursing system, the patient and the nurse have roles in the attainment of a self-care requisite. The nurse has a major role in self-care but the patient maintains ability to complete the self-care task. An example of this would be a nurse who assists a patient who has muscle weakness with ambulation by guiding the patient as he or she attempts to get out of bed while providing a standby-assist. Another example of this would be a nurse who consults a physiotherapist to assess a patient’s ability to ambulate and advise on the requirement of aids to assist with ambulation. Thirdly, the supportive educative nursing system provides a framework for describing how a nurse can assist patients in meeting self-care needs. The patient is able to perform self-care with the support, guidance, and teaching of the nurse (Orem, 2001). The nursing processes of wholly compensatory, partly compensatory, and supportive educative (Orem, 2001) manifest at various stages in the transplant course. Basic conditioning factors, self-care requisites, and nursing processes will be discussed further with a focus on chronic graft-versus-host disease and the supportive-educative nursing process.

Supportive-Educative Nursing Process

Nurses are health care professionals associated with the highest percentage of direct patient care delivery, 80% (Antrobus, 1997). The supportive-educative system describes a framework where nurses employ support, guidance, and teaching in situations when patients can perform self-care measures but require assistance to be informed and act competently (Orem, 2001). Merriam-Webster (2009) defines support as “to promote the interests or cause of (2) to
uphold or defend as valid or right, to assist, help and be an advocate.” The definition of educate includes “to train by formal instruction and supervised practice… to develop mentally… to provide with information, to persuade or condition to feel, believe, or act in a desired way (Merriam-Webster, 2009). Patient education is an essential component of nursing practice (Zuk & Quinn, 2002). Nurses have the unique opportunity, by nature of unwavering and dependable presence, to teach patients and families about how the treatments affect health and can impact lives (Murphy & Canales, 2001). The goal of patient education is to help patients and families to understand the disease and care required in the treatment of the disease. This promotes patient involvement in care and improves overall outcome of therapy. “It often falls to nurses to explain information obtained from other health care professional that was only partly understood by patients” (Schaefer, 2002, p.479).

Patients undergoing bone marrow transplant (BMT) for hematologic malignancies require extensive patient education to be able to cope with illness, foster compliance, and encourage participation in treatment (Treacy & Mayer, 2000). Timing and degree of information will vary between individuals. Physical, cognitive, cultural, and emotional factors (basic conditioning factors) influence the ability to learn (Chelf et al, 2001; Jacoby et al, 1999). Different ways of delivering education include one on one discussions, group presentations, printed material, audio/video, and computer (Bakker, Blais, Reed, Vaillancourt, Gervais, & Beaulieu, 1999). Health literacy must be considered. Learning ability must be assessed, including assessment of the ability to read materials in the language provided, often English, and comprehension (Freda, 2004). Readability formulas, such as the Simple Measure of Gobbledygook (SMOG) formula, can be used to assess written materials. Materials should be of a junior high reading level (Mclaughlin, 2008), consistent with the recommendation of
literacy reading experts (Wilson & Williams, 2003). As health care professionals, nurses have
the responsibility to provide support and education to patients and families. The goal of nursing
interventions is to promote quality and quantity of life, fostering patients’ ability to make
appropriate decisions regarding care with safety and best interests in mind.

Overview of Stem Cell Transplantation

Stem cell transplantation is a very aggressive form of therapy involving the
administration of high dose chemotherapy and/or radiation therapy followed by stem cell rescue
with the aim of curing patients with certain hematologic malignancies or bone marrow failure
syndromes. Over the past 50 years, advances in supportive care and refinement of transplant
preparative regimens, chemotherapy, and radiation therapy have resulted in an improved
tolerance to SCT (Niess & Duffy, 2004). Despite this, SCT is still associated with significant
morbidity and mortality rates (Grant, Cooke, Bhatia & Forman, 2005). Risks of SCT include
profound myelosuppression, infection, sepsis, and potentially irreversible organ damage (Saria
& Gosselin-Acomb, 2007). SCT is associated with invasive medical procedures such as: central
line insertion, distressing physical symptoms such as mucositis, isolation; changes to the body
such as edema and alopecia; loss of independence; and, threat to personal goals. SCT impacts
recipients' quality of life and may elicit physical, social, psychological, and emotional stress for
the patient and the family. The causes of mortality include regimen-related organ toxicity,
infection, graft-versus-host disease (GVHD), and disease relapse (Leger & Neville, 2004).
Despite these risks, SCT offers patients and their families hope for a cure where alternative
options are generally ineffective. Prior to transplantation, patients focus on the transplant and
being cured. They may accept risks without understanding their significance because they do not
want to contaminate their optimism for a positive outcome with negative information (Bywater
& Atkins, 2001). Thus, educating patients and their families about potential acute and chronic complications of their transplant is challenging. Nonetheless, receiving information about BMT that is understandable, timely, and facilitates engagement, has potential to enable patients and their loved ones to better understand and cope with the overall BMT experience (Treacy & Mayer, 2000). One question I frequently contemplate is, "could patients who develop adverse outcomes such as chronic GVHD have understood its implications prior to their transplant?"

*The Transplant Course*

The transplant trajectory begins with an initial diagnosis, includes a process of exploring potential treatment options, and may last for an indefinite period of time. Phases of transplant consist of the pre-transplant period, the transplant day, and the post-transplant period (Leger & Neville, 2004). Specific developments of these phases are discussed below.

The pre-transplant period begins at the time of referral to the SCT program and continues through to completion of administration of the preparative therapy. This referral may occur within weeks of a cancer diagnosis, such as in the case of high-risk acute myeloid leukemia (AML), or it may occur several months or years after initial diagnosis such as often the case for patients with lymphoma. The pre-transplant period involves both outpatient and inpatient care. Physical, psychological, financial, and spiritual needs of patients and families or informal caregivers must be considered at this time and throughout the transplant course (Ferrell, Virani, Smith & Juarez, 2003).

Nurses educate patients and families and organize tests to be completed that will help the transplant team assess the SCT patient's physical fitness to undergo SCT. Nurses work with the transplant team, comprised of physicians, social workers, pharmacists, and other nurses, to prepare patients and families, physically, socially and emotionally, for the transplant. Nurses are
heavily involved with delivering education to the patient and family on the subject of SCT. Nurses must evaluate the effectiveness of interventions and the ability of learners to understand the knowledge provided. Nurses must focus on the unique needs of each learner so that together the nurse and those in their care can establish realistic learning goals and expectations. The nurse applies the steps of the nursing process, assessment and diagnosis, to identify the learning needs and, together, set goals with patients and families. Through teaching, sharing, and listening, nurses work to prepare the patient and family for the pending transplant.

Patients are admitted to hospital and receive intensive chemotherapy and/or radiation therapy usually over the course of one week in preparation for their transplant or stem cell infusion. Again, the nurse must be cognizant of the physical, emotional, economic, and spiritual needs of the patient and their family. Major physical side effects that the patient may experience at this time include nausea and vomiting, diarrhea, fluid retention or dehydration, hematuria, fever, and fatigue. The nurse provides supportive care to the patient to mitigate the effects of the chemotherapy. Teaching occurs throughout the continuum of care. The nurse must continually reinforce teaching and adapt the teaching approach to meet the individual needs of the patient and his/her family. Patient teaching at this time is often centered on the side effects of chemotherapy and how patients’ and families, along with the health care team, can work to prevent, identify, and manage these side effects. Everyday routines for the patient and family change making it "impossible for individuals to carry out roles they routinely assumed" (Fife, Huster, Cornette, Kennedy, Akard & Braun, 2000, p.1539). The nurse must address the impact of these role changes on the emotional well-being of both the patient and their family as they adjust to these changes, by talking with them, actively listening to their concerns, and involving additional resources, as necessary. The nurse must also be cognizant of logistical issues that may
arise for the patient and family. Financial strain may arise because of the possible loss of income plus expenses for gas and parking when family members come to the hospital to visit. Additionally, daycare services may need to be arranged if the SCT patient has young children. As part of providing holistic care the nurse must work with patients and their families to identify issues of concern and develop a plan to address these.

The transplant period is usually one single day. On this day, the necessary stem cells are administered with the goal of repopulating the patient's stem cell source or rescuing the patient from this otherwise lethal therapy (Niess & Duffy, 2004). The nurse again educates the patient and family about this procedure, monitors the patient for adverse reactions throughout the infusion, and provides emotional support to the patient and family.

The initial post-transplant or engraftment period begins the day after stem cell infusion and continues through white blood cell count recovery and discharge from hospital. During this time period, the patient remains in hospital where the nurse provides ongoing monitoring and supportive care. The nurse may apply the nursing processes of wholly compensatory, partly compensatory, and supportive educative in assisting the patient to cope with the side effects of therapy. These side effects may include low complete blood counts, which could result in potentially life-threatening infection, anemia, weakness, and thrombocytopenia, as well as malnutrition, diarrhea, dehydration, and mucositis. These processes will be elaborated on as the self-care requisites are discussed.

The late post-transplant phase, or the period of immunoreconstitution, usually commences after initial discharge from hospital. Therefore, it is important for teaching to begin prior to discharge. Topics to be addressed for pre-discharge teaching include: central venous catheter care; management of fluid and nutrition intake; nausea, and vomiting; monitoring and
prevention of infection; GVHD implications, assessment, and management; and, adjustment post-hospitalization (Grant, Cooke, Smith & Forman, 2005, p.E1). In the event of severe complications of the SCT and a lengthy hospital stay, this period begins before discharge. During the post-engraftment phase, patients are at risk for myelosuppression, recurrent diarrhea, nausea and vomiting, dehydration, renal impairment, development of GVHD and bacterial, fungal, and/or viral infections (Leger & Neville, 2004).

Following discharge, patients are primarily responsible for their own care. Such care however, is often assisted by family or friends who take on a caregiver role. Transplant patients may experience “dry mouth, tiredness, lack of energy, tension, headaches, decreased sexual interest, irritability, lower back pain, sore mouth, and shortness of breath” (Grant, Cooke, Smith & Forman, 2005, p.E2) as well as body image changes related to alopecia, edema, or skin rash. The nurse provides support to the patient and family as they develop their capacity for the patient’s self-care. The role of the nurse in this phase will be discussed under the section on health-deviation self-care requisites focussing specifically on self-care, GVHD, and related side effects.

Overview of Graft Versus Host Disease

Allogeneic SCT involves a recipient (host) and donor (graft). GVHD occurs in 20% to 70% of people undergoing allogeneic SCT who survive greater than 100 days post-transplant. GVHD is “the most serious long-term complication” of allogeneic SCT (Lee, 2004, p.4200) and is a significant cause of non-relapse mortality. GVHD occurs when T-cells from the donor (graft) recognize the recipient (host) environment as foreign and mount a response, attacking the recipient immunologic tissues (Woltz, Castro & Park, 2006). This reaction can be acute (aGVHD), occurring during the first 100 days post transplant, or may be chronic (cGVHD),
usually developing after 100 days post transplant. The three main target organs of GVHD are the skin, gastrointestinal mucosa, and liver. Lungs, eyes, sexual functioning, and emotional well-being may also be affected and this can be catastrophic, adversely effecting quantity and quality of life. The following quote taken from a patient information handbook provides a summary:

In more serious cases, GVHD can affect major body organs and can be life-threatening. Acute GVHD may resolve itself with treatment, or in some cases, it merges with the onset of chronic GVHD. The effects of chronic GVHD include dry eyes, dry mouth, skin and joint problems, or problems with organs such as the liver or lungs. The severity of GVHD varies dramatically from patient to patient, as does its time of onset and duration. Some patients who receive marrow from a donor experience no GVHD whereas others experience extensive GVHD. A variety of methods are used to prevent or reduce the incidence of GVHD. Patients receive immunosuppressive drugs which weaken the immune system, thus reducing the severity of the attack on viral organs. Unfortunately, they also increase susceptibility to infections and prolong the period of immunosuppression. These drugs may also affect one’s emotional and mental state. While on these drugs, some patients experience drug induced depression, confusion, anxiety, roller coaster-like mood swings, and exaggerated feelings of anger or excitement. It is helpful to keep in mind that these effects are temporary and that many people do not experience these side effects. (Stronach, 2002)

This information is useful in trying to convey to potential transplant patients the seriousness and potential risks of undergoing allogeneic SCT. However, it reads at approximately a grade 12.49
reading level (McLaughlin, 2008) and the terminology is complex. It behooves nurses to address not only these potential risks but also to teach patients and families in a manner with which they can understand. Information provided must be simple and relevant (Lieb, 2009). The nurse must individualize education and reinforce to patients and families that all symptoms and concerns are legitimate and they should be encouraged to contact health care providers if concerns develop. The teaching should include what people can do to provide self-care to prevent, manage, and cope with GVHD because patient education, preventive measures, and appropriate follow-up contribute to improvement in the quality and quantity of life post-transplant (Couriel, Carpenter, Cutler, Bolanos-Meade, Triester, et al., 2006).

**Chronic Graft-Versus-Host Disease**

Chronic graft-versus-host disease (cGVHD) will develop in 6% to 80% of individuals who have undergone an allogeneic SCT with symptoms presenting usually within three years after SCT (Filipowich, Weisdorf, Pavletic et al., 2005). GVHD can affect the skin, gastrointestinal tract, liver, lungs, and other organ systems. Patients commence taking immunosuppressive agents before their day of transplant and are monitored for the development of GVHD. If GVHD does not develop or if it subsides, the immunosuppressive therapy is tapered off over a period of weeks to months. Patients are monitored for signs of recrudescence of GVHD. As previously discussed, there are known risk factors for the development of GVHD (age, sex, human leukocyte antigen (HLA) mismatch, disease). It is impossible to predict at the onset of the transplant course exactly who will develop how much GVHD and what impact this will have on their life. It is imperative that patients monitor for development of GVHD, report symptoms or signs of GVHD to their health care professional in a timely manner, and remain compliant with medication therapies directed at preventing and controlling complications related
to GVHD. Ancillary and supportive care are central components in long-term management of chronic graft-versus-host disease (cGVHD) (Couriel et al., 2006). This care is provided by a variety of health care professionals and specialists as well patients and their families.

There are many therapeutic regimens available to control and manage complications of cGVHD but, cGVHD has the potential to be life-lasting. Chronic GVHD can affect every organ system and usually develops once the immediate side effects of transplant have subsided. Chronic GVHD can be debilitating physically, emotionally and socially. Management of cGVHD is complex and requires a multidisciplinary approach to treatment of which the SCT patient is a key player. With decreased hospital stays resulting in an increase in the burden of care for patients, families, and healthcare resources (Grant, Cooke, Bhatia & Forman, 2005) the role of the nurse in the management of complications will be discussed.

Literature Review

“Nursing: Concepts of Practice” (Orem, 2001) and a selection of articles obtained through literature searches serve as the major sources of information about the SCDNT. An electronic search primarily using Cumulative Index for Nursing and Allied Health Literature (CINAHL) was performed. Terms used in varied combinations include: self-care, self-care deficit nursing theory (SCDNT); SCDNT and cancer, SCDNT and chronic illness, SCDNT and GVHD, SCDNT and SCT, GVHD, GVHD and nursing, SCT and/or GVHD and cultural influences, family, socioeconomic status, gender, age, self-care, isolation, exercise, psychological changes. My initial CINAHL search on the SCDNT identified 200 related articles. Biggs (2008) had completed an extensive literature review of the SCDNT limiting the search to the years 1999 to 2007. Despite identifying over 400 articles, a total of 335 articles were reviewed for the Biggs project.
The goal of my project was not to repeat work of this nature but to identify literature that I could use to explore how the SCDNT is useful for nurses caring for SCT patients. Over 584 articles were identified under the subject of GVHD yet no articles were identified that addressed the SCDNT and SCT, nor SCDNT and GVHD. Ten articles were identified under SCDNT and chronic illness. These referred to management of migraine, heart failure, and diabetes and therefore were not reviewed further. Eight articles were identified on SCDNT and cancer. Two of these related to children, 3 to breast cancer, and a few others not relevant to my subject of interest. When searching GVHD and relevant basic conditioning factors such as age, gender, and socioeconomic status, few relevant articles were identified. In total, 40 articles on GVHD were reviewed. Pivotal articles were selected on which to focus on SCDNT, transplant related complications, and acute and chronic GVHD, and related organ system toxicities (Couriel et al., 2006; Filipovich et al. 2005; Mattson, 2007; Grant, Cooke, Bhatia & Forman, 2005).

Basic Conditioning Factors

Orem (2001) describes aspects of life referred to as basic conditioning factors which are always present and may affect an individual's ability to meet their self-care requisites. These include age and gender, developmental state, health state, location and type of residence, sociocultural and socioeconomic factors, family system factors, environmental factors, health care system factors, and resource adequacy (Orem, 2001; Foster & Bennett, 2002). Examples of how these relate to self-care will be discussed.

Gender

Males are slightly more likely to undergo SCT than females by approximately 5% (CIBMTR, 2007). The significance of gender in the setting of SCT relates to the circumstance where the donor is a female. There is an increased risk of GVHD when there is a
gender mismatch, specifically when the donor is a female and the recipient is a male. Additionally, females who have been pregnant develop more white cell antigens and this contributes to an increased risk of development of GVHD in the recipient regardless of the recipients’ gender (Vogelsang, 2004).

Although I could not find strong evidence that women and men differ in their transplant experience, the impact on normal routines and responsibilities will occur. Feminist work suggests women carry more responsibility for practical and emotional support whereas hegemonic forms of masculinity focus on strength, control, and success (Emslie, Browne, MacLeod, Rozmovits, Mitchell & Ziebland, 2009). Family role shifting occurs as a result of illness and the required treatment, such as hospitalization and inability to work (Grant, Cooke, Bhatia & Forman, 2005). Further research aimed at examining how people adapt their traditional family role in the situation of illness, specifically SCT, is required.

**Developmental Stage**

Age is a conditioning factor associated with physical and social issues and developmental stage in life. SCT may be a treatment choice for infants to adults. For the purpose of this project I am focusing on cognitively intact adult patients. The conditioning factor of age would have different implications for different patient populations. Children as dependants have different needs depending on their age and developmental level. An individual with learning disabilities would have unique needs. For example, an adult with developmental delays may require involvement of a psychiatrist who assesses their ability to provide informed consent. Additionally, a parent, or patient advocate, may be appointed for this purpose. A SCT patient who is a single, young adult, still living at home might have different responsibilities and life experience than an adult SCT patient with dependents, such as a spouse or children. Each SCT
situation is unique and nurses must be proactive in advocating for the needs of patients and families throughout the transplant process.

In the setting of SCT there are criteria that determine eligibility to undergo SCT. As advanced age is one such factor, advanced age may result in a person being deemed ineligible for SCT. Older individuals are at increased risks for developing organ toxicities related to their transplant and for developing acute GVHD and subsequently chronic GVHD (cGVHD) (Mattson, 2007; Arai & Vogelsang, 2000).

Health State

Health is characterized by Orem as being a basic conditioning factor, one variable used to characterize features of the individual. Health is also a state, defined by the World Health Organization as a state of “physical, mental, and social well-being and not merely the absence of disease” (Orem, 2001, p.184). Orem describes the meaning of health as a dynamic entity that consists of well-being even in the presence of illness (Orem, 2001). A diagnosis of leukemia or bone marrow failure requires immediate and aggressive care and will have an impact on physical, social, spiritual, and emotional well-being (Rawl, Given, Given, Champion, Kozachik, Barton, Emsley & Williams, 2002). This will have an impact on the individual’s ability to continue to meet self-care needs, to care for oneself and others such as dependents, and will likely be associated with factors such as stress, that inhibit the learning process (Stephenson, 2006). Common issues patients may encounter post-transplant include, “infection and prevention of infection, medication management, graft-versus-host-disease, nutritional issues, nausea, fatigue, family role shifting, family distress, coping, slowly returning to a “new normal”, and existential issues” (Grant, Cooke, Smith & Forman, 2005, p.E1). All allogeneic SCT patients are immunosuppressed. The duration of immunosuppression varies for each
individual depending on the degree of donor human leukocyte antigen (HLA) matching, presence of graft-versus-host disease, and the recovery course post transplant. Patients with chronic myelogenous leukemia (CML) or aplastic anemia are more likely to develop cGVHD. Patients with lymphoma or leukemia, particularly those with CML, are more likely to benefit from the graft-versus-leukemia effect associated with GVHD. In this, the graft recognizes leukemia cells as foreign and tries to mount an immunologic reaction against them which helps with curing the primary disease (Arai & Vogelsang, 2004). This is beneficial for the patient but also fraught with the potential for increased transplant-related complications.

*Location and Type of Residence*

Stem cell transplant patients are required to remain in close proximity to the transplant centre for the first 100 days after transplant. Chronic GVHD typically develops after 100 days, possibly when individuals have returned to their home communities under the care of a community-based physician who may not be as familiar with the diagnosis and management of cGVHD and its related complications (Rao, Darrington, Schumacher, Devetten, Vose & Loberiza, 2007). The primary responsibilities of the SCT health care team are to teach the patient and family signs and symptoms of cGVHD, to liaise with the community physician, and to encourage the patient to maintain regular contact with the transplant centre for routine follow up, prevention, and management of symptoms related to their transplant.

*Sociocultural and Socioeconomic Factors*

In Canada, we have the benefit of access to healthcare services without having to worry about health insurance and coverage for treatments such as SCT. There are however significant costs incurred by the individual and family that are not covered by health insurance (Wagner & Lacey, 2003). These include costs incurred by patients for medication to be taken after discharge
and transportation costs to and from clinic appointments. Patients who undergo transplant often cannot work for a significant period of time, therefore there may be a loss of income related to decreased productivity and inability to work. Rarely do patients return to work shortly after their transplant. It is not uncommon for someone to be away from school or work for anywhere from 3 to 12 months, or longer, and this is often after a period of hospitalization and treatment prior to their transplant. For example, patients with acute myeloid leukemia require immediate admission to hospital for treatment that usually consists of a one month minimum hospital stay. Following this, the patient may undergo three months of chemotherapy while waiting to proceed to SCT. After recovery from transplant some people may eventually return to part-time employment while others never return. This can have significant effects on individual and family finances. The individual may not be able to meet their financial self-care needs and may need to rely at this time on a significant other to continue to work to maintain an income. Families may have to adapt their lifestyle accordingly.

*Family System Factors*

Orem outlines three fundamental types of familial situations. One is family as a basic conditioning factor that according to the SCDNT has the potential to significantly influence an individual’s ability to provide self-care or to meet self-care needs with assistance. Family is also a structure or setting where the “kind of care needed varies according to the nature of the dependent care unit (infant, child, dependent adult) and the reasons for the dependency, which may be related to age, developmental state and health state” (Taylor, 2001, p.7). Family is a unit whose central purpose is to “create, maintain, and promote the social, mental, physical, and emotional development of each and all of its members (Taylor, 2001, p.7). Family is also a unit of service that provides an environment for the individual to thrive and have their self-care
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needs met. Family units vary in structures, which include nuclear, extended, multigenerational, blended, split, adult-only, or single parent families; different developmental stages, such as child-bearing or child-rearing; and families with altered health states, with sick children, or sick adults (Orem, 2001). As such, family members perform different tasks specific to their role of dependent care agent, assisting patients to meet their self-care needs. The relationship between a nurse and patient exists as long as specialized care is required, or until a patient or family member can become responsible for maintaining and managing the necessary function for self-care (Orem, 1971). The dependent care theory parallels the self-care deficit nursing theory and outlines the role of family as dependent care agents (Taylor, Renpenning, Geden, Neuman & Hart, 2001). Role shifting occurs when the patient, because of illness and required treatments, becomes the dependant who requires assistance to meet self-care needs. When family members take on the role of the dependent care agent, they “accept and fulfill the responsibility to know and meet the therapeutic self-care demand of the relevant others who are socially dependent on them to regulate the development or exercise of the person’s self care ability” (Taylor, Renpenning, Geden, Neuman & Hart, 2001, p. 40). This may involve taking on different social roles, learning about SCT, expected side effects and treatment regimens, as well as preventive measures. At different times, family members may be called upon to assist with meeting the various self-care requisites.

Environmental Factors

Orem discusses the environment as directly influencing a patient’s ability to provide self-care. She describes universal self-care requisites, the “need for air, water, and food….preventions to hazards of life” (Foster & Bennett, 2002, p.144) as influences of an external environment on humans. Humans must adapt to their environment to be able to perform
self-care. Environmental factors pertinent to the SCT patient include safe living conditions which are free from risks of infection, such as mould, excessive dirt, and construction. During the immediate transplant course, patients are admitted to hospital where they remain on a HEPA (high-efficiency particulate air) filtered unit until neutrophil recovery and discharge. At discharge, nurses support SCT patients to achieve their self-care goal by using their expertise and knowledge to educate patients, with a focus on preventing complications or disease (Hickman, 2002). Prior to their transplant, patients are provided information about precautions to be taken after transplant. This information is reviewed and reinforced prior to discharge and includes specifics about reducing the risk of infection such as the need to avoid areas where there is excavation, areas of building construction or renovation, occupations involving soil, and foods that contain moulds (e.g., blue cheese) to minimize their risk of contracting a fungal infection (CDC, 2009).

*Health Care System Factors and Resource Adequacy*

Diagnostic services and availability of appropriate health care resources is of paramount importance to the success of SCT. Patients require abundant resources, both personnel and technology, to support them post-transplant. Personnel include nurses, physicians from varying specialities, laboratory technologists, and other members of the multidisciplinary team. SCT patients are cared for by a team of health care professionals in the out-patient and in-patient settings. As cancer is a chronic illness, patients and families become co-partners in the care process as they continually manage the burden of illness daily and become experts in their own condition (Titter & Calnan, 2002). Increased survival and decreased hospital stays result in an increase in the burden of care for patients, their families, and healthcare resources (Grant, Cooke, Bhatia & Forman, 2005). Patients may experience prolonged wait times for services
such as nurse or physician assessment or even intravenous therapy treatments in the out-patient setting. Technology required throughout the transplant course ranges from those used to perform a variety of diagnostic services, such as magnetic resonance imaging (MRI) and computed tomography (CT) scans, cell processing therapies used to preserve the integrity of hematopoietic progenitor cells, and that used to perform testing on blood samples to identify anything from HLA typing, electrolyte abnormalities, or infections.

Self-Care Operations

The individual, according to Orem’s SCDNT, uses three sets of operations in managing self-care and meeting self-care requisites. These include estimative self-care operations, transitional self-care operations, and productive self-care operations (Orem, 2001). Estimative and transitional self-care operations include cognitive processes. Estimative operations require the patient to think about and assess their situation. The individual deliberates about choices and actions that can be taken. These may relate to management of symptoms and whether or not assistance is required for management of the symptoms. The choices may relate to medications and decision making on whether or not they want to or should take prescribed medications. Additionally, estimative operations may be about preventing risks to health, for example weighing the pros and cons about abstaining from cigarette smoking in an attempt to meet the self-care requisite of preventing hazards to human life. Transitional operations focus on making judgements and decision making as one course of action is chosen over another. Courses of action include contacting the health care provider, taking medication or continually assessing symptoms before making a decision to take action. Lastly, productive self-care operations result when engagement in action occurs (Cox & Taylor, 2005). The results of the actions are to bring about benefit for the individual and avoid harm. Examples of actions which should be beneficial
include taking prescribed therapy or medication and seeking appropriate medical attention. Other possible results of productive self-care operations include taking no action at all which may be damaging. An individual may choose actions that are potentially harmful, such as not seeking medical advice in a timely manner, or continuing a behaviour that may be contraindicated in the post-transplant period, such as continuing to smoke. Cox and Taylor (2005) also describe the category of antecedents to competent action which refers to the necessity of the patient to have appropriate knowledge on which to engage in self-care operations. The role of the supportive-educative nursing process includes educating the SCT patient about risks of transplant in a manner that they can understand. In addition to providing information, nurses have the responsibility to facilitate a nurturing, caring environment with patients and families that supports patients and families in “the right to self-determination, the right to access information, the right to make decisions about their health care” (CANO, 2006, p.4). As well, patients and families must be supported to promote their involvement as active participants in their care. Another way this can be accomplished is by providing resources that enable them to develop strategies to complement their choices.

Self-Care Requisites

Self-care requisites are the required actions known to be necessary in maintaining human development and function (Taylor, 2002). These are classified into three categories: universal self-care requisites, developmental self-care requisites, and health deviation self-care requisites. Rationale for why a self-care requisite occurs, consequences of a deficit, and solutions to reverse the self-care deficit will be discussed. Throughout the stages of transplant the universal and health-deviation self-care requisites must be met. Application of the nursing processes provides a framework for the nurse to assist the patient with meeting their self-care needs.
Universal Self-Care Requisites

Universal self-care requisites exist across the life-span (Denyes, Orem & Sozwiess, 2001). Attending to and meeting universal self-care requisites permit the individual to maintain human functioning and development (Allison, 2007). Post-transplant, because of the complexity of the treatment, the ability to meet self-care needs is difficult or cannot occur without assistance from others (Saria & Gosselin-Acomb, 2007). The universal self-care requisites include: maintenance of sufficient intake of air, water, and food; provision of care associated with elimination; maintenance of a balance of activity and rest, solitude and social interaction; preventions of hazards to human life, human functioning, and human well-being; and, the promotion of human functioning and development within social groups in accord with human potential and the human desire to be normal in society (Orem, 2001). Self-care regarding the universal self-care requisites will be discussed below with a specific focus on how these pertain to the SCT patient.

1. Maintenance of sufficient intake of food. A significant percentage of cancer patients (40% to 80%) will develop malnutrition at some point in their illness (Bloch, 2000). Appetite and the ability to eat are important components of physical and psychological well being. Psychological factors such as depression can contribute to a decrease in nutritional intake. Cultural influences may also be contributory (Cunningham & Bell, 2000). Admissions for transplant vary in length from four to six weeks and sometimes longer. During this stay, patients are provided with meals, at scheduled times of the day, usually on disposable dishes with disposable cutlery on covered trays. Family members are encouraged to bring in food as the patient desires, but eating habits and environment contribute to alterations in normal mealtime routine.
Chemotherapy agents vary in their emetogenic potential. A patient receiving high-dose cyclophosphamide will be at much greater risk for nausea and vomiting than a patient receiving fludarabine (BC Cancer, 2009). Nausea may inhibit desire and ability to eat. Thus, the ability to maintain a sufficient intake of food and adequate nutrition to promote normal gastrointestinal function and to maintain weight and strength is difficult. Mucositis is a complication of chemotherapy and/or radiation therapy that may cause severe irritation of mucosal integrity resulting in edema to the oral cavity, impaired tissue integrity, and pain (Eilers, 2004). Patients will receive analgesics for pain control to foster oral intake (partly compensatory). Some patients with mucositis may find it difficult to ingest anything by mouth and thus may have a small bowel feeding tube inserted to allow for enteral nutrition (Bloch, 2004) (fully compensatory). They may receive analgesics to reduce the pain of mucositis with the goal of encouraging some oral intakes (partly compensatory). Oral care regimens are initiated by the nurse. The patient is taught the importance of rinsing his or her mouth, usually with sodium bicarbonate or saline solutions, and cleaning with toothette swabs (supportive-educative). The nurse may set up the mouth care equipment for the patient (partly compensatory) or may perform the cleaning if a patient is unable to do so (fully compensatory). More severe cases of mucositis or neutropenic enterocolitis (NEC) may prohibit any form of oral intake and therefore total parenteral nutrition (TPN) to obtain adequate caloric intake may be required (wholly compensatory) (Eilers, 2004).

Patients who experience severe mucosal damage at the time of transplant will be at an increased risk for the development of GVHD of their oral mucosa. Nursing care must focus on teaching patients about signs, symptoms, and management of oral GVHD, prevention of exacerbations of GVHD and treatment (supportive-educative).
2. Maintenance of a sufficient intake of water. The universal self-care requisite of maintaining adequate intake of water refers to the maintenance of an adequate intake of fluids or water to prevent renal dysfunction and dehydration in the SCT patient (Orem, 2001). Stem cell transplant patients may experience nausea and vomiting or other gastrointestinal complications of GVHD such as diarrhea and nausea. They may have a suboptimal desire and ability to drink fluids to maintain sufficient fluid intake and a constant intracellular volume. Maintaining a sufficient intake of water to prevent dehydration and related sequelae such as nausea, vomiting, drug toxicity resulting from increased serum concentrations (Leather, 2003), hemorrhagic cystitis, hypotension, and weakness is imperative in this patient population. Hospitalized patients who are not able to take in sufficient amounts of fluid by mouth are administered intravenous fluids and thus, are wholly compensated for the deficit. Fluid intake is monitored in hospital. Patients are offered oral fluids (water, juice, Gatorade) with the goal of encouraging fluid intake when they are in hospital (partly supportive). At the time of discharge patients are taught the importance of maintaining fluid intake and are encouraged to take in “adequate” amounts of fluid. As such, it is recommended that patients consume two litres of non-alcoholic beverages per day. If fevers are present or diarrhea develops this intake would need to increase (Bush, 2004). The outpatient nurse reviews the patient’s bloodwork, takes vital signs, and asks about any problems that have arisen. Patient ability to meet self-care need related to fluid intake is assessed and rationale for meeting this self-care requisite is reinforced. Thus, the nurse is providing supportive-educative nursing care. If the patient is not able to meet the fluid requirements or shows signs of fluid deficit, arrangements for intravenous hydration may be made. This may involve short-term intravenous therapy (partly-compensatory) or continuous hydration requiring readmission to hospital (wholly compensatory).
3. Maintenance of a sufficient intake of air. Sufficient intake of air is required by all human beings to survive. Air is required to promote oxygenation, prevent hypoxia, promote tissue perfusion and is vital for maintaining function of body systems. Air quality is critical for prevention of infection in the SCT patient. In Winnipeg, hospitalized patients remain on a high efficiency particulate airflow (HEPA) filtered unit. Visitors are screened by hospital staff and those with active colds or flu symptoms who present infection risks are not allowed on the unit (wholly compensatory). Patients who need to leave the unit, do so with a high-efficiency mask and their time off the unit is limited.

Pulmonary complications post-SCT may be infectious or non-infectious and are connected with significant morbidity and mortality. Therefore, it is critical to identify factors that predispose an individual to pulmonary complications and to institute a preventative care plan (Ho, Lee, Alyea, Antin & Soiffer, 2001). Patients are taught the importance of doing deep breathing and coughing exercises to promote airflow, strengthen respiratory muscles and reduce the risk of atelectasis and pneumonia (supportive-educative). They are monitored daily in hospital for signs of fluid overload or infection. At the time of discharge, patients are taught the importance of notifying the health care team should any problems with breathing develop (supportive-educative). It is at this time that the individual then applies self-care operations to choose an appropriate course of action.

4. The provision of care associated with elimination processes and excrements. Vomiting, diarrhea, fever, GVHD of the gastrointestinal tract, bowel or ureteric obstruction, hemorrhagic cystitis, amenorrhea, prolonged menstruation, bacterial or viral infections are all potential complications for the SCT patient. Individuals, when able, will attend to their own elimination processes. It is necessary for the nurse to monitor the patient for the above
complications and to administer or request appropriate therapy as indicated. An example of this is an individual who receives high dose cyclophosphamide and also hyperhydration (fully compensatory) to promote excretion of the drug and reduce the risk for development of hemorrhagic cystitis. The nurse monitors the quality and quantity of urinary output and observes for signs of decreased urine output or hematuria. The patient is taught the side effect of the chemotherapeutic agent and the importance of frequent voiding (supportive educative). This frequency does impact the self-care requisite of balance between sleep and rest as the patient is awake frequently at night to void.

5. The maintenance of a balance between activity and rest. Human and environmental factors influence the ability of a person to maintain adequate periods of activity and exercise as well as appropriate amounts of rest and relaxation. Human factors such as states of weakness or debility caused by disease or treatment disrupt this balance. Medications can disrupt the balance between activity and rest as some cause sedation whereas others may result in a restless state. The human response to an illness situation can result in enhanced emotional states. Anxiety and uncertainty can also interfere with the ability to maintain a balance between activity and rest. The environment is not conducive to rest in the hospital setting. Change in daytime activity, noise, and night-time disturbances inhibit adequate rest patterns.

An individual’s activity may change due to the presence of weakness caused by the cancer itself, cancer therapy, and various sequelae including anemia and GVHD which may be associated with muscle fibre necrosis (Mello, Tanaka & Dulley, 2003). The environment, presence of equipment (IV pole), or isolation to a single room on the SCT unit can alter normal activity. Exercise is important in the management of fatigue that results from cancer treatment and also in the prevention of progressive loss of functional capacity that is associated with
physical inactivity (Carlson, Smith, Russell, Fibich & Whittaker, 2006). The nurse supports patients by encouraging them to walk regularly, whether in hospital or their own homes (supportive-educative). The nurse may assist patients as they ambulate in their room or hall (partly compensatory). Additionally, the nurse may engage the services of a physiotherapist to work with patients to develop safe exercise programs or an occupational therapist to assess safety in the home after discharge (partly compensatory) or inform patients of available community resources that focus on rehabilitation for patients recovering from cancer treatment (Rady, 2009).

6. The maintenance of a balance between solitude and social interaction. Meeting this self-care requisite like many others is a challenge for the SCT patient. Aggressive infection control measures within the hospital environment are standard practice in many institutions performing allogeneic SCT (Hayes-Lattin, Leis & Maziarz, 2005). This may include isolation to a specific hospital unit or to an individual patient’s room. Visitors are screened by unit staff to prevent individuals who may have active infections from coming onto the inpatient unit (partly compensatory). Prior to admission patients are made aware of the visiting guidelines and are encouraged to follow the same after discharge (supportive educative). Patients in Winnipeg have a private hospital room and are encouraged to walk in the hall. A significant proportion of their time may be spent in their own room in isolation. Isolation may be associated with an increased risk for development of agitation, anxiety, depression, and insomnia. It is necessary for the nurse and health care team to be aware of these risks, monitor them, and implement measures to provide socialization for SCT patients (Sasaki, Akaho, Sakamaki, Akiyama, Yoshino, Hagiya & Atsumi, 2000). An example of this would be when a family member cannot visit because of a cold or other reason. In such situations, nursing staff could engage the assistance of social
workers, spiritual care providers, or volunteer services, to arrange for volunteer visitors spend
time with the patient (partly compensatory). Additionally, patients are encouraged to be
ambulating in the hall for exercise and socialization on the unit (supportive educative).

Striving to meet all of the universal self-care requisites previously addressed will promote well-
being and reduce hazards to human life. How this applies to the SCT patient will be discussed in
further detail in the section on health-deviation self-care requisites.

8. The promotion of human functioning and development within social groups in accord
with human potential, known as limitations, and the human desire to be normal. Physical,
emotional, and cognitive changes may develop as a result of the SCT and can last from months
to years post SCT having an impact on quality and quantity of life (Sherman, Cooke & Grant,
2005). Normalcy is used in the sense of that which is essentially human and that which is in
accord with the genetic and constitutional characteristics and talents of individuals. The early
post-transplant period may find patients more concerned with survival. As patients recover and
begin to ponder resumption of activities and roles they had prior to their illness the
reestablishment of a normal life may become a greater concern (Andrykowski, Cordova, Hann,
Jacobsen, Fields & Phillips, 1998; Hacker, 2003). The health care team, led by the nurse, needs
to utilize all nursing processes to support patients post-transplant as they transition from their
role of SCT patient to transplant survivor who attempts to reintegrate into society.

Developmental Self-Care Requisites

Developmental self-care requisites “promote processes for life development” (Taylor,
2002, p.192). Parents as dependent care agents must meet the developmental self-care requisites
of children. For example they must provide food and water necessary for physical development.
They must provide shelter and safe physical, social and environmental conditions for the child to thrive. For an adult, marriage, death of a family member, or starting a new career are all developmental challenges that contribute to the development of the individual (Orem, 2001).

**Health-Deviation Self-Care Requisites**

Health deviation self-care requisites exist for persons who are ill or injured (Orem, 2001). Health-deviation self-care deficits are to be expected for the person undergoing SCT who may experience changes in structure (such as developing edema), physical functioning (respiratory complications), or habits of daily living (related to isolation). The changes a SCT patient undergoes may result in dependence on another person, the nurse as nursing agent, or a family member as dependent care agent. The patient is the receiver of care (Orem, 2001). The health-deviation self-care requisites categories include:

- seeking and securing appropriate medical assistance; being aware of and attending to the effects and results of pathologic conditions and states; effectively carrying out medically prescribed diagnostic, therapeutic, or rehabilitative measures; being aware of and attending to or regulating the discomforting or deleterious effects of prescribed medical care measures; modifying the self-concept (and self-image) in accepting oneself as being in a particular state of health and in need of specific forms of health care; learning to live with the effects of pathologic conditions and states and the effects of medical diagnostic and treatment measures in a life-style that promotes continued personal development.

(Orem, 2001, p.235)

**Health Deviation Self-Care Requisites and Chronic Graft-Versus Host Disease**

1. Seeking and securing appropriate medical assistance. “Chronic GVHD can lead to debilitating consequences; e.g. joint contractures, loss of sight, end-stage lung disease, or
mortality” (Filipovich et al., 2005). Estimative self-care operations include being aware of when to obtain medical assistance. The health care team has the obligation of ensuring patients are aware of possible side effects of cGVHD and understand when health care services should be obtained. Allogeneic SCT patients must remain in close contact with their primary transplant centre who provide the expertise in management of cGVHD and the associated complications should these develop. The goal is to prevent further damage from cGVHD and to try to reverse the disease. Transitional self-care operations place the SCT patient, and their supports such as an involved family member, in the position of decision maker. The patient needs to make judgements based on symptoms as to whether or not they will seek medical advice, attempt to manage the situation on their own, or wait until symptoms change and reassess their initial decision. Productive self-care operations involve meeting the health-care requisite and seeking medical assistance.

2. Being aware of and attending to the effects and results of pathologic conditions and states. In order for patients to seek appropriate medical assistance, they need to be aware of circumstances where this would be prudent. The patient will have to learn about circumstances where it is appropriate for them to obtain medical assistance or advice. This will require them to learn about signs and symptoms of GVHD, risks, benefits, and side effects of their therapy. Hence, the value of the supportive-educative role of the nurse.

3. Effectively carrying out medically prescribed diagnostic, therapeutic, or rehabilitative measures; and 4. Being aware of and attending to or regulating the discomforting or deleterious effects of prescribed medical care measures. A variety of medications are required for the SCT patient. These include immunosuppressive agents, antibiotics, antifungal, or antiviral agents. Failure to administer these properly can lead to problems with serum concentrations which lead
to increased toxicity and decreased therapeutic benefit of the medication (Leather, 2003). Ultimately, patients are responsible for performing the productive self-care operations such as taking their prescribed medications. In order to perform the necessary self-care operations and effectively carry out prescribed therapy or prevent side effects of the therapy, the nursing diagnosis of knowledge deficit must be addressed. Patients need to be provided with the opportunity to learn about their proposed treatment and the impact this has on self-care. Characteristics of adult learning must be applied to maximize the benefit of education for patients and families and thus indirectly benefiting the healthcare team. These include prioritizing learning objectives; engaging the learner through interaction and solicitation of feedback; individualizing the information; fostering a teaching and learning process; and focusing on relevant information that will be perceived as important and useful by patients and families (Donaldson, Rutledge & Pravikoff, 1999). Relevant written material that is presented in simple terms can be provided for patient and family review and to enhance comprehension.

5. Modifying the self-concept (and self-image). An appropriate nursing diagnosis associated with this health deviation self-care requisite would be altered body image related to chronic GVHD and side effects of medication (Buchsel et al, 1996, p. 1286). As suggested above, numerous medications are required at different times in the post-transplant course. Medications, such as immunosuppressive agents, are used to control T-lymphocytes from reacting against the recipient’s immunocompetent cells or tissues. T-cells are active in the causation of GVHD. Steroids may be added to the treatment armamentarium to try to control T-cell proliferation and ultimately GVHD (Alcoser & Burchett, 1999). Steroids are associated with physical side effects such as weight gain, hyperglycemia, avascular necrosis, cataracts, as well as psychological effects including psychosis and insomnia (BJH, 2004). SCT patients need to
weigh risks and benefits of prescribed therapy that may cause these body image changes. SCT patients need to be able to make informed decisions related to the consequences of therapy. Side effects may have to be accepted with the hope that one day things will return to “normal”.

Conversely, SCT patients may endure negative consequences if they do not or cannot follow recommended therapy. Nurses provide emotional and physical support. They advocate, listen, care, and teach.

The interactive and interpersonal qualities of talking help to transform extraordinary situations in which patients are vulnerable, uncertain, and fearful, into states which can be endured, transcended, survived, or from which it is possible to recover; such states usually centre around the dysfunctions and disfigurements of the physical body and distresses of human embodiment, fear of death, disease, or the persons ability to endure suffering. (Lawler, 1997, p. 44)

6. Learning to live with the effects of pathologic conditions and states and the effects of medical diagnostic and treatment measures in a life-style that promotes continued personal development. A knowledge deficit regarding late effects of bone marrow transplant (Buchsel et al., 1996) is almost a guarantee in SCT patients. The focus for the patient may be on curing the disease (malignancy) for which they are undergoing a SCT. The ramifications of potential complications of SCT may not be understood at the outset of the transplant course (Bywater & Atkins, 2001). SCT can result in “long hospitalizations, isolation, physical changes, life-threatening toxicities, anxieties, and depression” (Sherman, Cooke & Grant, 2005, p.2). Chronic GVHD can affect every part of the body including the skin, oral cavity, eyes, genitalia, gastrointestinal tract and liver, lungs, hematopoietic system, neurologic, immunologic, and
musculoskeletal systems (Couriel et al 2006). Prevention of further complications is important with every organ system. The nurse and health care team must work with patients and families to learn ways to prevent further organ damage. For example, the use of sunscreen and protective eye wear can help prevent the complications of UV radiation and exacerbation of GVHD. Smoking of tobacco products post-SCT is associated with lung damage, including interstitial pneumonitis, bronchiolitis obliterans, chronic obstructive lung disease, and related pulmonary infections (Rizzo, Wingard, Tichelli, Lee, Van Lint et al, 2006).

Psychological problems related to changes in body image, fatigue, sexual dysfunction, and role change have been identified in SCT survivors as risk factors for depression (Buchsel, Leum & Randolph, 1996). The nurse who anticipates these problems can provide support to patients and families and involve necessary resources that enable people to live life safely, and to make lifestyle choices that engender their ability to thrive in family and society. Lifestyle choices post-SCT include decisions about exposure to environmental situations, travelling against the recommendation of the healthcare team, and management of nicotine addiction. For example, a farmer may not be able to resume working for an extended period of time because of the risk of acquiring a fungal infection from dust and soil. A patient who has received total body irradiation as part of the transplant conditioning regimen will have an increased propensity for skin damage when exposed to extreme heat or cold and this may impact activities or plans such as holiday destinations and scheduling.

Limits of the SCDNT and Recommendations Arising

The SCDNT is a general theory that provides a basis for understanding the requirements for successful delivery of nursing care in many situations. Applying the SCDNT to the SCT population has been informative for me but has also been a challenge. There is a lack of
literature and empirical evidence available discussing the SCDNT and allogeneic SCT. SCT and associated complications are perhaps too broad an area of concern to be addressed in this project. Areas for further exploration and development might include an indepth analysis and literature review of individual basic conditioning factors such as the need for air or balance between activity and rest in general and then relating findings to allogeneic SCT patients. Another option would include examination of one system complication related to SCT such as pulmonary complications or infections and the SCDNT, in similar fashion to Cox and Taylor (2005) in their examination of the SCDNT and pediatric asthma.

The role of the family unit is acknowledged by the SCDNT as being diverse, it is not limited to one type of family unit, such as a traditional family, and therefore is not exclusionary. The fact that the dependent care theory exists gives evidence to the knowledge that there are many components of the SCDNT, such as family, that warrant their own unique body of knowledge to be better understood.

Conclusion

Orem has been instrumental in helping to define what nursing is and when nursing is needed. The SCDNT provides direction to the nurse regardless of the setting. Advanced Practice Nurses (APNs) are leaders, role models, mentors, researchers, administrators, educators, and direct-care providers. The holistic approach nurses bring to the delivery of care positively impacts clinical care thus promoting quality and quantity of life for patients and families (ONS, 2003). The specialized oncology nurse teaches and coaches patients and families. The nurse prepares individuals with cancer and families for many different aspects of the cancer experience by providing education, psychosocial-spiritual support and counselling across the continuum of care (CANO, 2006). Prevention and treatment of side
effects or complications are a significant part of caring for a SCT patient. Although the risks of SCT can be applied to the patient population in general, each individual experience will be unique. The art and science of nursing are applied to individual situations. Clients are goal-directed, hence the goals of nursing must remain directed at meeting the client’s goals or with assisting the client to meet the goals required for their health. Nurses must assess the abilities of individuals to meet self-care needs and the resources available to patients and families when the patient cannot meet the needs. Nursing that implements Orem’s SCDNT is teleologic, the aim is for good, restoration, prevention, or adaptation to an illness, injury, or disease process (Oberle & Allen, 2001). I believe this is part of the reason why Orem’s theory is significant to me and the nursing profession. The SCDNT is practical, useful, and illustrates the important role a nurse has in caring for patients and families. Examining the concepts of the SCDNT reinforces the considerable impact that SCT has on individuals and the challenges that must be overcome if self-care requirements are to be met.
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